Supporting the delivery of good maternity care for parents with learning disabilities

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ABSTRACT

Background and objective: Despite directives to improve maternity care in general and to improve care for parents with learning disabilities, the maternity experience of parents with learning disabilities is often poor and lacking reasonable adjustments to care. The objective of this study was to develop resources - in collaboration with key stakeholders - to support the workforce in delivering good maternity care to parents with learning disabilities.

Design: A two-phase mixed-methods study.

Participants: Phase 1: 16 key stakeholders (health and social care professionals, parents with learning disabilities and their informal supporters/carers) were interviewed to understand views of best practice and inform resource development. Phase 2: 20 healthcare professionals engaged with the resources and gave feedback via online survey or discussion group to further refine them.

Findings: Thematic analysis of key stakeholder interviews indicated that good maternity care for parents with learning disabilities requires a positive and proactive approach to identifying need; reasonable adjustments to communication and providing information; and professionals working together to support and enable parents.

Key conclusions: Health and social care professionals identified barriers to the delivery of good maternity care for parents with learning disabilities, including how to identify whether a parent has learning disabilities. Professionals in maternity services require additional resources to ensure parents' needs are recognised and they are provided with personalised preparation for parenthood and sufficient support.

Implications for practice: The Together Toolkit and Maternity Passport were coproduced to support the workforce to deliver good maternity care to parents with learning disabilities, these resources are free and accessible for use [https://www.surrey.ac.uk/research-projects/together-project-supporting-delivery-good-practice-maternity-services-parents-learning-disabilities]. Further evaluation will explore acceptability and perceived impact of these resources in maternity services.

Introduction

A substantial number of parents across the world have learning disabilities; a paucity of data prevents accurate prediction but estimates suggest between 0.5% to 5% of parents have learning disabilities (Kaye, 2012; Man et al., 2017; Patient Experience Network & Change, 2015). Women with learning disabilities currently experience poorer pregnancy outcomes (Mitra et al., 2015; Tarasoff et al., 2020) and are more likely to have their children removed from their care (Tarleton et al., 2006). Numerous interrelated factors determine the

outcome for parents with learning disabilities and their children, including societal factors, parenting skills, social support and services (Feldman and Aunos, 2020). Maternity services play an important role in addressing these factors.

In England, the National Maternity Review, 'Better Births' (National Maternity Review, 2016) set out the vision for a maternity service that improves outcomes and reduces inequalities, stating 'people with learning disabilities would benefit from the option of accessing information in easy-read format, and healthcare professionals taking time to ensure that they understand what is happening and the choices they

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can make' (p.58). Despite this vision, reasonable adjustments do not appear to be commonplace in NHS Trusts in England (Malouf et al., 2017; Homeyard and Patelarou, 2018).

The recent report 'Better Health and Care for All' published by the National Institute for Health Research (NIHR) acknowledged that many parents with learning disabilities will experience a formal assessment of their parenting and recommended they 'should be supported by maternity services to give them the best possible chance of passing the assessment' (NIHR, 2020). However, a systematic review of antenatal care provision for women with learning disabilities reports that midwives do not feel they have the necessary knowledge to do this well, and that they want guidance on how to meet the care and communication needs of parents with learning disabilities (Homeyard et al., 2016). Midwives report feeling unsupported in delivering good maternity care to people with learning disabilities (Castell and Stenfert Kroese, 2016).

The present study - in collaboration with key-stakeholders - aimed to develop resources to support the workforce in delivering good maternity care to parents with learning disabilities.

Design

A two-phase mixed-methods study. Phase 1 aimed to understand views of best practice in maternity care for parents with learning disabilities and the challenges and opportunities to delivering care well. Phase 2 aimed to develop and pilot resources to support the workforce to deliver good maternity care to parents with learning disabilities. As phase 1 informed phase 2, the methods and results for each phase are presented in turn in the sections that follow.

The study was underpinned by Appreciative Inquiry (Watkins and Cooperrider, 2000), selected because: it focuses on what works well and on how things might be better; it has excellent potential to develop trust and meaningful collaboration with staff in pre- and post-natal care rather than identifying failings and blame; and it contributes to the development of an appreciative learning culture where a research team can work collaboratively with health and social care professionals.

The inclusion of people with learning disabilities in both the research team and in the advisory group ensured that the study was co-produced to be relevant and targeted to the issues of importance to parents with learning disabilities.

This study received a favourable ethical opinion from the University of Surrey Ethics Committee (UEC ref: FHMS 19-20 004 EGA).

Phase 1: Understanding views of best practice in maternity care for parents with learning disabilities

Method

Materials

Study materials were designed with experts by experience to be accessible for parents with learning disabilities. This included an audio version of the information sheet, a film of a father with learning disabilities introducing the study, and an 'easy read' information sheet and consent form. The issue of confidentiality and exceptions to this were made clear within study materials, ensuring safeguarding issue could be acted upon.

In consultation with the advisory group, the research team developed a set of questions to elicit the experience of parents with learning disabilities and their informal supporters/carers. Shaped by the 'appreciate' and 'imagine' stages of appreciative inquiry, questions asked for the best example of support they had received during pregnancy, birth and the year beyond (if appropriate). Enquiring 'what was good about it?' and for them to describe the best possible support they imagined could be given to parents in the future. These questions could be answered in an online survey (https://www.onlinesurveys.ac.uk/) or via interview with the study researcher.

Interviews with health and social care professionals explored experiences of working with parents with learning disabilities. Also drawing on appreciative inquiry, the questions focused on what currently works well and what could be improved to support the delivery of good maternity care.

Procedure

Parents with learning disabilities, their informal supporters/carers, and health and social care professionals were invited to participate in phase 1 of the study. Invitations were shared via social media sites, through groups and charities supporting people with learning disabilities, at learning disability focused conferences, via member organisations, and via health and social care professionals already engaged with the study. In addition, the Specialist Midwife for Learning and Physical Disabilities at the local NHS trust shared information about the study with parents they were supporting. Participants with learning disabilities were able to look at the questions prior to the interview to further consider their participation and responses.

Interviews were conducted remotely using audio-visual technology and recorded for transcription, with consent.

Interview participants

A total of 16 key stakeholders were interviewed regarding their experience of maternity care. Table 1 gives details of interviewees by role, area of the UK, and the duration of the interview.

Despite a broad recruitment approach, both parent participants and informal supporters/carers were recruited via the Specialist Midwife for Learning and Physical Disabilities. The specialist midwife was able to ensure the information was understood and that consent was informed. Parents and informal supporters/carers chose whether they wanted the specialist midwife to be present during the interviews.

All professional participants had experience of supporting a parent with a learning disability in the last two years. The cumulative experience of participating health and social care professionals covered the whole maternity journey from pregnancy, through birth and the postnatal period to the first years of life. Both parents interviewed were mothers who had given birth within the last year.

Survey participants

No complete responses were received via the online survey.

Data analysis

Interviews were transcribed in full, anonymised and thematically analysed (Braun and Clarke 2006). Transcripts were read and reread, followed by systematic line-by-line coding. Codes were reviewed and refined through constant comparison, then amalgamated, or sometimes expanded, to form themes. Two members of the research team (AC & TP) independently coded the data and discussed the development of themes. The data for each theme was collated and reviewed by a third researcher (AG) to ensure the viability of individual themes, that they were clear and distinct from each other, and that they were underpinned by a unifying concept.

Results

One analytical theme emerged, encompassing professional, parent and informal carer views. That is, good maternity care for parents with learning disabilities requires: a positive and proactive approach to identifying need; reasonable adjustments to communication and providing information; and professionals working together to support and enable parents. This analytical theme has three descriptive themes underpinning it: 1) Identifying need: 'Parents with a learning disability can slip

Table 1
Phase 1 interviews.

Participant	Role	Area	Interview length
TP001	Midwife	Surrey	90 min
TP002	Advanced Social Work Practitioner	Greater London	30 min
TP003	Community Support Worker	Leeds and Bradford	40 min
TP004	Community Support Worker	Coventry and Warwickshire	38 min
TP005	Social Worker	Surrey	30 min
TP006	Deputy Service Manager (non-profit organisation)	London	33 min
TP007	Community Support Manager	Greater Manchester	29 min
TP008	Midwife	Suffolk	38 min
TP009	Midwife	Sussex	27 min
TP010	Midwife	Devon	27 min
TP011	Learning Disability Nurse	Nottingham	33 min
TP012	Learning Disability Nurse and Health Visitor	Surrey	36 min
TP013	Mother with learning disabilities	Surrey	40 min
TP014	Informal carer – friend of family	Surrey	29 min
TP015	Mother with learning disabilities	Surrey	35 min
TP016	Foster mother during mother and baby placement	Surrey	23 min

Table 2
Illustrative quotes for theme 1.

Identifying need: 'Parents with a learning disability can slip through the net'	
Learning disability awareness	*'I only qualified two years ago, we had no training at all throughout our midwifery training, and then qualified, so for the first year we didn't have any training at all, then the second year we merged with another Trust who had an online package, but it's literally a half an hour package about learning disabilities and autism'* [TTP08 - Midwife]
Thinking beyond a diagnosis	*'…about 50% of people with a learning disability will have mental health issues, they come with substance abuse sometimes, they come with domestic abuse, they might be teenagers, that there's all sorts of confounding issues ..[..].. the trouble is people aren't seeing the bigger picture, that actually what encompasses everything is the learning disability'* [TTP01 - Midwife]
Adopting a positive mindset	*'they were expecting a mum who didn't really care, they hadn't sent [child's name] , and so they said, "You know, have you named him?" and she said, "Yeah, his name's [child's name]," they knew all that, and someone had told them that [mother's name] didn't want to go there, so they were thinking they had a non-caring mum turning up, which was, you know, not the case at all'* [TTP14 - Informal supporter/carer]
Asking key questions	*'..it can work out from just a few key questions, so it's about taking that time and often to talk about things like about their broader life and not just about their health problems that they're presenting with or you know, that kind of thing'* [TTP04 - Community Support Worker]

through the net'; 2) Preparing for parenthood: 'She needed to be treated differently to make it equal'; 3) Supporting the journey to baby and beyond: 'I had all the support that I needed from people' (see tables 2 – 4 for illustrative quotes).

Descriptive theme 1–identifying need: 'parents with a learning disability can slip through the net'

This first theme brings together views about the importance of getting to know parents to determine their individual needs. Professionals reported feeling that many parents with a learning disability were failed at the very start of their journey to parenthood as their needs were not recognised. One participant stated *'parents with a learning disability can slip through the net and I think particularly people who have milder learning disabilities'* [TTP12 - Learning Disability Nurse and Health Visitor]. This descriptive theme has four subthemes that illustrate participant views on how the needs of parents can be identified more effectively with an informed, flexible, positive and curious approach. See Table 2 for illustrative quotes for this theme.

Subtheme 1a: learning disability awareness

The majority of professionals interviewed referred to a lack of training or education regarding learning disabilities and how this might impact the care they deliver. Where training had been received, it was felt to be insufficient. Professionals voiced enthusiasm for training and role modelling of good practice, to enable them to *'get it right'* for parents with learning disabilities in the future.

Subtheme 1b: thinking beyond a diagnosis

Professionals in maternity services spoke of accessing systems and *'trying to marry up all of the records'* [TTP08 - Midwife] to see if the parent had diagnosed learning disabilities. This subtheme describes the need to routinely consider whether a parent requires reasonable adjustments to

be made, regardless of whether they are known to have a diagnosed learning disability. Thinking beyond a diagnosis also includes looking past other existing labels or classifications. Many of the interviewees referred to factors that make identifying a learning disability challenging. Parents with learning disabilities may be young, in care, and experience poor mental health or domestic abuse. These factors must be considered alongside their disability rather than overshadowing their need for a different pathway of maternity care.

Subtheme 1c: adopting a positive mindset

Recognition that a parent with learning disabilities may experience stigma and fear ran through the interviews. Parents provided examples such as the fear of judgement and fear of losing their child. Professionals felt these fears prevented parents with learning disabilities from sharing important information with them. One parent with learning disabilities described feeling judged by staff before they had even met her. Participants challenged the fairness of a system where parents with learning disabilities had to prove their worth. Interviews with parents, carers and professionals suggested that there was a need for a positive mindset to be adopted and communicated, a mindset focused on strengths and capabilities and the belief that people with learning disabilities *'can be good enough parents'*.

Subtheme 1d: asking key questions

Health and social care professionals who are not specialists in learning disabilities suggested they need to know parents well to feel able to ask directly if they have learning disabilities. This may be indicative of a lack of confidence or a discomfort in enquiring about learning disabilities generally. In comparison, professionals who specialise in working with people with learning disabilities felt confident to identify parents with learning disabilities and outlined key questions they would ask parents as part of this identification.

Table 3
Illustrative quotes for theme 2.

Preparing for parenthood: 'She needed to be treated differently to make it equal'	
Tailoring communication	'..to you and I, you know, they're little nuances, colloquialisms, but to a woman with a learning disability that can, you know, be terrifying' [TTP10 - Midwife]
	'.. it's about looking at role-modelling, you know, lots of kind of practical resources, and that might be as simple as kind of having a baby doll and mirroring what they might be doing with their baby so that they can actually see and watch what's happening' [TTP06 - Deputy Service Manager]
Accessible information	'every parent who comes in will have kind of different needs, a different ability to learn and take on information, and so we really have to work with them to make sure that it's going to suit them and that it's something that they can take home and continue to work with' [TTP06 - Deputy Service Manager]
Adjusting time & place	'they're very much smaller groups, like I say, and it's over a much longer period of time, and they have two family support workers generally who run those, so they're much able to be individualised and take questions and explain things in a way that people can understand' [TTP01 - Midwife]

Descriptive theme 2–preparing for parenthood: 'she needed to be treated differently to make it equal'

The second descriptive theme draws together participants' perspectives on preparing people with learning disabilities for parenthood. The inequality of a standard approach across all parents was captured by a community support worker: *'they've treated her like, you know, everybody else. But, actually she needed to be treated differently to make it equal'* [TTP03 - Community Support Worker]. The need to make reasonable adjustments when working with people with learning disabilities was understood, however, participant narratives suggested these adjustments are not always made in maternity services. The descriptive theme 'preparation for parenthood' has three subthemes that illustrate participant views on how communication, information and the time and space allotted to preparation for parenthood need to be adjusted. See Table 3 for illustrative quotes for this theme.

Subtheme 2a: tailoring communication

Health and social care professionals described how choices regarding communication can demonstrate respect, or a lack of, for the parent with learning disabilities. Offering choice, checking understanding and creative delivery of information were all recognised as positive approaches to ensuring good communication. Parents with learning disabilities expressed confusion when professionals used long words or spoke too quickly and looked to other people in their support network to provide clarity, emphasising the need for professionals to check understanding at the point of information delivery. The value of checking that information had been meaningfully understood was powerfully demonstrated by several stories involving parents with learning disabilities processing information in its literal form.

Practical and physical demonstrations that were fun and involved miming, role playing, and games were suggested by a range of health and social care professionals (midwife, community support worker, social worker, deputy service manager) as more successful communication strategies that could and should be employed with parents with learning disabilities.

Subtheme 2b: accessible information

Many professionals reported not having time to source suitable resources to share with parents with learning disabilities. However, this subtheme encompasses more than the need for information to be provided in an understandable format. It also highlights the value of enabling parents to have continued access to accessible information in

their own home, to reflect on and make sense of information as and when they choose. Paper records that include information *on* and *for* parents were suggested as an empowering innovation, enabling a parent-led sharing of personalised information with professional and informal networks, as well as permitting any gaps in information provision to be identified and actioned.

Subtheme 2c: adjusting time & place

Professionals highlighted that good maternity care for parents with learning disabilities requires adjustments to the time and place in which support is delivered. However, language such as 'luxury' and 'beauty' were used regarding allowing extra time for parents. Maternity staff reported feeling the pressure of high caseloads, a lack of time and busy waiting rooms resulted in consultations being rushed.

Participants suggested adjustments that could benefit parents with learning disabilities in preparing for parenthood, including extra time to become familiar with the ward or birthing unit before the birth, extra time in classes to prepare for birth and beyond, or one-to-one preparation classes within the home. While these adjustments were described positively, the discussion around these personalised preparations for parenthood felt aspirational rather than realistic.

Descriptive theme 3–supporting the journey to baby and beyond: 'I had all the support that I needed from people'

This third and final theme draws attention to poor support networks and an experience of feeling socially isolated; and details a positive approach to supporting the journey to parenthood for people with learning disabilities. This theme has four subthemes that illustrate participant views on the importance of a complete circle of support, requiring professionals to work together to enable the parent, recognising that familiarity and trust are essential elements of providing support for parents with learning disabilities. See Table 4 for illustrative quotes for this theme.

Table 4
Illustrative quotes for theme 3.

Supporting the journey to baby and beyond: 'I had all the support that I needed from people'	
Working together	'overall it was just ensuring as well that everyone was sort of linked up with each other, because I think sometimes, you know, with parents with learning disabilities they might have lots of different people involved, so their parent might have a Social Worker, their child or unborn child might have a Social Worker, and then they've got the hospital person, they might have previously had community learning disability team involved, so it's, I think part of it as well is with the person's permission, ensuring that everyone's keeping up communication' [TTP12 - Learning Disability Nurse and Health Visitor]
Building trust	'I don't really like, I obviously am talking to like some people, I'm quite, I don't know, just me in a way, I prefer to talk to someone that I know that would understand me' [TTP13 - Mother with learning disabilities]
Filling gaps in support	'..not replicating the support that someone's getting but just finding the gaps really and sort of fitting in where there's things missing' [TTP04 – Community Support Worker]
	'They aren't getting any support, they've lost their baby because of their learning disability, there's no other reason that they've lost it, you know, and there is nobody that is going to help them grieve or help them through that process. And I think that that is a massive gap' [TTP03 – Community Support Worker]
Enabling parents	'So often the conversations are between professionals and between the mum's family but not, not sort of directly with her, I felt like she wasn't involved enough in the meetings or to have a voice of her own really' [TTP02 - Advanced Social Work Practitioner]

Subtheme 3a: working together

Health care professionals shared positive examples of working in partnership with their health care colleagues to deliver good maternity care. However, interviews suggested there were some difficulties in joint working and information sharing between health care and social care, and between adult social care and children's social care (although no professionals working in child social care were interviewed for this study). The benefits of a united circle of professional support and a common agenda that recognises the support needs of the entire family were recognised by health and social care professionals.

Subtheme 3b: building trust

The importance of a support network that is familiar and trusted was emphasised by all of the parents and informal supporters interviewed. They explained that continuity in their support network helped them to feel understood and they did not like change. Every professional interviewed perceived trust and rapport as important to successfully supporting parents with learning disabilities. However, professionals did not describe the value of trust in terms of how it made the parent feel, rather that it was an aid to communication and learning. Many professionals will play a role in supporting a parent with learning disabilities, however interviews suggested that the importance lies on there being one consistent professional.

Subtheme 3c: filling gaps in support

The difference that a complete network of support can make to a parent with learning disabilities was reflected upon by one parent. She compared her previous experience of postnatal depression, when support had been lacking, to her recent and much more positive experience of motherhood where she felt she had the support she needed. Many examples were given by professionals of areas where they had identified a gap in support: someone to attend appointments with them, a 'mothering' role model, a birth partner, respite from caring for a baby, breastfeeding support, someone with whom to attend a playgroup, or an advocate through a child protection case. Best practice was felt to be limited by lack of awareness of and access to supportive resources; this involved looking to the third sector and localised provision meant parents could experience a 'postcode lottery'.

Given that a high percentage of parents with learning disabilities have their children removed, three social care professionals expressed concern that the system does not provide support to parents at this challenging time.

Subtheme 3d: enabling parents

One participant described health and social care professionals as 'problem solvers' with a tendency to tell people what to do, suggesting that professionals may need to reflect on their instincts and step back. In the context of supporting care for the baby, professionnals described that an enabling approach was being alongside people and not telling them what to do. However, participants mainly spoke of enablement, or a lack of, in terms of information provision. Parents, informal carers and professionals all referred to information being witheld from parents on the assumption that they would not understand. One parent shared her experience of a professional not taking the time to provide explanations in a way that she could understand; she reflected on wanting time and privacy.

Identifying what 'good' looks like in maternity services is only the first step in improving the experience of parents with learning disabilities. Phase 2 of this study built on this understanding and developed resources to support the workforce to deliver good maternity care to parents with learning disabilities

Phase 2: Developing and piloting resources to support the delivery of good maternity care to parents with learning disabilities.

Method

Co-development of materials

The research team and advisory group synthesised findings from phase 1 with their existing knowledge and experience to develop the Together Toolkit and Maternity Passport to support the delivery of good maternity care to parents with learning disabilities. In addition to the contribution of parents/people with learning disabilities, the expertise of the research team and advisory group spanned learning disabilities, maternity, health visiting, family law, care ethics, social work, clinical psychology and health psychology. Development was iterative, with three rounds of review informing the co-production of the Together Toolkit and Maternity Passport.

The Together Toolkit consists of a set of guidelines that propose that good maternity care for parents with learning disabilities requires a focus on three key areas: identifying need; preparing for parenthood; and supporting journey to baby and beyond. Values were drawn up to underpin the guidelines. For each of the three elements of practice, the Together Toolkit provides a practice discussion followed by actions to complete and questions for reflection and discussion. At the end of the Together Toolkit, there are relevant resources or "tools" to support the delivery of good maternity care for parents with learning disabilities.

The Maternity Passport accompanies the Together Toolkit, however is completed with and held by parents with learning disabilities. Within three accessible and 'easy read' sections ('about me and my pregnancy', 'getting ready to be a parent' and 'the support I need'), the Maternity Passport details information about: the parent, their communication needs, their experience of practical parenting tasks, their antenatal and postnatal preferences, and the support they need on their maternity journey.

Procedure for piloting

There were two approaches to piloting the Together Toolkit and Maternity Passport with the maternity workforce. Parents with learning disabilities were not invited to give feedback at this stage. Firstly, a link to an online survey was distributed via social media groups focused on relevant professionals. This anonymous survey collected basic demographic information, ascertained professional role, length of work experience, county in England in which they worked, and experience of supporting a parent with learning disabilities. Participants were then asked to feedback on the resources in terms of clarity of presentation, ease of navigation, whether it would give confidence in identifying and supporting a parent with learning disabilities, whether it would be useful in their professional practice and whether they would recommend it to others. A five-point Likert scale allowed participants to indicate how much they agreed or disagreed with each statement. This was followed by a free text section where participants could suggest changes to the resources.

The second approach was a discussion group with four representatives from safeguarding maternity teams recruited through contacts at NHS Improvement, the London Maternity Partnership and the London Clinical Networks.

Participants

Twenty health care professionals took part in the pilot. Sixteen people responded to the online survey. Thirteen respondents gave details of their profession: eight midwives (including one practice development midwife, one community midwife and two safeguarding midwives); one support manager; one student health visitor; one acute liaison nurse; one consultant obstetrician; and one teaching fellow. All had supported a parent with a learning disability during pregnancy, birth or in the postnatal period. In addition, four safeguarding nurses and midwives took part in the discussion group.

Table 5

Online survey feedback for maternity passport.

Question	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
The content of the Maternity Passport is presented clearly	0	0	0	11 (73.3%)	4 (26.7%)
The layout is logical and easy to understand	0	0	0	10 (66.7%)	5 (33.3%)
The Maternity Passport contains information which would be useful for a maternity professional	0	0	0	8 (53.3%)	7 (46.7%)
This Maternity Passport contains information which would be useful for a parent with a learning disability	0	0	4 (26.7%)	6 (40%)	5 (33.3%)
I would find the Maternity Passport useful in my professional practice	0	0	1 (6.7%)	8 (53.3%)	6 (40%)
I would recommend the use of the Maternity Passport to other professionals	0	0	0	9 (60%)	6 (40%)

Table 6

Online survey feedback for toolkit.

Question	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
The content of the Toolkit is presented clearly	0	0	1 (6.3%)	11 (68.8%)	4 (25%)
The layout of the Toolkit is logical and easy to navigate	0	0	1 (6.3%)	11 (68.8%)	4 (25%)
This Toolkit would give me confidence in identifying a parent with a learning disability	0	1 (6.3%)	2 (12.5%)	12 (75%)	1 (6.3%)
This Toolkit would give me confidence in supporting a parent with a learning disability	0	0	3 (18.8%)	11 (68.8%)	2 12.5%)
I would find this Toolkit useful in my professional practice	0	0	2 (12.5%)	10 (62.5%)	4 (25%)
I would recommend this Toolkit to others	0	0	1 (6.3%)	9 (56.3%)	6 (37.5%)

Results

All respondents reported that the Maternity Passport was clear and easy to understand, that it would be useful for maternity professionals and they would recommend it to their colleagues. The majority of respondents felt it also contained information that would be useful to parents with learning disabilities (73%).

Respondents felt the Together Toolkit was clear (81%), easy to navigate (94%), and would develop confidence in identifying (81%) and supporting (81%) parents with learning disabilities. The majority of respondents reported that the Toolkit would be useful in practice (88%) and they would recommend it to colleagues (94%) (see Tables 5 and 6 for full results).

Feedback given both online and in the discussion group led to refinements to the Together Toolkit and Maternity Passport. Amendments included changing colours away from a traffic light system that some found confusing, adding a printable checklist of recommended actions for professionals to the Together Toolkit, and within the Maternity Passport a checklist for parents was added to enable parents to indicate whether they are comfortable with certain tasks (for example, changing a nappy).

Discussion

This study collected views and experiences of 'good practice' from the perspectives of parents with learning disabilities, their informal supporters/carers, and the health and social care professionals who support them. A multi-disciplinary team, including parents/people with learning disabilities, built on these findings using their experience and expertise to develop and pilot resources to support the delivery of good maternity care for parents with learning disabilities.

The first and arguably the most significant barrier to 'good practice' was how to identify whether a parent has learning disabilities. Participant opinion was that 'parents with a learning disability can slip through the net' and, as such, are failed by services at the very start of their journey to parenthood. Midwives reported feeling unprepared and unsupported to identify which parents have learning disabilities. The need for learning disabilities training was emphasised, as it has been in previous studies (Malouf et al., 2017). The introduction of mandatory learning disability training for all health and social care professionals is a positive step in this area (Department of Health & Social Care, 2019).

Our findings suggest that health and social care professionals need to develop confidence in how to talk about learning disabilities, this supports previous suggestions that practitioners would benefit from opportunities to engage with parents with learning disabilities (Godsell and Scarborough, 2006), to gain insight on how it feels to be asked, or not asked, important questions regarding their disabilities.

A fundamental element of 'good' maternity care is a positive mindset towards the parenting capabilities of people with learning disabilities. There is a stigma experienced by parents with learning disabilities and a pressure to prove themselves to be able parents (Theodore et al. 2018; Gould and Dodd, 2014; Walsh-Gallagher et al., 2012; Malouf et al., 2017). Our data provides further support that parents with learning disabilities experience negative perceptions of their capabilities as parents. Participants in this study felt stigma and a focus on limitations hindered presentation at and disclosure to maternity services for parents with learning disabilities. This study did not interview parents who had avoided engagement with services, so this could not be explored. People with learning disabilities value a workforce with a positive attitude (Davies and Matuska 2018), how to support and sustain this attitude requires deeper exploration.

Professional intentions regarding accessible information provision aligned with legal requirement (Office for Disability Issues, 2011; Public Health England, 2016; NHS England, 2015, 2017). However, our findings support previous research in suggesting suitable information resources are not always available (Homeyard and Patelarou, 2018; Patient Experience Network & Change, 2015). Without the provision of

accessible information, meaningful involvement in decision-making is impossible. The Together Toolkit responded to this finding and provides maternity services with the details of resources considered accessible by participants.

Time was commonly cited as a barrier to preparing people with learning disabilities for parenthood. The pressure on health professionals within maternity services is highlighted in 'Better Births' (National Maternity Review, 2016) and a lack of time has been reported to significantly influence support available for women with learning disabilities (Castell and Stenfert Kroese, 2016; Tarleton et al., 2006). The Together Toolkit aims to save practitioners time by signposting to accessible written materials and providing direction and reflection on suitable communication styles. However, the most significant time related barrier to effective preparation for parenthood is the time required for longer and additional appointments, this would require change at a policy level.

'Better Births' (National Maternity Review, 2016) suggests that pressure on health care professionals could be reduced if all maternity data were captured electronically rather than 'paper-based'. Our interviews suggested that this is not best practice for parents with learning disabilities who find paper notes more accessible. Paper notes that include information on and for parents were proposed to enable parents to reflect on and make sense of the information they need to support their journey through maternity services.

Consistent sharing of information was reported as a barrier to good maternity care for parents with learning disabilities. Paper records held by the parents themselves would be a potential low cost and simple method of ensuring consistent and individualised information sharing. Paper notes for parents with learning disabilities and autism have been proposed and developed in the past (Vernon, 2019) but the extent of their implementation and evaluation is unclear. Data collected in our study informed the development of a 'paper based' Maternity Passport. The Maternity Passport provides the parent with a place to record the information about themselves and their journey through maternity services, thus supporting opportunity for individualised and consistent information sharing with professionals, family and friends.

Parents with learning disabilities are more likely to experience social isolation or weak support networks and are less likely to have parenting role models or intergenerational support (Emerson et al., 2005, 2015). Inter-professional collaboration is essential as it is associated with positive outcomes for parents (Aunos and Pacheco, 2013; Castell and Stenfert Kroese ,2016). The Maternity Passport seeks to support inter-professional collaboration by enabling each professional to see who else is involved in the parents' support circle and to understand what has, or has not, been discussed with them. The Maternity Passport will also support identification of gaps in support to alert professionals to necessary referrals.

Continuity of midwifery care is thought to contribute to a positive birth experience for women generally (Dahlberg and Aune, 2013), and as such is recommended within 'Better Births' (National Maternity Review 2016). There are challenges to the continuity of care model (Taylor et al., 2019), but our findings suggest that this should be considered best practice for women with learning disabilities, acknowledging that trust could be more challenging for parents with learning disabilities who may be fearful of losing custody of their child (Höglund and Larsson, 2013; Sheerin et al., 2013).

There are many factors that may inhibit a parent with learning disabilities from flourishing as a parent and not all are able to succeed. However, it should not be assumed that parents with learning disabilities will be unable to raise their child well, the focus should be on enabling parents with learning disabilities to be the best they can be, while safeguarding the interests of their child/ren. That said, parents with learning disabilities are less likely to raise their children than parents without disabilities. In fact, it is estimated that as many as to 40 – 60% of parents with learning disabilities have children removed from their care (Emerson et al., 2005). For the high number of parents who

do lose custody of a child, it may not be a one-off experience and their support needs may be complex and change across time (Mayes and Llewellyn, 2012). Health and social care professionals require appropriate knowledge and skills to determine parents' needs and respond effectively to their grief. Our findings reiterate the need for further work in this area (Baum and Burns, 2007).

The values recommended within the Together Toolkit (trust, open-mindedness, gentleness, enablement, time, humility, equality, and respect) pave the way for a values-based approach to the development of authentic partnerships with parents with learning disabilities. Enacting these ethical values will support professionals, using the toolkit, to be responsive and sensitive to parents' needs and preferences. In most situations, it will be possible for parents and professionals to work together effectively to support parents to be the best they can be.

Limitations

One limitation of the study was that the parents and informal supporters/carers were all recruited by a specialist midwife for physical and learning disabilities, who was also present during the interviews. While this ensured that participants were supported to understand the study and give informed consent, it may have caused a response bias, as they were talking in front of a professional involved in their care. Additionally, it meant only parents who had received specialist support were involved in the study. Good practice guidance on working with parents with learning disabilities recommends the development of a range of specialist services, including expertise in working with parents with learning disabilities within midwifery (Department of Health & Department for Education and Skills, 2007). Specialist midwives for physical and learning disabilities are rare and this study was not designed to evaluate their effectiveness, however it is notable that the parents and their informal supporters/carers described a trusted, consistent relationship and requested the presence of the midwife in their interviews. The value of specialist midwife roles in learning disabilities warrants exploration.

Even though many community groups and health and social care professionals were approached to help recruit parents with a learning disability, recruitment proved difficult and only two mothers with learning disabilities participated in interviews. The challenges of recruiting parents with learning disabilities have been noted in previous research (Malouf et al., 2017; Theodore et al., 2018). Many parents with learning disabilities have had experiences that have left them wary or fearful of sharing their stories (Homeyard et al., 2016). Recruitment challenges were amplified by restrictions impacting the collection of data during 2020.

As none of the parents interviewed were going through care proceedings, this study cannot comment on what 'good' support looks like in this specific context. Our invitations to participate in research were for 'parents' so not specifically aimed at mothers. However, we did not have any responses from fathers. Previous research has indicated that fathers feel excluded in research on parents with learning disabilities (Homeyard et al., 2016).

This study represents inclusive research, it was strengthened by input from an expert by experience who has learning disabilities and is also a father, and therefore has first-hand knowledge of the challenges and opportunities of being a parent with learning disabilities. Transparency regarding the role of people with learning disabilities is beneficial to future inclusive research (Walmsley, 2004). The expert by experience advised on the design of the study and on the accessibility of recruitment and materials. He recommended organisations to support recruitment, shared information on the study at learning disability conferences and he prepared an introductory film on the study for parents with learning disabilities. He guided an accessible summary of report findings, advised on the content of publications and has been invited to co-present the findings at a conference with the lead researcher. In addition, both the expert by experience in the research team and the expert by expe-

rience in the advisory group (a mother with learning disabilities) are continuing to support the evaluation of these resources in practice.

Conclusion

This study contributes to our understanding of 'good practice' in maternity care for parents with learning disabilities through the views and experiences of parents with learning disabilities, their informal supporters/carers, and the health and social care professionals who support them. Building on this understanding, resources to support the workforce to deliver good maternity care to parents with learning disabilities were co-produced, piloted and are free and accessible for use [https://www.surrey.ac.uk/research-projects/together-project-supporting-delivery-good-practice-maternity-services-parents-learning-disabilities]. Further evaluation will explore acceptability and perceived impact of these resources in maternity services.

Author contributions

Anna Cox: Conceptualization, Funding acquisition, Methodology, Resources, Formal analysis, Writing - Original Draft. **Treena Parsons:** Study administration, Investigation, Formal analysis, Writing - Review & Editing. **Scott Watkin:** Resources, Writing - Review & Editing. **Ann Gallagher:** Conceptualization, Funding acquisition, Methodology, Writing - Review & Editing

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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.2021.103073.

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