



# Implementing and evaluating resources to support good maternity care for parents with learning disabilities: A qualitative feasibility study in England

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## ABSTRACT

**Problem:** Parents with learning disabilities are often disadvantaged and their needs not well understood in maternity services.

**Background:** Despite a global vision to improve maternity care, current evidence confirms poor pre- and post-natal care for parents with learning disabilities and their families. Midwives have expressed a need for support in the delivery of good care to this population of parents.

**Aim:** To test the feasibility of implementing and evaluating two evidence-based and values-based resources – the Together Toolkit and Maternity Passport – to support good maternity care for people with learning disabilities.

**Methods:** A qualitative feasibility study employing semi-structured interviews with 17 midwives and 6 parents who had used the resources in practice in four NHS Trusts in the south of England.

**Findings:** Midwives and parents described how the resources positively impacted maternity care by enabling midwives, connecting networks and empowering parents. Factors affecting effective implementation of the resources were reported at an individual and setting level.

**Discussion:** Staff training to raise awareness and confidence in supporting parents with learning disabilities, and improved systems for recording parent's individual needs are required to enable the delivery of personalised care.

**Conclusion:** Reasonable adjustments need to be prioritised to facilitate implementation of resources to support personalised maternity care and to address inequity for parents with learning disabilities. Aspirations for equity suggested commitment from midwives to challenge and overcome barriers to implementation. Recommendations were made to improve the resources and their implementation. These resources are free and accessible for use [[www.surrey.ac.uk/togetherproject](http://www.surrey.ac.uk/togetherproject)].

## Introduction

Transforming care for people with learning disabilities is a priority within the UK (NHS England, 2019a; NHS England 2015, 2018, 2021a, NIHR, 2020) and specifically within maternity services (National Maternity Review, 2016; NHS England, 2021). Mencap defines a learning disability as a life-long reduced intellectual ability and difficulty with everyday tasks - such as household duties, socialising or managing

money (Mencap, 2024). The Nursing and Midwifery Council's standards of proficiency for midwives (Nursing Midwifery Council, 2019) highlight the midwife's role in recognising who has a learning disability and subsequently meeting their needs and preferences. However, evidence reveals that people with learning disabilities in the UK have poor experiences of maternity services (Malouf et al., 2017, Redshaw et al., 2013), poorer outcomes (Tarasoff et al., 2020) and are more likely to have their children taken into care than those without learning

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disabilities (NIHR, 2020, Booth et al., 2005). Midwives have reported feeling ill-prepared and unsupported to provide the care parents with learning disabilities need and prefer (Beake et al., 2013) and have expressed a need for support in the delivery of good maternity care to this population of parents (Castell and Stenfort Kroese, 2016).

A global vision of improving maternity care for mothers and newborns is supported by a quality of care framework (World Health Organization, 2016). In line with the framework, eight standards indicate priorities for quality improvement. The needs of parents with learning disabilities need to be considered in line with these standards, which include effective communication, to ensure equity of maternity care.

The World Health Organization (WHO) have outlined their goal to engage and empower people and communities to co-produce services that meet their needs and respect their preferences (World Health Organization, 2016). Adopting this people-centred approach, enables individuals, families and communities to collaborate with healthcare professionals to shape health services; this approach is crucial to ensuring equitable health and well-being for all and progressing towards the United Nations' Sustainable Development Goals (United Nations, 2024). Co-producing healthcare services is not only a more ethical approach but it is also more likely to lead to effective change (Elwyn et al., 2020). Arguably, this people-centred approach is particularly warranted to improve maternity care for people with learning disabilities, who experience inequity in experience and outcomes in this context.

In response, the Together Project ([www.surrey.ac.uk/togetherproject](http://www.surrey.ac.uk/togetherproject)) has adopted a people-centred approach to improving maternity care for parents with learning disabilities. Involving both individuals with learning disabilities and the professionals who support them, the Together Project co-produced two evidence- and values-based resources to support good maternity care, the development and piloting of these resources has been previously reported (Cox et al., 2021). In line with UK Medical Research Council (MRC) guidance (Skivington et al., 2021), the next step was to test the feasibility of implementing and evaluating these resources in practice.

## Participants, ethics and methods

### *Aim and objectives*

The aim of this study was to inform the future design and implementation of the Together Project resources within three specific objectives, to determine: (1) how midwives and parents with learning disabilities perceive the Together Project resources to impact on maternity care; (2) what factors affect the implementation and evaluation of the Together Project resources in maternity services; and (3) how the Together Project resources should be refined and improved. Informed by the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2022), both innovation deliverers (midwives) and recipients (people with learning disabilities) were included in feasibility testing.

### *Study design*

A predominantly qualitative feasibility study was conducted to meet the study objectives. This involved remote semi-structured interviews with midwives and parents with learning disabilities who used the Together Project resources, and also collection of quantitative data about eligibility and recruitment rates. The study is reported in line with the Consolidated Criteria for Reporting Qualitative Studies (Tong et al., 2007).

### *Setting*

Four NHS Trusts (health care providers of secondary care) across Kent, Surrey, Sussex and Wessex took part in the study. These four Trusts

included six hospitals with maternity services.

### *Together project resources*

The Together Project previously co-produced two resources to improve maternity care for parents with learning disabilities: (1) the Together Toolkit for professionals working in maternity services, including guidelines, actions to complete, and questions for reflection; and (2) a Maternity Passport, to be held by parents with learning disabilities, and to include the relevant parental information required by maternity professionals to support the delivery of good maternity care. These resources are free and accessible for use [[www.surrey.ac.uk/togetherproject](http://www.surrey.ac.uk/togetherproject)].

### *Participants*

Midwives were invited to take part in the study if they were: over the age of 18 years; a midwife at the participating trust; and if they thought they may be currently supporting a parent with learning disabilities. People with learning disabilities were invited to participate if they were: over the age of 18 years; a pregnant woman registered or identified as having learning disabilities/a pregnant woman whose partner was registered or identified as having learning disabilities/a partner of a pregnant woman who was registered or identified as having learning disabilities; under the care of maternity services within participating NHS trust; and judged by the project midwife to have the capacity to consent to the study. Many adults with learning disabilities are unregistered (NHS Digital, 2023), therefore those that self-identified as having a learning disability were also included.

### *Recruitment*

Potentially eligible parents were referred by their midwife to a project midwife who called to assess eligibility and invite parents to participate. Project midwives were trained by the project team (including SW, a father with learning disabilities) to use respectful questions to determine eligibility. The participant information sheets informed all potential participants of the purpose of the study and who was conducting it. Parents were informed via their participant information sheet and the researcher that they could have a family member, friend or health professional present in interviews, if they wanted. Following recruitment of parents, the midwife caring for the parent(s) was invited to participate. Anonymised records were kept by the Project Midwife to inform assessment of recruitment rate and conclusions regarding the feasibility of evaluating the resources in practice, and to provide recommendations for the refinement of implementation procedures.

### *Data collection*

Semi-structured interviews with midwives and parents were carried out virtually via Zoom, MS Teams or telephone. The topic guides were informed by the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2022), an evidence based framework to guide effective implementation, with a particular focus on domain IV (Individuals Domain) which in turn is based on the COM-B model of behaviour change (Michie et al., 2011). Parents with learning disabilities were asked after the interview whether they would like to take part in a follow-up interview (interviews could be completed during the second trimester, third trimester, and following the birth of the baby, if within the study period).

### *Analysis*

Interview data were analysed using framework analysis (Richie and Spencer, 1994) due to its systematic and flexible approach to analysing

qualitative data. Data was managed on QSR NVivo 12 software. Data collected from midwives and parents were analysed separately. Five stages of framework analysis were followed: familiarization; identifying a framework; indexing; charting; and mapping and interpretation. In the initial stage of analysis, transcripts were read repeatedly by two qualitative researchers (AI and AC) to ensure familiarity before independently coding 30 % of the transcripts. Codes were compared between researchers during data analysis meetings. The framework was developed through discussion and applied to all interviews by the lead analyst (AI), who indexed subsequent transcripts using the existing categories and codes. Data were charted into the framework matrix and interpreted using the Consolidated Framework for Implementation Research (CIFR) (which also includes COM-B constructs to explore individual factors). CIFR was used as it provides a useful framework to evaluate an implementation study. A reflexive approach was adopted, and themes represent the authors' interpretive analysis of the data. An additional author (CT) who did not conduct interviews or code data, reviewed the data analysis to ensure credibility.

Public and community involvement

Public and community involvement was integral to the project. For example, an expert by experience who was a paid member of the project team (SW) contributed to the development, delivery and dissemination of the project. A support group for parents with learning disabilities also advised the project. Their contribution included helping to create a short film on the project for midwives and guiding improvements to the resources informed by a discussion of study findings. They received a voucher as a thank you for their contribution at each engagement.

Ethical considerations

Accessible Participant Information Sheets and consent forms enabled a meaningful informed consent process. This study received a favourable ethical opinion from Camden & Kings Cross Research Ethics Committee (ref: 21/PR/0633). The overall conduct of the project was informed by the Together Project values: Trust; Open-mindedness; Gentleness; Enablement; Time; Humility; Equality; and Respect.

Findings

Recruitment rates

Implementation periods across the four participating NHS Trusts ranged from 22 weeks (Site D) to 34 weeks (site A). During the recruitment period, 9566 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 (7/15 parents, 50 %) gave informed consent, and six parents were interviewed. Supplementary file 1 presents the recruitment of parents within the four participating NHS trusts and their journey to interview, or not, with reasons.

A total of 21 midwives self-identified as supporting a parent who may have learning disabilities across the four NHS trusts, of these, 19 midwives met the eligibility criteria and 17 midwives (17/19, 89 %) gave informed consent and were interviewed. Supplementary file 2 presents the recruitment of midwives within the four participating NHS trusts and their journey to interview, or not, with reasons.

Characteristics of interview participants

A total of 17 midwives took part in this study, across four NHS trusts. Interviews ranged from 34 to 73 min (average= 51 min) and took place via Zoom, MTeams or telephone. Majority of participants (9/17, 53 %) were specialist midwives. Six parents across three NHS trusts participated in the study. Interviews with parents ranged from 8 to 22 min (average = 18 min) and took place over telephone or Zoom. All participants were White British and female. Ages ranged from 21 to 37 years and majority (4/6, 67 %) were in their second trimester at the time of their first interview, only two parents (33 %) were interviewed in their third trimester. Two parents had children previously, for the remaining parents it was their first pregnancy. Two parents took part in a follow-up interview when they reached their third trimester, lasting on average 16 min. Participant pseudonyms are used when presenting verbatim quotes.

Summary of overarching themes

Four analytical themes were identified: (1) perceptions of benefit; (2) setting level barriers; (3) individual level barriers; and (4) adaptations to further support accessible and personalised maternity care. Each analytical theme is presented below with any subthemes underpinning them (Tables 1–3 provide illustrative quotes).

(1) Perceptions of benefit: ‘The information’s in there for them to read’

This first theme describes the positive impact that both midwives and parents perceived the Together Project resources to have on maternity care. Two subthemes are presented from interviews with midwives (enabling midwives; connecting networks) followed by a subtheme constructed from interviews with parents (empowering parents).

Subtheme 1a: enabling midwives

Midwives reported that the Together Project resources had a positive impact on their skills and confidence in supporting parents with learning disabilities. The resources provided questions to help identify whether

Table 1  
Illustrative quotes for theme 1 - Perceptions of benefit.

Perceived benefit	Illustrative quote
Enabling midwives	<p>‘We started filling in the passport and it almost like prompted us to different conversations that we hadn’t had before’ [Alex, Community midwife, Site A]</p> <p>‘A nice document to sort of inform and help guide us because that’s, ultimately as a midwife, whatever amount of time you’ve got, it’s knowing what can I do with the information that’s been provided to me from this woman, how can I best help her? And if you’ve got something like that then you’ve got those tools to be able to say okay, I can draw upon this and that’ll help me’ [Louise, Specialist midwife, Site C]</p>
Connecting networks	<p>‘I just found the whole thing was quite useful, just learning about how to approach it and you know, getting the multidisciplinary agencies all involved in the care because, you know, it took a lot of different agencies to be able to support her, so that was quite useful’ [Denise, Community midwife, Site B]</p> <p>‘I’ve referred her to things like our Family Nurse Partnership who have accepted her, I think if they’ve got access to this as well, then we can use it in a bit more of a team approach to supporting her needs, everyone can see what helps her in her understanding’ [Jerry, Specialist midwife, Site B]</p>
Empowering parents	<p>‘One of the things what I liked about using it, I take it with me like with my appointments all the time, so I don’t forget and keep on top of things, like what, know what to do and stuff you know. Basically, it will help my little one as well’ [Laura, Parent with learning disabilities, Site B]</p> <p>‘Because they’re easy to explain to people without having to talk to someone, stuff like that. The information’s in there for them to read.’ [Georgina, Parent with learning disabilities, Site C]</p>

**Table 2**  
Illustrative quotes for theme 2 - Setting level barriers.

Setting level barriers	Illustrative quote
Busy clinics	<i>'the problem we have is our time is really limited and our clinics are chock-a-block and we work all the way through our lunchbreaks and you know, so it's having time to read it but it's there and it's available so that's great, so had I had a bit more time I would have, I would have had a good old read through of it.'</i> [Kelly, Community midwife, Site B] <i>'I think the challenge maybe is having time to sit with somebody to do it. So, I've got the time as a specialist, I can give that time, but maybe a general community midwife might struggle to sit with the patient to go through the passport in detail, at the right stage as well of their pregnancy maybe as well because they don't have very long for appointments'</i> [Louise, Specialist midwife, Site C]
A lack of resources and training	<i>'last year I did say I could do with some more training really, but there's no time, there's no time, the job's massive and I never get any time to do anything other which is a bit of a shame, so sometimes I do feel a bit out of my depth'</i> [Courtney, Specialist Midwife, Site A] <i>'Usually my go-to place is the Futures Platform and I can just see what people in various other Trusts use and kind of pinch some of their bits and pieces so yeah, it's all stuff that's been devised by other people in similar positions in other Trusts'</i> [Rachel, Community midwife, Site B]
Digital systems	<i>'Difficulty that we have now is that we're we've gone over to all digital things. So a lot of the majority of our things are now digitally provided or you know on iPads and whatever information which for a whole multitude of problems can cause a whole multitude of problems for mothers with learning disabilities'</i> [Nicky, Specialist midwife, Site A] <i>'we're all on electronic notes now, the timing is that we've just gone to electronic notes about a year ago, so people don't tend to have bits, they don't have a folder where they would flick through and see there was a passport'</i> [Carol, Specialist midwife, Site B]
A need for specialist support	<i>'I think having a designated lead on that would be very useful for community and you know, in the unit if yeah, I think it'd be very helpful, because they need it, because you know, other fields have, you know, specialities like diabetes and yeah safeguarding, and things like that, so yeah I do think it'd be very advantageous to have somebody to be able to reach out and help you look after the ladies correctly, and so they get everything that they should get, so you know, that best outcome for baby and mum'</i> [Sophia, Specialist midwife, Site A] <i>'It can be quite challenging in maternity care especially. In this Trust we do have a learning disability team for the Trust, so they're not specific to maternity, but in this role, I've always found that they're very approachable for advice and support and will actually come and help with people who have particular difficulties, they will come and support with those women and suggest things that might help them.. So quite a positive service I think for us here, but yeah, nothing specific for maternity, that'd be the difficulty that we have'</i> [Louise, Specialist midwife, Site C]

someone had learning disabilities and enabled them to reflect on how they delivered care to this population and how it could be improved. They described how the Together Project resources facilitated good communication with parents with learning disabilities, providing them with prompts for conversations they would not otherwise have had. Furthermore, the resources were considered to facilitate a structured pathway of maternity care, to ensure that the time available was used to understand the parent's needs whilst also documenting the process to inform the best care for the parent moving forward. The benefit of the resources was less apparent for some midwives (particularly specialist midwives) who reported feeling that they knew the information in the toolkit already.

*Subtheme 1b: connecting networks*

Midwives expressed that the Maternity Passport enabled a connection between members of the network supporting a parent with learning

**Table 3**  
Illustrative quotes for theme 3 - Individual level factors.

Individual level factor	Illustrative quote
A lack of learning disability awareness	<i>'I wouldn't say I'm very confident at identifying whether it's a disability versus a difficulty versus just a general challenge'</i> [Nicky, Specialist midwife, Site A] <i>'sometimes it can be a bit awkward, getting something like that out, you don't want to, even with some people that you think really do need it, I do sometimes wonder are they going to take offence at this'</i> [Sophia, Specialist midwife, Site A]
Assumptions of parent capability and preference	<i>'they're really, you know, chaotic. They're living in a, emergency accommodation with all their stuff in plastic bags, so they don't take anything to appointments.'</i> [Carol, Specialist midwife, Site B] <i>'I never left the passport with her because she was quite chaotic generally in her life, which we later found out when we went to see her house and it would be, it was better that I just kept it on me'</i> [Sophia, Specialist midwife, Site A]
Parent support needs	<i>'Oh, well my mum is doing that because I, I'm not really good at filling it in'</i> [Georgina, Parent with learning disabilities, Site C] <i>'My keyworker, she helps me to write things down and then she asks me some questions, and then she can write things for me and stuff'</i> [Laura, Parent with learning disabilities, Site B]
Aspirations for equity	<i>'Individualised care for everybody regardless of their need is a must. We can't do it any different, you know, not everybody fits in a little box nice and neatly and that's the care that we offer and take it or leave it, we have to have something for everybody, you know, and even for those women with specific needs they're all going to have different needs and different methods that they need for communication etc. So yeah, I think it's not a nice to have, I think it's a must have for everybody, definite'</i> [Louise, Specialist midwife, Site C]

disabilities, facilitating a broader team approach to meeting the individual's needs. They perceived the resources to help parents to feel in control of their care, ensuring that their voices are heard by professionals, but without the need to repeat themselves as their needs and preferences were documented and shared.

*Subtheme 1c: empowering parents*

Parent data supported the midwives' perceptions that the Maternity Passport empowered people with learning disabilities. Parents reported that the Maternity Passport facilitated good communication with midwives. They felt it enabled professionals to understand their needs and preferences without having to tell them, which is especially important for people who may not feel comfortable talking to unfamiliar professionals. They also thought the Maternity Passport would help ensure they received support to learn the practical tasks needed to care for their baby.

*(2) Setting level barriers: 'Our time is really limited'*

Midwives highlighted many factors affecting implementation of the Together Project resources at a setting level. The implementation of the Together Project resources took place during the pressures of the COVID-19 pandemic, the barriers presented in these subthemes should be considered within this context. Four factors affecting implementation of the Together Project resources were constructed from interviews with midwives, these are presented in the subthemes: busy clinics; a lack of resources and training; digital systems; and a need for specialist support.

*Subtheme 2a: busy clinics*

Time was expressed by many midwives as a barrier to using the Together Project resources, specifically the challenge of completing/

reviewing the Maternity Passport with parents within appointments. Some midwives expressed that specialist midwives have more opportunity to spend extra time with parents to use the resources, compared to midwives working in community. Midwives suggested that time pressures could be mitigated by directing parents to other members of their support network (e.g. health visitor, support worker, keyworker) to help them complete sections on the Maternity Passport.

#### *Subtheme 2b: a lack of resources and training*

Midwives reported limited resources within their Trusts to meet preferences for alternative methods of communication or information provision. The need for learning disability awareness training was consistently expressed by midwives. Those who had supported parents with learning disabilities reported having to independently seek learning or support, as no specific training was routinely provided.

#### *Subtheme 2c: digital systems*

Digital records were considered a barrier to implementation of the Together Project resources, due to the way in which learning disabilities were recorded on databases. Learning disabilities were often grouped with other needs, for example, learning difficulties, midwives reported that this made it hard to determine who should be offered the Maternity Passport. In addition, midwives recognised that an option to hold a paper copy of important information, such as the Maternity Passport, could be more beneficial to people with learning disabilities, but as paper notes are not commonplace anymore, they did not know to ask to see them so the Maternity Passport could be overlooked.

#### *Subtheme 2d: a need for specialist support*

Participating midwives worked across four NHS Trusts and reported varying types of specialist support available, for example learning disability teams, safeguarding teams, and vulnerable women's teams. Examples were given of these teams providing advice and resources to support parents with learning disabilities and supporting the use of the Together Project resources. However, midwives reported that much of the learning disability specialist support available was not specific to maternity care.

Several midwives referred to the role of a specialist midwife in disabilities, which had previously existed within their Trust. They expressed that this was helpful as they did not have the time to fully support parents with learning disabilities and having a dedicated midwife allowed the parent to have continuity of care whilst providing midwives with a point of contact if they needed further support or specific resources.

(3) Individual level factors: 'I do sometimes wonder, are they going to take offence at this?'

In addition to setting level barriers, four individual level factors impacting the implementation of the Together Project resources were constructed from interviews. Midwives described two factors that served as barriers to implementation (a lack of learning disability awareness; and assumptions of parent capability and preference) and parents described the support they needed to successfully engage with the Maternity Passport (parent support needs). These barriers and how they interact, are presented below, however implementation was facilitated by the aspiration for equity held by midwives.

#### *Subtheme 3a: a lack of learning disability awareness*

The majority of midwives interviewed reported they lacked experience of supporting parents with learning disabilities and felt, 'out of my depth'. Those midwives who reported experience were specialist midwives, who were more likely to come across people with learning disabilities or learning difficulties within their caseload. Most midwives did not feel confident in recognising when a parent had learning disabilities as they had not had specific learning disability awareness training.

Midwives reported a lack of confidence in differentiating between learning disabilities, learning difficulties or other learning needs.

Midwives expressed an awkwardness approaching the topic of learning disabilities. They expressed discomfort with asking whether someone has a learning disability, as they were worried about offending them. Some spoke about ways of approaching it, for example not making it obvious or waiting for a midwife who is experienced with supporting parents with learning disabilities to start the conversation.

#### *Subtheme 3b: assumptions of parent capability and preference*

A lack of learning disability awareness can lead to incorrect assumptions about the capability and preferences of people with learning disabilities. Many midwives perceived people with learning disabilities to lack the capability to complete the Maternity Passport, or to understand the information it included. They felt that some parents with learning disabilities have complex lives which would prevent them from using the Maternity Passport. This included the overwhelming nature of having many people involved in their care; a need to prioritise other aspects of their life over maternity care; or unstable living arrangements which would make it hard to guarantee that the Maternity Passport would be consistently brought to appointments and updated/shared. These assumptions were confirmed for some midwives, who described parents attending hospital without their Maternity Passport.

Midwives also made the assumption that parents with learning disabilities preferred not to be seen as different. They felt that the stigma experienced by parents with learning disabilities outweighed the potential benefit of maternity care that is tailored to their needs. To be able to use the resources effectively, midwives reported that it was important to establish trust with the parent, and then offer them the choice to use the Maternity Passport. They highlighted the importance of continuity of care particularly for this group of parents.

#### *Subtheme 3c: parent support needs*

Parents described the support they needed to complete the Maternity Passport. Some reported support from their social network, however, the majority of support was sought from professionals. This subtheme particularly links to the barrier reported by participant midwives, 'assumptions of parent capability and preference', in which they questioned whether people with learning disabilities would be able to complete and manage the Maternity Passport. Parents acknowledged that they often forgot to take the Maternity Passport with them to appointments. Furthermore, parents spoke about not having the 'right headspace' or being distracted by other aspects of their lives. This subtheme highlights the need for a strong circle of support around parents with learning disabilities, supporting them to prepare for and attend their maternity appointments. Parents did not refer to stigma impacting their engagement with the resources, but only parents who *had* engaged with the resources were interviewed.

#### *Subtheme 3d: aspirations for equity*

The subtheme 'aspiration for equity' presents a commitment from midwives to challenge and overcome setting barriers. A tension for change was present, a commitment to pursuing individualised care for every parent, including those with learning disabilities, which motivated midwives to challenge the setting barriers. Concerns around the consequences of not providing good, personalised maternity care to parents with learning disabilities, including safeguarding issues or health problems for the baby, were also expressed by midwives.

(4) – Adaptions to further support accessible and personalised maternity care: 'Anybody with any vulnerability'

Parents and midwives considered the Together Project resources to be simple and accessible in their layout and content, and parents expressed their appreciation of a handheld resource as opposed to electronic records. Minor alterations were recommended regarding



colour and personalisation, but adaptations predominantly focused on the need to 'broaden inclusion' beyond people with learning disabilities.

Midwives felt that the Maternity Passport could be helpful for anyone with a vulnerability, learning needs or challenges, and felt it could support the midwifery workforce to recognise and support individual needs. A minority of midwives reported having already used the resources with other populations (e.g. people with ADHD or autism) and that it had been helpful. Two parents had already recommended the resources to others, including a friend who had learning difficulties and someone who suffered from anxiety, to help them express their needs and preferences.

## Discussion

This multi-site study has responded to a global vision of improving maternity care (World Health Organization, 2016), in testing the feasibility of implementing and evaluating two novel resources in maternity services. Our findings have demonstrated that whilst the Together Toolkit and Maternity Passport have clear benefit to maternity care for people with learning disabilities, several setting level factors effected implementation and evaluation of the resources, these include busy clinics; a lack of resources and training; digital systems; and a need for specialist support. Individual level factors also effected implementation and evaluation, these include a lack of learning disability awareness; assumptions of parent capability; and the support parents needed to successfully complete the maternity passport. The principal findings from this qualitative feasibility study are discussed using the domains of the CIFR, to inform the future refinement and implementation of the intervention.

At an individual level, midwives were motivated to use the resources to improve interprofessional relationships and the care that they provided; and to empower parents. However, their perceptions of the capability of parents with learning disabilities, and their discomfort discussing learning disabilities served as a barrier to using the resources effectively. Midwives reflected on needing to improve their learning disability awareness, to help them to identify which parents may have a learning disability. This supports previous research that identified a lack of experience and provider assumptions as barriers to good perinatal care for people with learning disabilities (Saeed et al., 2022). Mandatory Training in Learning Disability and Autism (Department of Health and Social Care, 2019) is a celebrated step forward in supporting improved awareness in health and social care staff in the UK, however midwives in this study suggest they would also benefit from learning disability awareness training that is specific to maternity care. People with learning disabilities fear losing custody of their child and may not always feel safe to disclose their diagnosis. In order to support people with learning disabilities, midwives need to be skilled and confident to sensitively and respectfully identify when someone has a learning disability and to tailor the maternity care they provide accordingly (Höglund and Larsson, 2013). Multi-agency maternity specific learning disability awareness training could go one step further and support professional groups to collaborate effectively to deliver good maternity care to parents with learning disabilities.

Parents were 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 resource. A lack of co-ordinated care and gaps in available social support have been reported by previous studies exploring the prenatal experiences of people with disabilities (Tarasoff et al., 2023, Potvin et al., 2016). The importance of support and advocacy have also been highlighted by women with learning disabilities in pregnancy recommendations to their peers (Khanna et al., 2022), the Maternity Passport aims to support this by facilitating parents to identify their support network (including an advocate) so that gaps in support are evident and action can be taken.

Although the commitment of NHS midwives to providing equitable and individualised care to all parents was evident in the interviews, it

was also clear that the NHS setting presented many barriers to the implementation of the Together Project resources. The resources were implemented during the COVID-19 pandemic, but setting level factors identified preceded the additional pressures of this time. Midwives expressed how personalised care for people with learning disabilities was complicated by busy clinics and a lack of time; a lack of specialist support; and a lack of accessible resources. Under the Equality Act 2010 (UK Government, 2010), all disabled people have the right to reasonable adjustments when using public services, including maternity services. These adjustments include giving extra time for appointments, working with learning disability specialists, and providing information in an accessible format (NHS England, 2016). However, a survey of NHS Trusts in England in 2018 reported that less than half offered extra time at the booking or routine antenatal appointments, less than a quarter had accessible routine antenatal information, and only a half had a specialist learning disability nurse in post (Homeyard and Patelarou, 2018). Reasonable adjustments facilitate good perinatal care for people with learning disabilities (Saeed et al., 2022; Khanna et al., 2022; Ransohoff et al., 2022), more support is needed within the maternity setting to ensure these are made in practice. Learning disability nurses hold unique skills, knowledge, and values to support midwives in making reasonable adjustments but this study supports that work is needed to raise the profile of their role (Royal College of Nursing, 2021). Furthermore, pregnancy and birth are specialist subject areas which may require midwives who specialise in disabilities to meet the needs of this population.

Harnessing digital technology is considered a system enabler in England's National Transformation Programme (NHS England, 2024), but this feasibility study has identified digitalised maternity systems as a barrier to implementing the Together Project resources. Consistently across all NHS Trusts, the databases used to identify people with learning disabilities did not distinguish between learning difficulties and learning disabilities, making it difficult for midwives to identify parents who were eligible for the study as well as identifying those who needed further support. A reasonable adjustment digital flag (NHS Digital, 2024), focused on recording need, has been trialled in England with positive results (Ford, 2020). Future research involving people with learning disabilities could guide and evaluate the implementation of the flag within maternity services. Capturing the Maternity Passport within existing digital systems could also flag that a parent may require reasonable adjustments and enable engagement with the resource, even if a parent forgets to bring their paper copy to an appointment.

At an innovation level, parents with learning disabilities and the midwives who supported them reported that the Together Project resources were accessible in terms of both content and format. The innovation was considered to offer benefit for parents more broadly than those with learning disabilities. This could include people with a spectrum of learning needs, those for whom English is not their first language, or those experiencing mental health challenges. In response to these findings, the Maternity Passport has been refined to include information and support details for a broader population of parents to ensure that it is a meaningful resource for all parents who would prefer an accessible version of a Personalised Care and Support Plan (NHS England, 2019a, b). This adaption benefits the interests of a broader population of parents without impacting the resources suitability to support parents with learning disabilities.

Regarding implementation process, project midwives highlighted the value of the training they received as part of their role within the Together Project. The element of training which they found most impactful was the opportunity to speak to a parent with learning disabilities about their experiences and to seek advice first hand on respectful and sensitive communication. This supports previous studies highlighting the value of training being delivered with experts by experience (NHS England, 2021; The Health Foundation, 2016) and should be included in future implementation of Together Project resources and other maternity interventions. Future large-scale evaluation of these

resources should employ outcome measures that are accessible and meaningful to people with learning disabilities (Ip et al., 2023).

Strengths and limitations

The strength of this study is that it has drawn on an evidence-based implementation framework to identify both individual and setting level barriers to implementing and evaluating novel resources to support personalised maternity care for parents with learning disabilities. Challenges to recruiting people with learning disabilities to qualitative health research have been documented by previous studies (Banas et al., 2019; Shariq et al., 2023), the inclusive approach to research adopted by this study is a notable strength that supported a high recruitment rate of eligible midwives (17/19 eligible midwives consented, 89 %) and eligible parents (7/14 eligible parents consented, 50 %) across four participating NHS Trusts. The high recruitment rate of midwives and parents in this study, support the feasibility of evaluating these resources in practice. Conclusions are limited by the small number of parents recruited to the study and notably a lack of partners, or parents from ethnic minority groups. Future studies should employ recruitment approaches to secure representation of these groups and collect longitudinal data to determine any ongoing impact of the resources on the experience of parents engaging with the resources.

Conclusion

People with learning disabilities may flourish as parents when support and services are personalised to meet their needs (IASSID, 2008). Improving maternity care for mothers and newborns is a global priority; standards of maternal care and quality call for effective communication and co-ordinated care to ensure every parent receives adequate information and that their needs and preferences are met (World Health Organization, 2016). The Together Project resources respond to this standard by supporting professionals to deliver respectful, accessible and personalised maternity care ([www.surrey.ac.uk/togetherproject](http://www.surrey.ac.uk/togetherproject)). These resources were positively received by both midwives and parents with learning disabilities in England, but sustainable implementation will require greater support for reasonable adjustments to be made within maternity services, in line with legislation and policy (UK Government, 2010; United Nations, 2006). Further evaluation is required to determine the feasibility of implementing these resources in other countries beyond England, and to study if and how they support an equitable experience of maternity services for people with learning disabilities in other health care systems.

Contribution of paper

Problem	Parents with learning disabilities are often disadvantaged and their needs are not always recognised in maternity services.
What is already known	People with learning disabilities may flourish as parents when support and services are personalised to meet their needs. Midwives have expressed a need for support in the delivery of good care to this population of parents. The Together Project co-produced resources to support respectful, accessible and personalised maternity care ( <a href="http://www.surrey.ac.uk/togetherproject">www.surrey.ac.uk/togetherproject</a> ).
What this paper adds	This feasibility study contributes to the vision of equitable maternity care by reporting that while resources were positively received by both midwives and parents with learning disabilities, sustainable implementation will require greater support for reasonable adjustments within maternity services, in line with legislation and policy.

Ethical approval

This study received a favourable ethical opinion from Camden & Kings Cross Research Ethics Committee (ref: 21/PR/0633).

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CRediT authorship contribution statement

**Anna Cox:** Writing – original draft, Resources, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Athena Ip:** Writing – review & editing, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Scott Watkin:** Writing – review & editing, Resources, Funding acquisition, Conceptualization. **George Matuska:** Writing – review & editing, Resources, Funding acquisition, Conceptualization. **Sharon Bunford:** Writing – review & editing, Resources, Funding acquisition, Conceptualization. **Ann Gallagher:** Writing – review & editing, Funding acquisition, Conceptualization. **Cath Taylor:** Writing – review & editing, Methodology, Funding acquisition, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.midw.2024.104001](https://doi.org/10.1016/j.midw.2024.104001).

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