

Holding it all together

Understanding how far the human rights of women facing disadvantage are respected during pregnancy, birth and postnatal care



About us

Birth Companions is the UK's leading voice on the needs and experiences of pregnant women and new mothers facing severe and multiple disadvantage. We offer practical and emotional support to women before, during and after their baby's birth in prisons across England and in the community in London. We think much more can be done to improve care for pregnant women and new mothers who experience multiple disadvantage, so we commission research and develop policy to make services better during this crucial time.

Birthrights is the UK's only organisation dedicated to improving women's experience of pregnancy and childbirth by promoting respect for human rights. We believe that all women are entitled to respectful maternity care that protects their fundamental rights to dignity, autonomy, privacy and equality. We provide advice and legal information to women, train healthcare professionals to deliver rights-respecting care and campaign to change maternity policy and systems.

We are grateful to **Trust for London** for funding this important piece of research.



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To cite this research, please use:

Birthrights and Birth Companions (2019). *Holding it all together: Understanding how far the human rights of woman facing disadvantage are respected during pregnancy, birth and postnatal care.* London [online].

Acknowledgments

This report would not have been possible without the women, professionals and volunteers who shared their stories and experiences with us. We are very grateful to everyone who took part for their openness, honesty and expertise.

We are also very grateful to the steering group for the research: Tamsin Bicknell, Corinne Clarkson, Jill Demilew, Rayah Feldman, Tanya Pinnock and Zack Ahmed for their invaluable insight, and to the peer researchers from Revolving Doors Agency who shaped our early thinking.

Particular thanks are due to Philippa Machin, who was instrumental in organising the focus groups, to all the volunteers who transcribed interviews and to the team member from Hibiscus who acted as interpreter for one of the interviews.

We would like to thank all the organisations who helped us to recruit participants: the Happy Baby Community, Just4Kids Law, members of the London Network of Nurses and Midwives, the Faculty for Homeless and Inclusion Health, Family Nurse Partnership, the Institute of Health Visiting and Wilson Solicitors LLP.

Finally, we are grateful to Crisis, Maternity Action, NHS England, the Royal College of Midwives and Tower Hamlets Council, whose perspectives on our findings have strengthened this report.

Foreword

Kathryn Gutteridge, President, Royal College of Midwives

The complexity of maternity care in a multicultural United Kingdom with social and economic inequalities is acknowledged throughout service provision, commissioning and researchers alike. Women and their families expect to receive high quality, evidence-based care that will provide them with the cornerstone to their parenting journey. However, if you are a woman facing severe disadvantage then the story is very different.

Birth Companions and Birthrights have frequent contact with women in highly difficult circumstances and in *Holding it all together* they have explored the themes and realities of their journeys through our maternity systems. Some of these women will have experienced horrific traumas in the UK or in other countries, many are simultaneously dealing with a huge range of issues and needs, and some may have very little hope left for the future in their fragile lives. These women are at great risk of further traumatising, are fearful of authority and expect the worst or very little from care providers.

When working with women facing severe and multiple disadvantage, midwives and maternity professionals come up against a number of barriers. Education and professional knowledge is often lacking, so that the majority of maternity care is provided in a generic fashion, despite these women bringing with them a multitude of risk factors that require a personalised response. Women require care not only from the NHS; they need help from and coordination across public services.

One of the most basic and fundamental issues is that of housing, and yet we know that midwives struggle on a daily basis to access those who can assist with this issue. The movement of asylum-seeking women can also create problems and confusion.

Midwives speak of women being moved with little notice, late in the pregnancy and with no immediate maternity contact to pass on vital information. Mental health services admit that they are overwhelmed in some areas with the effects of asylum seekers and trafficked women's needs. These women more often will require treatment in some way or other throughout their psychological life, and one can only imagine the impact upon the children and family.

Undoubtedly, maternity providers will feel that they themselves are also in need of support when working with women who are in situations of difficulty and distress. We owe it to our midwives and maternity professionals to make navigating and providing the care for women much easier.

Whilst the problems in this report are clear, progress is already being made on some of the solutions. Continuity of carer mitigates many of the issues raised, particularly by simply reducing the number of times a woman has to tell her story, avoiding re-traumatising and confusion.

Provision of specialist midwives and teams for vulnerable women can, as the report highlights, hold significant benefits for women, while also reducing the impact upon maternity care providers, but these midwives and teams need to have optimal

caseloads if they are to be effective. It is vital that those providing care for such a group of women can access psychological supervision, thereby reducing the risk of acquired trauma.

I strongly believe that this report is vital to all services providing maternity care but also to those who are in the networks around them. Housing, mental health, police and border agencies, education and many more need to be more aware of the implications of working in silos. If we are to reduce the risk of stillbirth, maternal death and injuries acquired during the childbearing episode, and reduce the incidence and impact of health and social inequalities across generations, it has never been more important to highlight the needs of the women experiencing severe and multiple disadvantage.

Introduction

In 2017, Birthrights and Birth Companions started a joint project to explore women's experiences of maternity care in London through our combined prisms – Birthrights' expertise in human rights in childbirth and Birth Companions' experience in supporting women facing multiple disadvantage through their pregnancy. We set out to investigate whether women already experiencing disadvantage in many parts of their lives could access respectful maternity care that protected their fundamental rights to safety, dignity, autonomy, privacy and equality.

Our findings build on the growing body of evidence that women facing severe and multiple disadvantage are more likely to die during pregnancy or after childbirth,¹ and that their babies are also more likely to die.² Black women have five times the risk of dying during pregnancy compared to White women; Asian women have twice the risk.³ Women facing multiple disadvantage also experience poorer maternity care, need extra support and trusted relationships to navigate their care,⁴ and face inequities in the current provision of care. They are more likely to experience mental ill health during pregnancy, but less likely to be offered support.⁵ Support available to such women can vary widely between different geographical areas in London.⁶

Respecting women's fundamental human rights to dignity, autonomy and equality should be central to the delivery of high quality, safe maternity care, as the NHS Maternity Transformation Programme recognises.⁷ Yet our research highlights particular areas where the rights of women facing severe and multiple disadvantage may be under threat.

¹ Knight M, Bunch K, Tuffnell D, Jayakody H, Shakespeare J, Kotnis R, Kenyon S, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK (2018). *Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2014-16*; NHS London Clinical Networks (2016). *London maternal deaths: A 2015 review*.

² Draper, E, Gallimore, I, Kurinczuk, J, Smith, P, Boby, T, Smith, L & Manktelow, B (2018). *MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2016*

³ Knight M, Bunch K, Tuffnell D, Jayakody H, Shakespeare J, Kotnis R, Kenyon S, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK (2018). *Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2014-16*.

⁴ McLeish, J and Redshaw M (2019). 'Maternity Experiences of mothers with multiple disadvantages in England: A qualitative study'. *Women and Birth*, 32(2),178-184; Birth Companions and Revolving Doors Agency (2018) *Making Better Births a reality for women with multiple disadvantages*; Thomson, G and Balaam, M (2016). *Birth Companions Research Project: Experiences and Birth Outcomes of Vulnerable Women*. University of Central Lancashire.

⁵ Redshaw, M and Henderson, J (2016). 'Who is actually asked about their mental health in pregnancy and the postnatal period? Findings from a national survey' *BMC Psychiatry*, 15(1), 322.

⁶ Birth Companions and Revolving Doors Agency (2018) *Making Better Births a reality for women with multiple disadvantages*.

⁷ National Maternity Review (2016). *Better Births: improving outcomes of maternity services in England*.

These are the core themes in our report:

- Choice and consent
- Trauma and dignity
- Asylum and immigration
- Housing and hardship
- Specialist midwives and continuity of carer
- Navigating multiple systems and services

The time for change is now. We welcome the aspiration of the national review of maternity services, *Better Births* (2016), to achieve maternity care that is “*safer, more personalised, kinder, professional and more family friendly*”.⁸ We see the recent NHS Long Term Plan (2019) as an important step forward in addressing the needs of the most disadvantaged.⁹ We note its commitment that “*action to drive down health inequalities is central to everything we do*” and the positive pledges on “*enhanced and targeted continuity of carer to help improve outcomes for the most vulnerable mothers and babies*”, increased access to perinatal mental healthcare, and embedding women’s voices in work to improve care.¹⁰

We hope our research adds to the imperative to translate these goals into reality. Our findings demonstrate the value placed by both women and professionals on specialist support and continuity of carer.¹¹ Our findings also highlight areas where women’s rights are not consistently upheld, sometimes with devastating consequences.

We point to areas where further concerted action is needed to ensure that all women – but particularly those facing the greatest challenges – receive maternity care which is dignified, safe, trauma-informed and respects their fundamental human rights. We look forward to working with NHS England, the Royal Colleges, Public Health England, the Department for Health and Social Care and the Department for Education, as well as the Nursing and Midwifery Council, Local Authorities and Integrated Care Systems, the Voluntary and Community Sector and other partners, to take forward this important agenda.

⁸ National Maternity Review (2016). *Better Births*

⁹ NHS (2019). *The NHS Long Term Plan*. Available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>

¹⁰ NHS (2019). *The NHS Long Term Plan*.

¹¹ Throughout this report, for shorthand we refer to the women facing severe and multiple disadvantage who were interviewed as “women” or “a woman” and the professionals and supporters (who also happened to be all women) by their specific titles, where relevant, or as “professionals”.

Our action plan

Birthrights and Birth Companions have worked with a wide range of stakeholders to co-produce actions in response to *Holding it all together* . These have included women with lived experience of severe and multiple disadvantage during pregnancy, birth and early motherhood, NHS England, the Royal College of Midwives (RCM), the Royal College of Obstetrician and Gynaecologists (RCOG), and experts from across maternity care, family support services, local government, housing, and the voluntary and community sector (VCS). We look forward to continuing to work in partnership with these individuals and agencies, and with others, to ensure the human rights of women facing disadvantage are upheld during pregnancy, birth and early motherhood.

NHS England and NHS Improvement

- Ensure all workstreams across the Maternity Transformation Programme are developed and implemented with the needs of women facing multiple disadvantage as a central consideration.
- Incorporate the insights from *Holding it all together* and the evidence base on multiple disadvantage into the NHS Long Term Plan implementation framework and associated support packs for Local Maternity Systems (LMS), to ensure a strong focus on the needs of women facing multiple disadvantage.
- Include multiple disadvantage within the NHS Long Term Plan continuity of carer targets, to work alongside the existing focus on BAME groups and those in disadvantaged areas. This should prioritise those at greater risk of missing out on this care due to unstable housing or asylum and migration issues.
- Analyse the birth outcomes of women with factors of multiple disadvantage gathered in LMS datasets to understand both the impact of multiple disadvantage generally and the impact of continuity of carer and other targeted forms of care on outcomes.
- Prioritise and resource the implementation of the IDECIDE decision-making tool, designed to support choice and consent, so it can be rolled out effectively to women and healthcare professionals, with support from Birthrights, the RCM and RCOG.

NHS trusts, Clinical Commissioning Groups, Local Maternity Systems and Integrated Care Systems

- Review and adapt data collection to include factors of multiple disadvantage at women's booking appointments and throughout their care, in order to understand prevalence and co-occurrence at a local level.
- Develop co-produced care pathways for women and families experiencing multiple disadvantage.
- Ensure sufficient provision of accessible information and language support, including interpreting services, so there is a consistently high quality and responsive offer for all women who need or may benefit from this.

- Commission specialist midwifery services shaped by local need and protected as a ‘core function’.
- Identify and support at least one obstetrician in each Trust with a special interest in working with women with severe and multiple disadvantage.
- Embed housing and other local authority services in the governance, planning and service delivery of Integrated Care Systems. This should include the active involvement of housing services in the community hubs being rolled out as part of the Maternity Transformation Programme.
- In line with the NHS Long Term Plan, ensure data is securely integrated across health and care services, and within and beyond the NHS, so professionals are empowered to efficiently and effectively support women navigating multiple services.
- Ensure the experiences and views of women facing multiple disadvantage are actively sought, supported and valued by Local Maternity Systems, through the work of Maternity Voices Partnerships and more widely. This should include improved, ‘safe’ feedback mechanisms, access to de-briefing opportunities and other relevant, tailored systems of review as well as involvement in the co-production of pathways and co-design of services.
- Explore and trial care-coordinator or ‘maternity navigator’ roles for perinatal women facing multiple disadvantage, building on existing successful models.
- Develop a specific care pathway for women whose infants are removed through the Social Care Act in partnership with local authority services and women and families with lived experience. The proposed or likely removal of an infant should trigger an automatic referral to this pathway.

National Institute for Health and Care Excellence (NICE)

- Update NICE Guideline CG110 to reflect the reality of multiple disadvantage, using the evidence base to broaden the definition of complex social factors and acknowledge the impact of co-occurrence of multiple factors on pregnancy and birth.
- Use the evidence on effective care of perinatal women and families experiencing multiple disadvantage to develop specific recommendations for this group within CG110.

Department for Health and Social Care

- Ensure the forthcoming Prevention Green Paper addresses health and social inequalities among multiply disadvantaged groups in maternity care.
- Explore funding changes to enable portability of care across system and geographical boundaries, in the spirit of the Personal Maternity Care Budgets being developed as part of the Better Births maternity review.

Local authorities and Ministry for Housing, Communities and Local Government

- Work with NHS partners, via Integrated Care Systems, to join up housing and other local authority services with maternity care, including actively engaging with the community hubs being rolled out under the Maternity Transformation Programme.
- Refer to women and families facing multiple disadvantage in national government housing allocation guidance, so local authorities are required to address their needs in local policies.

- Consider how local housing allocation policies reflect the needs and rights of pregnant women and families facing multiple disadvantage, including how to protect housing access and stability during the first 1001 days (pregnancy, infancy and early childhood).
- Ensure housing policies allow adequate flexibility for trauma-informed responses to the specific needs of women and families who have experienced stillbirth or have had their babies removed into care, avoiding unwanted and unsupported changes in housing in the postpartum period, for example.
- Develop a specific care pathway for women whose infants are removed through the Social Care Act in partnership with maternity services and women and families with lived experience. The proposed or likely removal of an infant should trigger an automatic referral to this pathway.

Home Office

- Immediately suspend NHS charging policies and ensure women have equal access to pregnancy and maternity care, regardless of immigration status.

Professional bodies

- The Nursing and Midwifery Council (NMC) must ensure a strong focus on multiple disadvantage and trauma-informed care in its new strategy.
- Both the NMC and the Royal College of Midwives should contribute to the development of a national skills and competency framework for all midwives and midwifery support workers to improve knowledge, capability and confidence in multiple disadvantage and trauma-informed care, including for non-specialists.
- This should be mirrored by the Royal College of Obstetricians and Gynaecologists with an equivalent skills and competency framework for all doctors in obstetrics and gynaecology.

Birthrights and Birth Companions

- Review Birthrights' factsheets with Birth Companions' Lived Experience Team and women with specific needs, to consider and co-produce refreshed, accessible and targeted resources, including for women with language needs and learning disabilities (Birthrights).
- Embed *Holding it all together* research findings and good practice into training and resources for healthcare professionals (Birthrights).
- Work with stakeholders to refine a shared definition of multiple disadvantage and lobby for data gathering and sharing in this area (Birth Companions).
- Help to improve the level to which women with multiple disadvantage are heard and involved in Maternity Voices Partnerships (Birth Companions).
- Work with the voluntary sector, academics, professional bodies and the Royal Colleges to gather and disseminate good practice in supporting women facing multiple disadvantage during pregnancy, birth and early motherhood (Birthrights and Birth Companions).

Legal context

Human rights in maternity care

What are human rights?

Human rights are the rights we all share by virtue of being human. They are the basic rights and freedoms that belong to every person in the world – from birth until death – and have their foundation in shared values like dignity, fairness, equality, respect and independence.

Where do human rights come from?

In the UK, human rights are protected by law. The Human Rights Act 1998 incorporates into domestic law the rights protected by the European Convention on Human Rights. Human rights are also protected by common law (decisions passed in the law courts in the UK over the years). These laws set out the way we can expect to be treated by Government and all public bodies, such as the NHS. Public bodies are required to respect human rights when making decisions and caregivers working in public bodies are required to respect human rights as they go about their work.

Why are human rights relevant to maternity care?

The fundamental values of dignity, autonomy and equality are often directly relevant to the way a woman is treated during pregnancy and childbirth. For example, under the European Convention:

Article 2 protects the right to life and requires the state to provide access to basic life-saving health services, including maternity care. Examples of practices relevant to this research that may contravene Article 2 include: failing to provide adequate postnatal care to women who have had their babies removed into care by social services, leading to a risk to their lives; charging for maternity care where this discourages women from accessing care and risking their safety.

Article 3 prohibits inhuman or degrading treatment. Failing to provide care that is needed to avoid preventable suffering – such as pain relief – or failing to obtain consent, could be seen as inhuman or degrading treatment.

Article 8 protects the right to respect for private and family life. The courts have interpreted this to include the right to choose the circumstances of a woman's birth, including place of birth and choice of birth companion.¹² Failure to provide sufficient, objective and unbiased information for a woman to make an

¹² The European Court of Human Rights has held that the right to private life includes a right for women to make choices about the circumstances in which they give birth (*Ternovszky v Hungary* (2011); *Dubská v Czech Republic* (2016)). For more information see *Birthrights* (2017). *Human Rights in Maternity Care*.

informed choice, including by not providing adequate interpreting services, could violate Article 8.

Article 14 prohibits discrimination on a wide range of grounds including disability, sex, race, religion, language, immigration status and national origin. It requires that all of the rights and freedoms set out in the European Convention must be protected and applied without discrimination. In the maternity care context, this means all women, no matter who they are, should have equal access to safe and appropriate care that respects their dignity and autonomy.

In addition to Article 14, **the Equality Act 2010** requires public bodies to eliminate discrimination and advance equality of opportunity in the provision of services. This applies to the NHS and means making sure women with protected characteristics can access the same maternity care as any other woman, and that reasonable adjustments are made in order to facilitate this.¹³

Do human rights protect an unborn child?

No. Unborn children do not have separate legal recognition under the European Convention or in the common law of England and Wales, or the law in Scotland. Women are free to make choices against medical advice and cannot be forced to accept treatment whether or not it is said to be in the unborn child's interest.

If healthcare providers believe that a woman is putting her baby at risk, they may make a referral to social services. However, the threat of referral to social services should never be used to intimidate, bully or coerce a woman into accepting a particular medical intervention for her or her child.

What is informed consent?

For consent to 'count' in law, a person must genuinely agree to receive treatment. This means that a woman must be well enough informed about any proposed treatment or intervention during her maternity care, about any material risks involved and about any reasonable alternatives. She cannot have been put under undue influence by midwives, doctors or other supporters.

In the Supreme Court case, *Montgomery v Lanarkshire Health Board* (2015), the court stated that the test for whether a risk is a 'material' one, is whether a reasonable patient would attach significance to the risk, or whether the doctor should be aware that the particular patient would attach significance to it. This means that there must be a genuine dialogue between health professional and patient and the assessment of risk must be sensitive to the individual's characteristics and what is important to her.¹⁴

Hospitals cannot rely solely on printed leaflets or online material to provide relevant information; there must always be a personal discussion between the woman and the health professional. This should be facilitated appropriately, for example, by providing interpreting services if required. If the woman asks

¹³ For more information see Equality and Human Rights Commission (2019). *Public sector equality duty* [online].

¹⁴ *Montgomery v Lanarkshire Health Board* [2015] UKSC 11. See also *Birthrights* (2017). *Consenting to treatment*.

specific questions the healthcare professional must give full, honest and objective answers. A consent form on its own is not sufficient evidence of consent.

Are there any circumstances in which treatment can be given without consent?

In a life-threatening emergency, if a patient is unable to make their wishes known, treatment can be given without their consent in order to save their life or prevent serious deterioration in their condition.

The only other circumstance in which a patient's consent is not required is when they have been assessed as lacking the capacity to make that particular decision. However, the fact that a woman may have made a decision which health professionals believe is not in her or her baby's best interests is not a reason by itself to decide that she lacks capacity. If a woman is deemed to lack capacity, decisions about her treatment must be made in her best interests. The Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act (2000) set out the factors that should be taken into account in deciding someone's best interests. This includes taking account of any written statement of preferences or wishes, which could include a birth plan.

For more information please see: www.birthrights.org.uk

Policy context

Better Births

In 2016, *Better Births*,¹⁵ the report of an independent review of national maternity services commissioned by NHS England, delivered a bold vision for what it called “*safer, more personalised, kinder, professional and more family friendly*” maternity care. It said care would be made to “*wrap around*” the woman, rather than the individual being expected to fit into the system. A woman would receive maternity care from a named midwife or small team that she would come to know. She would be able to choose where to give birth and would be in control of a personalised maternity budget. More effective multi-disciplinary and cross-boundary team working among professionals would improve a woman's experience of care, while keeping both her and her baby safe. The historic underfunding of perinatal mental health and postnatal care would be addressed.

The report's authors emphasised that all the women they spoke to wanted the same things from healthcare professionals: understanding and respectful treatment. However, the *Better Births* authors also said that achieving a kind and personalised service requires a tailored approach for some women: extra time, information in easy-to-read formats, interpreting services, and specialist, dedicated support for women facing particularly challenging circumstances or with complex needs.

¹⁵ National Maternity Review (2016). *Better Births*.

Better Births said it was important that women themselves were involved in co-designing improvements in maternity services alongside commissioners and healthcare providers. Maternity Voices Partnerships were introduced to replace Maternity Service Liaison Committees and enable women and their families to work with maternity providers to improve local maternity care.

Three years into the five-year Maternity Transformation Programme to implement Better Births across England, our own research reinforces the Better Births aspirations, but also underlines the need to go further. Our findings have led us to conclude that the voices of women facing severe and multiple disadvantage risk being left out of this decision-making. This, in turn, could mean that their needs are not taken into consideration when services are designed. Voluntary and Community Sector (VCS) organisations, such as Birth Companions, are well placed to help Maternity Voices Partnerships and Local Maternity Systems do this.

Safer Maternity Care

In November 2017, the Secretary of State for Health published a review called 'Safer Maternity Care'¹⁶. It set the target of 2025 (brought forward from a previous goal of 2030 set in 2016) by which to halve the rates of stillbirths, neonatal and maternal deaths, and brain injuries that occur in the UK during or soon after birth.

Leaders of the Maternity Transformation Programme have been clear that this safe care and the personalised care we have just discussed are two-sides of the same coin – a welcome perspective, which is echoed in the Secretary of State's introduction to 'Safer Maternity Care':

"I believe that safe care is personalised care. There is good evidence that women who have 'continuity of carer' throughout pregnancy and one-to-one support in labour have safer outcomes for themselves and their babies. We need to provide women with the resources and support to make informed decisions and train clinicians to have individualised care planning conversations which uphold women's autonomy and meet their individual needs (including during labour where this can become more challenging when circumstances change quickly)."

In 2016, the Saving Babies' Lives care bundle was published. This guidance was designed to support providers, commissioners and professionals take action to reduce stillbirths and drive progress towards the Safer Maternity Care targets.¹⁷ However, the evaluation of its implementation¹⁸ found that pressure to meet those targets and reduce the incidence of stillbirths, injury and death was leading to what it called "intervention creep". In particular, increased numbers of ultrasound scans and increased rates of induction of labour and emergency caesarean sections were observed. It also found that there was scope for obstetric intervention to be better targeted to pregnancies genuinely at risk of complication. As a result, the second

¹⁶ Department of Health (2017). *Safer Maternity Care: The national maternity safety strategy - progress and next steps*.

¹⁷ NHS England (2016). *Saving Babies' Lives: A care bundle for reducing stillbirth*.

¹⁸ Widdows K, Roberts SA, Camacho EM and Heazell AEP (2018). *Evaluation of the implementation of the Saving Babies' Lives Care Bundle in early adopter NHS Trusts in England*. Maternal and Fetal Health Research Centre, University of Manchester, Manchester, UKs.

version of the care bundle emphasises women’s autonomy as the primary decision-maker in her own childbirth and the need to reduce unnecessary interventions.¹⁹ This is welcome but we await further evaluation.

While we support the goal of safer maternity care for both women and babies, pressure to achieve these targets must not lead to women feeling coerced into accepting unwanted interventions. Nor should women feel their behaviour or decisions are judged, especially where they decline the recommendations of professionals. Our report confirms that women experiencing severe and multiple disadvantage may be more likely to face this pressure and scrutiny, and less likely to feel like they have choices.

The NHS Long Term Plan

The Long Term Plan for the NHS,²⁰ published in January 2019, sets out an ambitious ‘life course approach’ to a person’s physical and mental health. This takes into account the range of social, economic and environmental factors which influence a person throughout their lifetime – from pre-conception through adulthood and into old age. It is to be implemented via community-based, integrated health and social care.

In relation to maternity care, the Long Term Plan aims to continue the implementation of the Better Births recommendations, with an emphasis on improving safety, continuity of carer, perinatal mental health and maternity digital care records. It also includes a commitment to tackling health inequalities, particularly those experienced by women from the poorest backgrounds and from Black and Minority Ethnic (BAME) groups.

The Long Term Plan builds on the 2016 £365m investment in specialist perinatal mental health services over five years,²¹ and promises increased access to mental healthcare for those with moderate to severe perinatal mental health issues. It also promises to widen access to therapies for fathers and to co-locate other services at maternity outreach clinics, which are intended to “*integrate maternity, reproductive health and psychological therapy for women experiencing mental health difficulties directly arising from, or related to, the maternity experience.*”²²

Such co-located services have the potential to benefit women facing severe and multiple disadvantage, given the difficulty of navigating multiple services highlighted by this research (see theme six). However, it is important that they are developed in collaboration with the women they are designed for and that they incorporate services from beyond the NHS. The Long Term Plan also states that Integrated Care Systems (ICSs) will be in place across England by 2021. These bring together NHS organisations, local councils and others to improve the health of the population they serve and provide a timely opportunity to shape and join-up health, care and other services around people’s needs.

¹⁹ NHS England (2019). Saving Babies’ Lives Version Two: A care bundle for reducing perinatal mortality.

²⁰ NHS (2019). *The NHS Long Term Plan*.

²¹ NHS England NHS Improvement and National Collaborating Centre for Mental Health (2018). *The Perinatal Mental Health Care Pathways*.

²² NHS (2019). *The NHS Long Term Plan*.

The Long Term Plan sets a new target of March 2021 for “most” women to receive continuity of carer from the same one or two midwives throughout their pregnancy, birth and postnatally. The MBRRACE report into maternal deaths, published in November 2018, showed that Black women were five times more likely to die in pregnancy or within 42 days of giving birth, and Asian women were twice as likely to die, compared to White women.²³ The babies of most mothers from ethnic minority groups also have a higher risk of death just before or after birth.²⁴ As a result, the rollout of continuity of carer will be particularly targeted towards women from BAME groups and those living in deprived areas, for whom midwifery-led continuity of carer is linked to significant improvements in clinical outcomes.²⁵

We welcome this focus within the rollout of continuity of carer, given that many of the women in our research would fall into these target groups, but we would like to see it widened to include women facing severe and multiple disadvantage as a specific group. This care should extend well into the postnatal period in order to achieve the reduction in health inequalities sought by the NHS Long Term Plan. The foreword to the MBRRACE report states:

“Yet again in this report it has been noted that maternal mortality is increasingly a problem for women with multiple vulnerabilities. Specifically, it highlights yet again that a number of women died by suicide after a pregnancy or postnatal loss, or after removal of their infant into care. For some women, pre-existing mental health conditions were exacerbated when their child was removed, and it is essential that care for the mother increases rather than decreases in these circumstances. On too many occasions the mother was forgotten once services were appropriately reassured that her child was safe.”²⁶

The lack of support for women after birth, particularly for those whose baby died or was removed, is a significant finding of our research.

To achieve the goals for continuity of carer, we also echo the Royal College of Midwives’ calls for: ring-fenced investment in its implementation; safe levels of midwifery and wider maternity team staffing; and flexibility and autonomy for continuity teams.²⁷

NHS England Review

In 2015, the Quality Working Group of the Maternity Review was asked to assess existing service quality across England. The report that followed, the National Review of Maternity Services: Assessment of Quality in Maternity Services, identified several key data points of concern:

- 26% of women did not always feel involved in decisions made about their care during labour and birth

²³ Knight et al on behalf of MBRRACE-UK (2018). *Saving Lives, Improving Mothers’ Care*.

²⁴ Draper et al (2018). *MBRRACE-UK Perinatal Mortality Surveillance Report*.

²⁵ Homer, C, Leap, N, Edwards, N and Sandall, J (2017). Midwifery continuity of carer in an area of high socio-economic disadvantage in London: A retrospective analysis of Albany Midwifery Practice outcomes using routine data (1997–2009). *Midwifery*, 48, 1-10.

²⁶ Knight et al on behalf of MBRRACE-UK (2018). *Saving Lives, Improving Mothers’ Care*.

²⁷ Royal College of Midwives (2018). *Position Statement: Midwifery Continuity of Carer (MCOC)*.

- the proportion of women who felt that they were left alone during labour or birth and were worried by this ranged from 0% to 21% across trusts
- of those women who raised concerns during birth and/or labour, one in five (19%) said they did not feel their concerns were taken seriously
- only 16% of women in labour reported having one-to-one personalised midwife care, just over a third had two midwives, with 26% having four or more midwives caring for them during the time they were in labour
- 85% of women reported not having previously met any of the midwives caring for them during labour and birth
- for 60% of the women, labour started naturally, but for those women who were induced, nearly half (45%) were not offered a choice about the induction
- 85% of women felt they were always treated with respect and dignity during labour and birth, with some variation by place of birth.²⁸

These statistics remind us that the challenges identified in our research are not only felt by women facing severe and multiple disadvantage. However, this group is disproportionately affected.

NHS charges for maternity care

People who are considered to be ‘ordinarily resident’ in the UK are entitled to free NHS care, including maternity care. However, women from overseas, including migrant women, can be charged for it, sometimes by up to 150% of the cost of their care.²⁹

The UK Government held a consultation on the extension of charging overseas visitors and migrants using the NHS in England. In 2017 it concluded:

“Having considered the views put forward, we intend to proceed with the extension of charging overseas visitors for most NHS services they can currently access for free, although this will be taken in a staged approach.”³⁰

In 2018, the charity Maternity Action looked into the impact of these charges on migrant women in their report *What Price Safe Motherhood*. They concluded that current legislation is unworkable, unjust and harmful to women, especially those who are living in poverty, destitute, or unable to work. The report stated:

“Charging has a deterrent effect on women’s access to maternity care which poses risks to their pregnancies and the health of their babies. Anxiety about charging has an adverse effect on maternal mental health with consequent effects on women’s pregnancies and pregnancy outcomes. Although all maternity care is

²⁸ NHS England (2015). *National Review of Maternity Services: Assessment of quality in maternity services*.

²⁹ Maternity Action (2018). *What Price Safe Motherhood: Charging for NHS maternity care in England and its impact on migrant women*.

³⁰ Department of Health (2017). *Making a Fair Contribution: Government response to the consultation on the extension of charging overseas visitors and migrants using the NHS in England*.

designated as immediately necessary, this does not compensate for the anxiety women feel knowing that they are unable to repay very high charges.”³¹

Although none of the women interviewed for our research was charged (four were asylum seekers who are not required to pay), midwives we interviewed talked about how difficult they found negotiating the charging regime.

We echo Maternity Action’s call for the immediate suspension of charging, in light of the deterrent effect it has on migrant women accessing maternity care.

Trauma-informed care

Trauma-informed care is a framework that helps services understand, recognise and respond to the effects of trauma. It means treating a person as a whole, taking any past trauma into account, avoiding re-traumatising and promoting a culture of safety, trust and empowerment amongst those delivering, as well as receiving, the service.

A growing international evidence base highlights the benefits of this kind of trauma-informed approach to care, which we are starting to see reflected in policy in the UK. NHS England has recently commissioned an organisation to identify best practice examples of trauma-informed care in maternity and perinatal mental health services during 2019. We welcome this step, which recognises the need to treat all women seeking maternity care as possible survivors of trauma without needing to rely on disclosure. We hope the work commissioned by NHS England will acknowledge the particular trauma-related experiences and specific needs of women facing multiple disadvantage.

Methodology

Study design

This research was designed as a qualitative study using semi-structured interviews with women, and a combination of semi-structured interviews and focus groups with professionals. The research team was advised by a steering group comprising specialist midwives, researchers, women with lived experience and staff from Birthrights and Birth Companions. They provided invaluable input to the study design, development of research materials, research methodology and approaches that ensured participants felt safe and supported. Peer researchers working on Birth Companions and Revolving Doors Agency’s research project ‘Making Better Births a reality for women with multiple disadvantages’ (2018) provided early input.³²

³¹ Maternity Action (2018). *What Price Safe Motherhood*.

³² Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

Detailed topic guides were developed for each of the following:

- Women
- Specialist midwives
- Non-specialist midwives
- Other professionals, such as health visitors, Family Nurse Partnership (FNP) nurses, or social workers.

Severe and multiple disadvantage

We know that definitions of disadvantage vary greatly across services and systems. For this project, we asked to speak to women who had experience of co-occurring factors at the same time in their lives including:

- Housing problems
- Poverty and/or no access to public funds
- Perinatal mental health problems
- Physical and/or learning disabilities
- Substance misuse
- Social services involvement, or history of safeguarding issues
- Experiences of asylum, immigration or trafficking
- Isolation
- History of domestic abuse, sexual violence or human rights violations
- Experience of detention or imprisonment
- Language issues (for example, not speaking English)
- Experience of sex work

Despite the complexity and severity of the recruited women's co-occurring disadvantages, only a minority reported experiencing one of the four 'exemplar' factors described in the National Institute for Health and Care Excellence's (NICE) Clinical Guidance on antenatal care CG110:³³ substance misuse, being under 20, experiencing domestic abuse, or being a recent migrant or asylum seeker or having difficulty speaking or reading English. This demonstrates that guidelines and policies will need to revise their definitions of complex social factors in line with the current evidence base to ensure all women who might benefit from specialist care are identified.

³³ National Institute for Health and Care Excellence (2010). *Clinical Guideline CG110 Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors.*

Recruitment

Women were recruited through support organisations such as Birth Companions and specialist healthcare teams. The researcher engaged with many organisations who agreed to seek participants, using the list of defining factors above. In the information sheet for women, the project was described as seeking “women living in difficult circumstances or who are facing lots of challenges”.

We sought women who were over 18, who had received maternity care in London in the previous two to three years, and who were not currently pregnant. Any woman expressing an interest was given an information sheet and offered an opportunity to ask questions and to consider participating. The researcher met or spoke to some interested women beforehand to discuss the project. Otherwise women were introduced by a trusted support worker or healthcare professional.

Professionals were recruited through networks and contacts such as the London Network of Nurses and Midwives Homelessness Group, the Institute of Health Visitors London Network, and through social media. Midwives were asked to self-classify as specialists or non-specialists, on the basis of information about the project.

Interviews

Interviews with women with experience of multiple disadvantage took place in person at a time and place to suit them, or at a group venue where they would already be. On a few occasions, after initial contact, women chose not to proceed with the interview. Travel was paid and the women were offered a thank you to the value of £10 for taking part. All participants were told they could choose what to tell the interviewer and that they need not answer every question. The process for withdrawing from the research was explained.

All interviews were audio-recorded and then transcribed, apart from one in which contemporaneous notes were made at the participant’s request. Women were offered support with childcare where possible within the setting, and interpreting services.³⁴ The limits of confidentiality and safeguarding were clearly explained, and written informed consent was taken before each interview. The length of interviews varied (from 25 to 58 minutes; median 33 minutes). Women were free to stop or pause at any point to ensure they felt safe and supported. The topic guide for women asked them about experiences of their most recent maternity care; in a few cases, women also talked about previous pregnancies and drew comparisons.

Most of the data collection with professionals was done through face-to-face focus groups of two to seven participants, with two additional face-to-face interviews and one by telephone. All interviews and focus groups were audio-recorded and later transcribed, with written informed consent taken beforehand. Focus groups and interviews were all similar length (median 91 minutes). Professionals were also offered a thank you to the value of £10 for taking part.

³⁴ The one woman who received support from an interpreter did so from a trusted individual who works for a support organisation. Her accounts are reported verbatim in this report: in some cases, her experiences were described in the first person and at other times, the third person is used.

The topic guides for professionals asked about their experiences providing support to women facing severe and multiple disadvantage and about what makes it easier and/or harder to support women.

Transcripts were subsequently reviewed by the researcher and analysis carried out to identify any recurring themes. Initial themes were identified through the reading and re-reading of transcripts, then refined through the latter stages of data collection. Emerging themes were identified by the researcher, before being tested with the steering group.

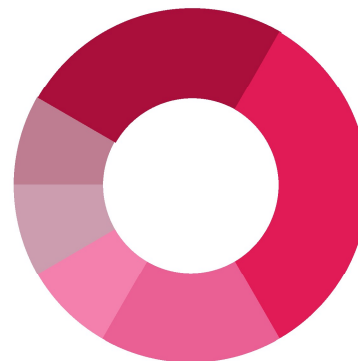
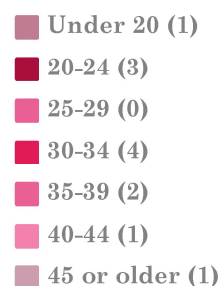
Participants

We interviewed **12 women** who faced severe and multiple disadvantage during their maternity care and **26 professionals and volunteers** who work with women dealing with complex needs.

Women

The women who took part were aged 19-45 years, with a median age of 33.

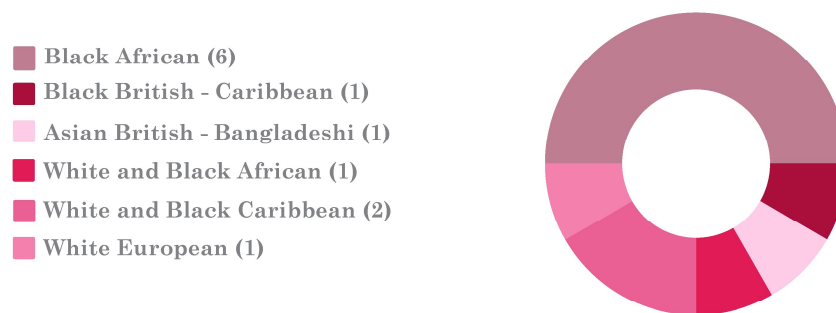
Age of the women taking part



The women were asked to describe their ethnic background using the harmonised country specific ethnic group questions for England set out by the Office for National Statistics.³⁵ Eleven women identified themselves as being from BAME groups, one as White European.

³⁵ Office for National Statistics (2015). *Harmonised Concepts and Questions for Social Data Sources: Primary principles Ethnic Group*.

Background of women taking part



Nine women indicated they were born outside the UK. Of these, five were born in Nigeria, with two others identifying African national backgrounds. One woman was born in a Caribbean country, and one elsewhere in Europe.

Seven women indicated they had had more than one child, although one woman said her older children were not living with her (not for safeguarding reasons).

When asked about the disadvantages they faced, all 12 of the women who took part in the research, experienced at least three; eight experienced five or more.

Number of disadvantages experienced



Women chose what to tell the interviewer, so it is likely this account understates their experiences. The most common disadvantages were:

- almost all the women were living in **temporary, unstable or unsuitable housing** during the perinatal period
- nine women were **not in a relationship with the father of their baby**, four of those women described being **alone** or feeling **isolated**. At least three women did not have (social) support from friends or family during labour
- six women described **historic or recent trauma**; three of these described multiple traumas or abuse

- five women said they **did not have enough money to meet everyday needs** including food, rent, travel and baby clothes
- five women described **mental health concerns** or engagement with mental health support
- four women had long-term **physical health conditions**; four had pregnancy-related conditions; three had concerns about their baby's health
- four women indicated they were current or recent **asylum seekers**, including at least two who had been **trafficked** and/or sexually exploited
- only three women described **having a job** during their pregnancy; one had to leave work earlier than planned because her managers were unhappy with her attending antenatal appointments; another was working a zero-hours contract and had her hours cut when she said she was pregnant.

Professionals

We interviewed 26 professionals comprising:

- nine specialist midwives working across public health, perinatal mental health, safeguarding and maternal medicine
- three 'non-specialist' midwives not working in specialist roles, but with experience supporting women facing multiple disadvantage
- two specialist health visitors
- two Family Nurse Partnership (FNP) nurses
- seven Birth Companions' volunteer birth supporters
- three members of Birth Companions staff

The specialist midwives were working in roles that involved supporting women with complex social and medical needs, usually working in a 'caseloading' team providing continuity of care to the women they support. The three non-specialist midwives were working in roles in community midwifery or in hospital. Both the FNP nurses and the health visitors worked in specialist teams supporting women with complex needs who were facing severe disadvantage.³⁶

The health professionals were evenly split between Band 6 and Band 7 level positions, with two individuals working in more senior roles. Length of service in current roles varied from less than a year to seven years (median three years); length of service in the health sector as a whole from two to twenty-eight years (median seven years).

The Birth Companions volunteers we interviewed supported women during pregnancy, labour and birth and in the post-natal period in prison and in the community. They had been volunteering for periods ranging from just under two years to five and half years (median four and a half years). The three Birth Companions staff members work with women and volunteers in community-based antenatal classes and the Community Link service run by Birth Companions. Community Link

³⁶ FNP nurses are specialist family nurses who deliver a voluntary home visiting programme for first-time young mothers and their families: <https://fnp.nhs.uk/about-us/>

offers one-to-one support to women during pregnancy, labour and birth and in the postnatal period. The staff members had been working with Birth Companions for between three and thirteen years.

Limitations

The study did not manage to engage women who were active substance users, who were sex workers or were street homeless (people who routinely find themselves on the streets during the day with nowhere to go at night). We also did not interview any women who had had their children removed by social services. However, perspectives on the needs of women with these experiences were fed in through interviews with the professionals and the steering group. Finally, despite attempts to reach out through a number of social care bodies, we were unable to recruit any social workers.

Recruitment of social workers would have added a useful additional perspective on the social care issues raised by many participants and should be addressed in future research.

Our steering group noted that the prevalence of reported domestic violence was lower than they might have expected, based on their professional experience. In addition, no women mentioned current substance use. It is possible that some chose not to disclose all their experiences in a one-off interview. The women were told that if they disclosed anything that raised safeguarding concerns, the researcher would make them aware of this, but may have to follow up with relevant organisations: it is possible this might have limited disclosures. In addition, the peer research carried out by Birth Companions and Revolving Doors Agency noted that researchers from outside peer communities may be viewed with some distrust.³⁷ While every step was taken to mitigate this, it is possible this factor might have influenced what the women chose to share with the interviewer.

³⁷ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

Thematic analysis

We are very grateful to the twelve women who shared their experiences of pregnancy, birth and maternity care with us. Their stories are at the centre of this report. This section sets out the themes which reflect their experiences, and the various challenges to their human rights. It then considers the models of care, which they said best supported them and explores the needs of the professionals and supporters who work with women facing severe and multiple disadvantage.

The six themes are:

- Choice and consent
- Trauma and dignity
- Asylum and immigration
- Housing and hardship
- Specialist midwives and continuity of carer
- Navigating multiple systems and services

Some women described positive experiences – and there were good practice examples, particularly of specialist midwife support and continuity of carer.

However, we are deeply concerned about the potential breaches of women's fundamental human rights we heard about, particularly their rights to:

- safe and appropriate maternity care
- respectful and dignified treatment
- autonomy, choice and consent
- respect for private and family life
- equality

Theme one: Choice and consent

Women's experiences

Three quarters of the women interviewed described situations where their choices were not respected or they were not supported to give informed consent. Choice and consent sit at the heart of safe and respectful maternity care. Article 8 of the European Convention on Human Rights guarantees the right to private and family life. The courts have interpreted this as the right to physical autonomy and integrity (meaning that consent must be sought before performing any medical procedure) and the right for a woman to make decisions about the circumstances in which she gives birth.

Giving consent to an intervention or recommendation requires a genuine dialogue between the person and the healthcare professional, which includes sufficient information about the recommended care, any alternatives (including doing nothing) and their risks and benefits.³⁸ That information should be personalised to the individual's situation and needs, and the individual should not be unduly influenced or coerced by healthcare professionals or family members.

In the interviews, women described situations where they had not had choices, or not known they had choices, and where they had not been supported to give informed consent. This was particularly the case for decisions about the place of birth and interventions carried out during labour. It was particularly striking in the accounts of women who were asylum seekers.

Previous studies have shown that choice and consent are valued by women and associated with positive experiences of birth.³⁹ Cook and Loomis, in their study of how women develop birth plans and how changes to the plan affect birth experience, conclude: “Women’s positive and negative recollections of their birth experiences are related more to feelings and exertion of choice and control than to specific details of the birth experience”.⁴⁰

As discussed previously, personalised care, offering women genuine choice, is safer and is associated with better outcomes.⁴¹ Choice and consent are important for all

³⁸ In the Supreme Court case *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 the court stated that “An adult person of sound mind is entitled to decide which, if any, of the available forms of treatment to undergo, and her consent must be obtained before treatment interfering with her bodily integrity is undertaken”. The court found that discussions about risk should be personalised to the woman involved: this means there must be a genuine dialogue between healthcare professional and patient and the assessment of risk must be sensitive to the individual's characteristics. Statistics alone will not determine whether a risk is significant for a particular patient.

³⁹ Downe, S, Finlayson, K, Oladapo, OT, Bonet, M & Gülmezoglu, AM (2018). What matters to women during childbirth: A systematic qualitative review. *PloS one*, 13(4), e0194906; Keedle, H, Schmied, V, Burns, E and Dahlen, HG (2019). 'A narrative analysis of women's experiences of planning a vaginal birth after caesarean (VBAC) in Australia using critical feminist theory'. *BMC Pregnancy Childbirth*, 19, 142.

⁴⁰ Cook, K and Loomis, C (2012). 'The impact of choice and control on women's childbirth experiences'. *The Journal of Perinatal Education*, 21(3), 158–168.

⁴¹ Raymont-Jones, H, Murrells, T and Sandall, J (2015). 'An investigation of the relationship between the caseload model of midwifery for socially disadvantaged women and childbirth outcomes using

women, but particularly for women facing severe and multiple disadvantage. As McLeish and Redshaw explain: “for women who often had little control over other aspects of their lives, it was of great significance to have some control over what was done to their bodies”.⁴²

Conversely, a lack of choice and consent in maternity care is associated with birth trauma and post-traumatic stress.⁴³ This is particularly pronounced for women who have a history of trauma and mistreatment.⁴⁴ Many of the women interviewed for this research reported a history of trauma.

Birth choices

In 2016 Better Births recommended that all women should have a full choice of place of birth.^{45,46}

Six women in our study said they had stated a preference: one woman wanted a vaginal birth after Caesarean (VBAC); two wanted to give birth in a birth centre; three said they had wanted water births.

But none of the six gave birth where or how they wanted and three women told us they were disappointed that they were unable to access their birthplace of choice, or were not given the opportunity to fully discuss their preferences during their care. Most of the women ended up giving birth on the labour ward.⁴⁷ The woman who wanted a VBAC had another Caesarean. One of the women who had wanted a birth centre birth was induced, and the other transferred to the obstetric ward during labour when meconium was detected in her waters.⁴⁸ All the women who had wanted water births had their labours induced and as a result were cared for on the labour ward.

One woman described a very limited choice. She told us that she wanted, and did have, a physiological birth, but she said this was the only choice offered to her during her maternity care. Another woman, an asylum seeker, described labouring in water but later told the interviewer she didn't think it was safe: “They have to put me in the bath ... that could be dangerous for your child”.

routine data - a retrospective, observational study'. *Midwifery*, 31(4), 409-17; National Maternity Review (2016). *Better Births*.

⁴² McLeish, J and Redshaw M (2019). 'Maternity Experiences of mothers with multiple disadvantages in England: A qualitative study'.

⁴³ Reed, R, Sharman, R and Inglis, C (2017). 'Women's descriptions of childbirth trauma relating to care provider actions and interactions'. *BMC Pregnancy Childbirth*, 17, 21; Harris, R and Ayers, S (2012). 'What makes labour and birth traumatic? A survey of intrapartum 'hotspots''. *Psychol Health*, 27(10), 1166-1177.

⁴⁴ Seng, J (2015) 'How does traumatic stress affect pregnancy and birth?', in Seng, J and Taylor, J (eds.) *Trauma informed care in the perinatal period*. United Kingdom: Dunedin Academic Press, 57-73.

⁴⁵ Home birth, freestanding or alongside midwifery-led unit, or obstetric unit.

⁴⁶ National Maternity Review (2016). *Better Births*.

⁴⁷ Not everybody stated explicitly where they gave birth. For three women, their narrative suggested they gave birth on an obstetric ward but this cannot be stated with certainty.

⁴⁸ NICE Guideline CG190 (2017). *Intrapartum care for healthy women and babies* advises that women should be transferred to obstetric care when significant meconium is present in the amniotic fluid.

Two women had planned Caesarean sections. One did not express any feelings about this to the interviewer. The other described being given little choice based on her obstetric history, with her maternity care team reported as saying “they can’t allow” a vaginal delivery.

—
“Each time I saw him, he [the doctor] would talk about Caesarean and I had to keep reminding him “look, I want to have vaginal delivery”.”

Case study: birth in prison

After entering prison, one woman felt: “everything was just decided for me”. She was unable to continue with her previous care team or with the date of the planned Caesarean she had agreed with her doctor. As a result, her partner was unable to attend the birth and, in the end, was not told when she had the baby. This is a clear failure to meet the call in Birth Companions’ Birth Charter that all women should have a birth supporter of their choice with them during birth.⁴⁹

In addition, the woman described the prison requirements for staffing of bedwatch or escort duty⁵⁰ being a determining factor in decisions made about her care. Previously, she had made plans with her community team for a reproductive healthcare procedure to be carried out alongside the Caesarean. Yet when she moved to the prison, she was denied this: “I might have to stay in hospital longer... I don’t think they were willing to sort of like pay... enough staff to sort of like watch, do bed watch”. This suggests her care failed to meet the benchmark of equivalence of healthcare between prison and the community.⁵¹

Another woman said she felt her birth choices were limited by her housing situation. She was housebound as she was unable to manage the stairs: she had a pre-existing medical condition and had had an accident in early pregnancy. She had been unsuccessful in securing more suitable housing while she was pregnant. As a result, she was reliant on hospital transport to get to maternity appointments, but found that she could not rely on them to arrive with sufficient manpower. This limited her birth choices and she chose induction of labour in hospital, as she was afraid of going into labour in her flat and being unable to get to hospital: “if I book an induction in hospital, I know I will be safe”. Her inability to make a free choice potentially undermines her Article 8 and 14 rights, which protect private and family life, prohibit discrimination and entitle women to equal treatment in their maternity care.

Four women, the three who had wanted water births and one who wanted to go to a birth centre, talked explicitly about how risk was used to frame discussions with healthcare professionals about their choice of place of birth. Whilst all four women described situations where clinical indications might mean birth on an obstetric unit would commonly be recommended, not all seemed to have had the opportunity to discuss this or explore whether their choices could be accommodated in another way.

⁴⁹ Birth Companions (2016). *Birth Charter for women in prisons in England and Wales*.

⁵⁰ Bedwatch or escort duty comprises two prison officers accompanying a person attending hospital from prison, whose role is to ensure the person remains in secure custody while off-site.

⁵¹ NHS England (n.d.). *Health and justice* [online].

Two of the four women said they did agree to their care providers' recommendations because of the risks as they understood them. One accepted an offer of induction: *"it was more you know, safer for my baby than for myself...for what I wanted"*.

The second said she specifically asked for more time to see what happened. However, she says she was told that if she did not agree to an induction at that point, the baby was *"gonna be so weak that we're gonna have to just you know [perform a Caesarean]"*. She said she felt able to decline, but she agreed to the induction because at *"that point it wasn't about what I wanted, it's about what was safe for me and my child to be delivered."* As a result, though, none of her other birth choices were respected. She described a series of *"had to"s* that meant none of her choices could be honoured, including the request that no men be present. It should be noted that she described the birth as *"a good experience and a great experience"* and she felt able to advocate for her choices during labour.

The other two women acquiesced to their care providers' recommendations but said they had not fully understood aspects of those recommendations. One explained that there had been some uncertainty about whether her waters had broken at home and said she was told *"they have to induce me because they have to be on the safe side"*. She felt she had some choice, but *"was scared"* and agreed on that basis.

The second woman had a pre-existing medical condition, which meant she was receiving care from a multi-disciplinary team. She said she was constantly told: *"You're more of a risk, your pregnancy's more of a risk... And it's not just one midwife or one doctor, it's **all** the doctors. They all tell you this"*. She said she felt both supported and, at times, smothered by the care team, but did not understand the explanations she was given when told a water birth was *"not an option"*:

*"The conversation went like this – "can we talk about me having a water birth?" – "let's talk about you **not** having a waterbirth!"."*

In the 2013 Birthrights *Dignity in Childbirth* Survey, which investigated experiences of women across the UK, 21% of respondents reported that they were not given adequate information by midwives or medical staff about their birth choices.⁵² While the sample size in this report is small, this suggests that the number may be even higher amongst the cohort of women facing severe and multiple disadvantage. We know that supporting women with multiple disadvantage to understand their care and choices helps build trust in maternity services.⁵³ Our findings suggest there is a missed opportunity to engage women in their care.

Antenatal support

Only two women said they were helped by a midwife or birth supporter to make a birth plan. A third woman described the midwife showing her where to write any preferences in her notes, but said she was not offered any support with it. A fourth said she was told her preference for admission to the birth centre was dependent on doing a birth plan, but that she didn't receive any support: *"I never had the option ... I*

⁵² Birthrights (2013). *Dignity in childbirth The Dignity Survey 2013: Women's and midwives' experiences of UK maternity care.*

⁵³ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages.*

wanted to have, to go to a birth centre but they said ... you will have to do the birth plan, they will take you, no one ever did a birth plan to me". Only three women said they were offered any antenatal education, either through the NHS or from Birth Companions.

Communication and understanding

Beyond decisions about place of birth, five women said they did not understand some aspects of their care. Three of the four women who were asylum seekers said they did not know they had the right to make any choices about their care. One woman, who said she was refused an interpreter, said she was only offered one choice: a physiological or a Caesarean birth. She said she had "no other option" than to do what she was told during her maternity care because she had no way of expressing herself.

One woman expressed surprise to the interviewer when asked whether she had understood that she could make choices about her care or decline aspects of care. Another said if she had known she could make choices, she would have asked for a specific intervention she had found helpful in a previous labour: "I thought about asking them but I just thought in my mind...maybe this is...the way it's been done over here".

Two other women said there were aspects of care that were confusing or difficult to understand. One described self-referral to maternity care as "a bit confusing...luckily I had a smart phone, which is why I could do it, but, if people haven't got, like, the access and stuff, it must be hard!" She said that at points in her labour, she had not known exactly what was happening, but that she preferred it that way. She said had she known what was happening, "I think I would've worried more". She also described being worried about her baby but uncertain about whether she was supposed to be looking out for signs of illness. Another woman said she had found the results of antenatal screening difficult to understand and this had caused significant worry during her pregnancy.

We welcome NHS England's commitment to roll out personalised care planning to every woman in Local Maternity Systems as part of Better Births. Along with the increase in access to continuity of carer, this should support more women to understand and make informed choices. Birthrights is also working with NHS England, the Royal College of Midwives (RCM) and the Royal College of Obstetricians and Gynaecologists (RCOG) to develop a tool to support women's decision-making in labour. This tool should help women facing severe and multiple disadvantage to access high-quality information and discussion, within a framework that makes clear that they are the decision maker.

Consent

Three women described interventions being carried out in situations where it seems that consent had not been obtained. One woman was told during labour "we're gonna give you an epidural!" which she challenged because she thought she was close to giving birth; nonetheless she received the epidural. Another woman said she did not know whether her waters had been broken by her midwife in hospital. This woman had previously been sexually exploited before seeking asylum in the UK.

"I don't know what they're doing inside my body".

Birthrights' *Dignity in Childbirth* survey (2013) found that 12% of women considered they had not given their consent to examinations or procedures, compared to 25% in this research.⁵⁴ While our sample size is small, this may indicate women facing severe and multiple disadvantage could be more likely to experience interventions without giving consent. Regardless, these findings are very concerning: the law is clear that no interventions should be carried out on a person with decision-making capacity without their consent, and it must always be clear to a woman that she may decline as well as consent. It is deeply worrying that two women described non-consented intimate and invasive interventions. It is also particularly egregious that one was carried out on a woman with a history of sexual exploitation, who might be particularly at risk of re-traumatisation.

Language barriers

One woman told us she was denied interpreting services. This means that she cannot have given consent because she was unable to understand the options available or communicate her choices: *"she asked all the times for an interpreter, but they never provided. There was one time she refused to go to the appointment unless there was an interpreter present and that was the only time an interpreter was provided"*. She told us she was unable to ask for the care and support she needed, a situation risking her and her infant's safety: *"language is crucial, it's key so, what could I do?"*

"In particular moments when I needed care and support, I couldn't do much because I couldn't communicate"

Clearly any woman who is unable to communicate with healthcare providers because of language barriers is not in a position to give consent. The woman's experiences recounted here are also echoed in Birth Companions' previous research with Revolving Doors Agency.⁵⁵

NHS commissioning guidance is clear that *"Patients should be able to access primary care services in a way that ensures their language and communication requirements do not prevent them receiving the same quality of healthcare as others."*^{56,57} Similar issues arise for women with other language and communication needs, for example disabled women with communication needs.⁵⁸ Clinical Commissioning Groups (CCGs) and Trusts that do not provide adequate interpreting services are failing to uphold women's Article 8 rights to private and family life and are putting healthcare staff in a position where they are unable to seek consent to treatment or intervention, and may therefore be acting unlawfully. They may also be failing to meet their requirements under the Equality Act 2010.

⁵⁴ Birthrights (2013). *Dignity in childbirth The Dignity Survey 2013: Women's and midwives' experiences of UK maternity care*.

⁵⁵ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

⁵⁶ NHS England (2018). *Guidance for commissioners: Interpreting and translation services in primary care*.

⁵⁷ NHS England (2016). *Equality objectives 2016-2020* [online].

⁵⁸ Hall, J, Collins B, Ireland J, and Hundley V (2018). *The Human Rights & Dignity Experience of Disabled Women during Pregnancy, Childbirth and Early Parenting*. Centre for Midwifery Maternal and Perinatal Health, Bournemouth University: Bournemouth.

Mental health and choice

One woman talked about mandatory engagement with mental health services and about being unable to be discharged from the postnatal ward until she had seen the

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“Now I’m really scared, what she said, they don’t let me go, I have to pretend everything is fine for me to go home.”

team: *“I just said why, I want to go today... she said, no you have to wait for the next day, they will come to see you the next day, I said who, they said the mental health team”*. She was unaware that the mental health team would wish to see her before she was discharged, saying that

no-one had spoken to her about this, despite her mental health history being in her medical notes. She found the experience very frightening, saying she had felt unable to talk about her feelings to anyone on the postnatal ward, in case it prevented her discharge or led to concerns about her ability to parent.

Good practice

One woman with a pregnancy-related condition said she initially found the discussions around choice and consent overwhelming but came to appreciate the level of detail:

“they went through every single thing, every single thing they explained me about, do they need to tell me all this, do they just want to scare me or what? And then I realise that okay, they did good. It’s that way things should be done, at least you know what you’re going through, so I really, really appreciate that”. The same woman described her midwife as *“brilliant, brilliant, brilliant”*. One woman, an asylum seeker, said she

was supported to make choices before and during her labour by a midwife she described as *“my saviour”*. Other women spoke more generally about feeling well supported by their midwives, particularly where they had continuity of carer. This is discussed further in theme five (specialist midwifery and continuity of carer).

Professionals’ experiences

Midwives (particularly specialists) and Birth Companions staff and volunteers talked about the extent of women’s understanding of choices in maternity care. They talked about how they themselves sought to empower women to ask questions, make choices and feel able to decline procedures. They felt that women dealing with severe and multiple disadvantage were often not aware they had choices.

Awareness of choice

Sometimes, midwives said they felt women facing multiple disadvantage had less of *“an inherent awareness”* of their bodies or the processes of pregnancy and birth, compared to the women they had cared for previously in non-specialist roles.

Migrant women were thought to have particularly limited understanding of their choices in maternity care in the UK, something reflected in the interviews with

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“Women have very little understanding or confidence in the number of choices and preferences that they can make in maternity care [...] They’re worried about all the kind of stuff that’s very traumatising [...] They never question that that shouldn’t happen”.

asylum-seeking women: “*Even the comprehension of having [a] choice as a woman isn’t there for lots of people*”. This was particularly true of women who came from countries where childbirth is treated as a medicalised procedure: “*The struggle there is to get them to question some things and take responsibility and ask questions and make choices*”.

Empowering women

Specialist midwives described taking time to ensure women understood their choices; that they were empowered to ask questions; and felt able to decline, as well as consent to, recommendations. This was thought particularly important for younger women and women who have multiple agencies involved in their lives: “*They’re so used to being told what’s what, a lot of the time, I think they do [get] used to not having choice*”.

This reflects the findings of the Better Births consultation, which found women under 25 were more likely than older women to say their experiences of labour and birth would have been improved if they felt listened to, respected and communicated with appropriately.⁵⁹ Specialist midwives

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“*There is a tendency unfortunately for people to be a bit patronising around teenage mums but I reiterate to them, you’re going to be a mum soon, you’re in charge of yourself and you’re going to be in charge of your baby’s care so you need to be asking lots of questions and don’t just go along with it.*”

recognised the crucial importance of supporting choice and control for women with the most complex lives: “*So much of their lives can be out of their control, so many things in there, you know, that happen to them or are done to them or decisions are made for them and actually the labour and the birth and what they choose in terms of their maternity care is actually a space where they can feel really cared for and able to make decisions*”.

Birth Companions volunteers said they felt there was a need for women to have advocates to support them expressing their choices because “*the medical staff just feels that she will consent*”.

However, in some cases, providing appropriate support could be a difficult balance: specialist midwives said they found that some women did not engage much in discussions about choice because they perceived birth was not “*a big deal*” in the context of other issues in their lives: “*I’m pregnant and my life is chaos. I’m just going to give birth in the chaos and it will be fine*”. They also wondered whether there was a risk that they imposed their own views on women if they pushed too hard. On the other hand, Birth Companions staff said, when given the opportunity to explore potential birth choices, some women would go on to express strong views on fundamental autonomy and privacy issues such as internal examinations, the presence of male staff and being naked or exposed.

Both specialist midwives and Birth Companions staff talked about providing specialised in-depth antenatal classes for women with complex needs to support women’s understanding of maternity care and choices within it. Some said they worried too many choices could be overwhelming; the important thing was to support

⁵⁹ National Maternity Review (2016). *Better Births*.

women “to work out which [decisions] are more important to them” and to articulate those choices and preferences to other healthcare professionals.

‘Out of guidelines’ choices

Midwives talked about the importance of communication and continuity of care to support respect for a woman’s birth choices, particularly where a woman is choosing ‘out of guidelines’ care.⁶⁰ This was thought to be particularly important for birth choices which might worry midwives (such as vaginal birth after Caesarean at home) or run counter to local guidelines (such as guidelines around who is usually considered ‘eligible’ to use a midwife-led birth centre).

“[At my hospital] the midwives have got a voice, and that voice facilitates women to have much more of a voice.”

One midwife gave examples of good practice, involving parties from a multi-disciplinary team working together to facilitate a woman’s out-of-guidelines choice. In many cases, midwives said they were thought to be crucial advocates and conveners.

In a few examples the approach to out-of-guidelines care, or even the guidelines themselves, seemed to depend on the perspective of one or two healthcare professionals. In one example, a hospital consultant was described as being instrumental in changing the policy at a birth centre which had previously excluded younger women, although even after the consultant’s intervention the lead midwife for the birth centre remained able to refuse admission. A birth centre admissions policy based on a blanket exception, taking no account of individual circumstances, cannot be justified under human rights law.

Some midwives were concerned they were not serving women well by preparing them to make choices, if they were not going to be supported to exercise those choices when the time came. They felt that in certain situations, such as acute clinical scenarios on the ward, women might be less well supported and communicated with about their choices. Women with limited English might be given no choices at all.

“The idea of choice I think goes completely out of the window”.

Similarly, Birth Companions staff said they were worried that the very concept of choice risked losing credibility if it was not supported in practice. They said that women need to be supported to understand that “You’re not allowed to tell me I’m not allowed to do that”. Even on occasions where women did find the confidence to decline care this was not always respected: birth supporters described a woman declining a vaginal examination and being told “Why? That’s ridiculous. We all need to do them”. The woman then acquiesced. Birth Companions staff commented that they thought she would be less likely to speak up for herself on another occasion as a result of this experience.

⁶⁰ Care that differs from the recommended care pathways set out in guidance available to medical professionals, such as Guidelines produced by the National Institute of Health and Care Excellence, and Guidance produced by the Royal College of Obstetricians and Gynaecologists.

Declining recommended care

Some midwives talked about barriers which prevented women declining recommended care. One birth supporter cited the case of a woman, who had declined a vaginal examination and was then denied a care plan. She said she was asked by a midwife to try to convince the woman to comply (something which would have been inappropriate for the Birth Companion to do). She described how eventually “*they did wear her down*” with “*relentless*” requests to do a vaginal examination. Other birth supporters described women experiencing “*coercion*” into an induction of labour and being “*frightened*” and “*emotionally blackmail[ed]*” into accepting recommended care, by being told their “*baby will die*” without it.

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“If they say no they can get really bullied... the senior midwife has to make sure [they understand the risks] and then the doctors have to make sure they’ve understood and these women just get browbeaten.”

Failure to secure consent

The midwives shared experiences of the failure of other professionals to secure consent. One described a woman involved in sex work not being treated respectfully or sensitively, with healthcare professionals “*barely getting consent to do vaginal examinations*”. Another described the trauma of women experiencing non-consented interventions and the difficulty of expecting a woman to be able to speak up if she is unhappy: “*They haven’t got the voice to say ‘Don’t do that to me’, because their experience has just told them ‘I’m not fighting anymore. I won’t be listened to’.*”

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“A person’s body is their own and it’s sacred and you don’t touch it unless you get permission... particularly if you know somebody has suffered trauma you go really gently”.

One professional described her personal frustration at “*seeing things happen to people that actually I didn’t feel like were necessary*” but were being framed as having ‘saved the baby’. It was thought by birth supporters and midwives that women facing severe and multiple disadvantage would be unlikely to challenge unwanted interventions in the moment and would therefore be at greater risk of experiencing non-consented ‘care.’

Practices such as ignoring a woman’s decision to decline examinations or procedures, or using undue influence, such as relentless pressure or threats to withdraw care, are inappropriate and unlawful. If a person’s consent is not obtained, any medical procedure or treatment will be against the law.⁶¹ It will be negligent, and in England and Wales, it will also constitute the crime of battery, and a civil wrong of trespass to the person. Failure to obtain consent also violates Article 8 of the European Convention. If the harm that occurs as a result is serious, it may breach Article 3 of the European Convention prohibiting inhuman and degrading treatment.⁶²

⁶¹ The only exceptions to this are rare cases either when a person does not have the capacity to make their own decisions; or in a life-threatening emergency when a person cannot consent because of their physical condition.

⁶² For more information see Birthrights (2017). *Consenting to treatment*.

Impact of other services

The specialist midwives said they believed there was a bigger risk for women who declined recommended care, if they had a pre-existing health condition, or were engaged with mental health services or children's services.

They said they thought children's services would sometimes “*start to panic*” when a woman's decision (for example, to decline an induction) meant they had less control over a situation (such as the timing of a birth). One example was given of a woman who thought her care team had recommended induction of labour to support the planned removal of her newborn, rather than for medical or obstetric reasons. Birth Companions staff members said women with current or historical engagement with social care often feel their choices are constrained.

The midwives said it was important to speak up to other services on behalf of these women to ensure that their rights are respected. On the other hand, they also said it was important to try to ensure women understood the perspectives of other services, and that they understood any potential implications of not following recommended care, for example if the woman's lawful choices might be thought of as evidence that she was not prioritising her baby.

One FNP nurse said a client had recently declined an antenatal test and “*it was noted in her maternity notes that she'd refused so I just wonder you know if something else had come up and she'd refused*”. The midwives said it was important that women should “*not feel cowed*” into making decisions that are not right for them, because of pressure, or fear of scrutiny from children's services who are focussed on the wellbeing of the baby.

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“*There would have been a perception that she was difficult and that probably would have gone on to raise questions about whether she could prioritise her baby*”.

Mental capacity and learning disability

A few professionals discussed difficulties which arise when there are questions about a woman's mental capacity⁶³ to make decisions. They also described some good practice cases where multiple plans had been developed for a woman with fluctuating capacity – that is, women whose condition and/or cognitive function varies, meaning they may have capacity to make a certain decision at some points in time, but not at others.

In other situations, professionals raised concerns about whether women with learning difficulties always received appropriate support from Trusts, particularly where family members spoke on their behalf: “*You do see a bit of, she's got really good family support... Yes, the mum, talk to the mum*”.

The professionals were concerned that women with reduced cognitive function could be hard to identify even for skilled staff, and that learning disabilities were not always

⁶³ It is always assumed that a person has the mental capacity to consent to treatment (or to decline it), unless it can be shown that they do not. In England and Wales, this principle is enshrined in the Mental Capacity Act 2005, which governs decisions about whether a person lacks capacity and how they can be treated if they do. In order to lack capacity under the law, a person must be unable to make a decision for themselves because of a problem in the functioning of their mind. A person might lack capacity in relation to some decisions and not others.

diagnosed. One commented, *“It’s so very, very difficult to get a cognitive assessment on a young person”*. Interviewees felt that doubts or concerns about capacity may be less likely to be followed up, and support may be less likely to be offered, if a woman makes the *“right decision”*. In addition, some midwives commented that care pathways for women with learning needs were not always well-understood, meaning that appropriate support was not always given.

One midwife gave examples of good practice support for women with learning disabilities. These included support at appointments from a known learning disability nurse, the provision of accessible communication aids and the use of role play to illustrate options in labour care. She also gave an example of providing interpreting services for a woman’s mother, so the mother could support her daughter with learning disabilities in understanding her maternity care and making choices that were right for her.

Some professionals commented that learning support needs, even for women with diagnosed cognitive problems, were sometimes deemed to be less important than mental health support needs. As a result, women might be referred to mental health support but not be offered cognitive assessments or specialised learning support in order to understand birth options and make the choices that are right for them.

These experiences raise questions about appropriate holistic care and decision-making support for pregnant women with multiple needs, especially given that mental health conditions are more than twice as common among individuals with a learning disability.⁶⁴ When women are not offered access to cognitive assessments and learning support, NHS Trusts may be in breach of the requirement to provide reasonable adjustments under the Equality Act 2010. Trusts may also be in breach of Articles 8 and 14 of the European Convention, if they fail to provide equal access to care which supports and promotes women’s autonomy in decision-making.

The professionals thought that continuity of carer was very important to allow midwives to develop a holistic understanding of the needs of women with learning or cognition issues: *“There’s no way you would be able to understand the layers of that person and their communication needs, their social needs, their support needs – how they’ve managed their condition, how they live their life unless you have seen them [on] multiple occasions”*.

Making complaints

The professionals in our study said it was rare for a woman facing severe and multiple disadvantage to make a complaint about her experience, even if encouraged to. They said that women, some of whom they described as *“just surviving”*, may not know or think to complain: *“The women who come forward saying ‘This wasn’t okay for me,’ are the women who’ve been taught in their lives to expect better”*. Two women we interviewed said they had thought about complaining: one said she didn’t know how to; the second said she felt she had too many other problems to consider it. She said she was also concerned she had no proof to verify her account.

The professionals we spoke to said they thought very few women with multiple complex needs accessed birth debriefing or reflections services, which give women the opportunity to discuss their birth experience with their maternity providers. If this is

⁶⁴ Mencap (n.d.). *Mental health* [online].

the case, the voices of women facing severe and multiple disadvantage are likely to be significantly under-represented in any feedback to Trusts that helps maintain and improve services.

Language barriers

Midwives and Birth Companions staff and volunteers spoke at length about the experiences of women who did not speak any or much English: *“I think people do get worse care when they don’t speak the language”*. *“If women aren’t able to understand what’s being asked of them or the information they’re being given, then that’s hugely disempowering and confusing”*. One midwife talked of: *“Huge issues to do with consent for women who don’t speak English in labour”*. Another midwife not working in a continuity of carer model described language issues as: *“Just a really complex thing to deal with especially within a service where you don’t really have the time”*.

“If someone doesn’t speak English, often informed consent is non-existent unless you get an interpreter on the phone and do your best but time doesn’t always allow for that”.

The professionals said they thought language support was important not only for women who spoke no English, but also for women with some English, who were unable to express themselves fully: women who can *“just about explain themselves”*. Birth Companions staff and volunteers and midwives felt that language support was not prioritised for women in this situation. As a result: *“they can’t really ask the questions that they need answered”*. One professional who taught specialist antenatal courses, described women coming with very basic questions, such as *“Could you tell me how pregnant I am”*, even after engagement with maternity services. Midwives described having to *“take the initiative”* to use interpreting services.

“There is a really big difference between being able to just about follow what’s being said and actually really understanding the detail and being able to ask about things that aren’t clear”.

Both the Birth Companions participants and midwives said they were concerned that women with basic English who didn’t have interpreting support sometimes indicated they had understood something which they hadn’t; either because of misunderstandings or because they felt under pressure to say they understood. In such circumstances, it is highly unlikely that a woman would be able to participate in the type of genuine

personalised dialogue about decisions described in the 2015 *Montgomery* Supreme Court judgement,⁶⁵ and therefore it is unlikely that a woman would be considered as giving valid consent to any interventions or tests.

Language support

Midwives’ experience of language support provision varied widely from those almost always able to access good quality support at their Trust in order to support women, to those with only very partial access. Specialist midwives tended to have a more positive

⁶⁵ *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

experience: “We’re quite hot within our Trust on making sure that we’re always using appropriate interpreting services and advocacy for our women to make sure they do understand what is going on”. Some midwives described specialist antenatal classes being run in languages other than English. At the other end of the scale, one midwife and a Birth Companions volunteer raised examples where telephone interpretation could not be accessed within ward rooms, but only from an office on the ward (if a woman was able to get there) or by using a dedicated telephone which was not always “readily available”.

Some midwives said that language support was only rarely used – usually during labour, major interventions or surgery. Some midwives described difficulties booking language support. Birth Companions volunteers and midwives gave examples of women who, like one of the women we interviewed, had been refused an interpreter during maternity or GP appointments whilst pregnant. This fails to respect the woman’s needs and her rights to autonomy and equality under Articles 8 and 14 of the European Convention.

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“You can never get an interpreter because even if you book someone you’re only ever allowed to book someone for four hours and nobody labours for four hours”.

Both midwives and Birth Companions staff described times when appropriate and effective language support was not used. They included occasions where relatives interpreted, either because of a lack of NHS interpreting services or because the woman had declined the official language support services. NHS Guidance states that: “The error rate of untrained interpreters (including family and friends) may make their use more high risk, than having no interpreter at all”.⁶⁶

Some midwives and Birth Companions staff illustrated this point. They said they wondered whether interpreters such as family members or community mentors always provided objective translation or were overlaying their own views and opinions. Others wondered whether family, or even professional interpreters, always accurately informed women that they had choices in their care; or represented midwives’ information and recommendations as instructions: “I’m sure I said we would recommend it but does that get translated across and did it come across as, ‘This is what will happen?’ I think that’s how it came across... I say, ‘How are you? How are you feeling?’ which I think is a nice question, but it gets interpreted in an angry tone. That’s not how I said that”.

The midwives emphasised the importance of using female interpreters when talking about intimate obstetric issues or personal vulnerabilities, especially for women who come from small or close communities, who may know the interpreter or worry about privacy. They also said it was important to support a woman to speak freely about her life and to talk comfortably about potentially embarrassing issues: “If you get him [the partner] out of the room... and get a woman in to sit with her and speak with her in her language... all of a sudden this monosyllabic woman turns into a complete chatterbox”.

⁶⁶ NHS England (2018). *Guidance for commissioners: Interpreting and translation services in primary care*.

Some midwives told of significant safety concerns that resulted from mistranslation, such as the case of an interpreter who told a woman to use a tampon instead of a sanitary pad to monitor fluid loss when she thought her waters had broken.

They also said they worried problems were more likely to be missed, if language barriers added to a woman's feelings that: *"The midwife's really busy, I don't want to bug her"*. The midwives said it might also be safer for women in other ways, if interpreting services were provided as standard from the start. They cited examples of women they suspected had been trafficked, who were being 'supported' by unrelated adults providing informal interpretation.

Theme two: Trauma and dignity

Women's experiences

Definitions of trauma vary, but a useful summary describes trauma as *"an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being"*.⁶⁷ All the women interviewed brought experiences of prior or current trauma, or very difficult life circumstances, to their maternity care. Some women raised wider issues – such as lack of privacy or support – which they felt compromised their dignity and exacerbated their trauma.

Six women described recent or childhood experiences of domestic abuse, sexual abuse or exploitation, previous birth trauma or referred to other unspecified historic trauma. Two women described multiple experiences of trauma, and two referred to highly stressful life events – such as the loss of a close relative – occurring during the perinatal period. Three women were worried about the health of their unborn babies, and one was worried about a possible cancer diagnosis during her pregnancy. One woman, an asylum seeker, referred in her interview to receiving counselling, but chose not to elaborate on the experiences which had led her there.

It is likely that the incidence of prior trauma described here understates the totality of women's experience, because it only includes what they chose to disclose during interview. There is evidence that many traumas are un-reported or under-reported.⁶⁸ For example, this could account for the lower reported experience of domestic violence amongst the women to whom we spoke compared to rates reported in other work.⁶⁹ The midwives we interviewed said they found women often downplayed, or were reticent to report, domestic violence, and that women in this study may not have wished to disclose their experiences in a one-off interview.

⁶⁷ Substance Abuse and Mental Health Services Administration (2014). *SAMHSA's Working concept of trauma and framework for a trauma-informed approach*. HHS Publication No. (SMA) 14-4884. Rockville, MD.

⁶⁸ Montgomery, E, Pope, C and Rogers, J (2015). 'The re-enactment of childhood sexual abuse in maternity care: a qualitative study'. *BMC Pregnancy and Childbirth*, 15, 194; Women's Aid (n.d.). *How common is domestic abuse?* [online].

⁶⁹ For example, Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

Support for prior or current trauma

The women reported mixed experiences of support during their maternity care for dealing with trauma. Some were able to speak very openly with a midwife they trusted: *“I saw her more like a friend, so I was able to be like really honest with her”*. The two women who reported particularly trusting support had both experienced continuity of carer throughout the antenatal period.

Case study: good practice

One woman who had experienced multiple traumas and had a longstanding relationship with the Trust where she gave birth, described having an *“amazing”* support network in the team of professionals around her. She said they told her *“Yes, we’re here to take care of you, we’re not here to just let you give birth and brush you off”*. Her team had looked up her history in previous notes to ensure they were well informed at the start of her care: *“which I thought was amazing”*.

In other cases, women said they felt they were unable or unsupported to talk about their experiences of trauma with carers. One woman, an asylum seeker who had experienced recent and multiple traumas, said that staff *“knew my situation”* but that *“I’m not really confident, erm, reason on my past and I just came so I not really talked to them”*. She said she would have liked to talk to someone, but *“it still depends on how they approach you, then you really want to open up, but I didn’t really get that”*.

One woman brought experience of prior birth trauma to her care, which midwives said may be overlooked when professionals are supporting a woman with multiple other needs.

Trauma during birth

Two thirds of the women described times during their maternity experience when they were frightened, denied pain relief or left alone or unsupported at a time when they did not feel safe. This is significantly higher than the rates reported in other research, such as the Birthrights Dignity Survey or Care Quality Commission Surveys of women’s experience of maternity care.⁷⁰ It is deeply concerning, since human rights law affords all women the right to access safe and appropriate maternity care which respects their fundamental human dignity. Failure to provide such care could lead to a risk to life and a breach of Article 2 of the European Convention (right to life).

Three women described feeling alone during labour and childbirth. This includes the woman who gave birth in prison, who had specifically requested that her partner was called. She said that the failure to do so exacerbated what she described as already a very *“traumatic period”* in her life.

Three women talked of difficult experiences during induction: one woman described the removal of a stuck pessary without pain relief, which she described as *“really really painful”*. Another was offered pain relief, but still experienced induction as *“you just feel like you’re not in control”*. After induction, a third was left in the care of a student midwife and said she felt unsupported: *“It was so terrible, she didn’t understand what to do”*. She described a crisis during labour when her blood pressure

⁷⁰ Birthrights (2013). *Dignity in childbirth The Dignity Survey 2013: Women’s and midwives’ experiences of UK maternity care*; Care Quality Commission (2018). *2018 survey of women’s experiences of maternity care: Statistical release*.

dropped and she felt unable to breathe. She said she felt that *“that time, I could lose my life”*.

In some cases, difficult experiences were ameliorated by good carers: *“The midwives I had were so encouraging, like, they did help a lot”*. In other cases, they were exacerbated by disrespectful care: *“When I told them I was in pain, they didn’t really acknowledge that”*.

Postnatal support

“They literally just left me there”

Some women talked of not being provided with the physical and emotional support they needed after labour. One described being forgotten about postnatally. Having been taken to see her baby in the neonatal unit, she had then been left there in a wheelchair, unable to move. Others described feeling unsupported with, or unable to share, current stressful circumstances: *“They [the midwives] know part of my situation... [it would have made a difference if]... they would have just tried to offer me support or just like when I was complaining, they would have given me a listening ear”*.

In this context, we welcome NHS England’s commitment that all Local Maternity Systems put plans in place to improve postnatal care, and we welcome the Long Term Plan pledges on postnatal physiotherapy and perinatal mental health clinics.

Privacy

A few women said they found the lack of privacy on the ward very challenging and that it was difficult to speak about personal matters. Birth Companions and Revolving Doors research had similar findings, with women describing the lack of privacy as both “shaming” and “isolating”.⁷¹ For some, especially women who had recently left situations of abuse or exploitation, this could be made worse when men were present. One woman talked about how uncomfortable she was having intimate procedures carried out on the antenatal ward with *“men around”*. Birth Companions volunteers reported women finding it *“humiliating”* when visits from social services could be overheard by others on the ward. These experiences raise serious questions about whether women’s fundamental right to privacy under Article 8 of the European Convention is being upheld.

“I was not really comfortable talking about it on the ward but I had no choice.”

“Even when I wanted to breastfeed they didn’t leave the room, so it was a bit heartbreaking”

Two women talked of experiences with male midwives or male social workers. Both described finding it difficult to build a trusting relationship with a man: *“You don’t know how to talk, how’s he’s going to react”*. One asked to see a woman instead but was told that would not be

⁷¹ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

possible. A third woman said male prison officers were with her after she had given birth, whom she described as “*very arrogant, and very rude*”.

Birth Companions’ Birth Charter states that: “[Prison] Officers should be respectful to women’s needs for privacy (e.g. when breastfeeding or during medical consultations).” It goes on to say that: “*Research has demonstrated the importance of respecting a woman’s dignity and privacy during birth and breastfeeding. In birth, we know that a stressful environment can impact on labour and mother/baby bonding.*”⁷² We are deeply concerned about examples where women’s fundamental Article 8 right to a private and family life appear to have been breached.

Professionals’ experiences

The professionals discussed their experiences supporting women dealing with historic or current trauma. They also talked of the risk from trauma faced by healthcare staff themselves. They said they felt that all maternity services need to be trauma-informed. Trauma-informed maternity care has the potential to “prevent adverse outcomes, help break intergenerational cycles of maltreatment and mental health disorders, and change the mother’s and child’s life-span trajectories into a positive direction.”⁷³

Trauma-informed care

In the interviews, most of the discussion focussed on the identification and support of women who have experienced trauma. This is a crucial part of trauma-informed interventions and woman-centred care, but not the whole picture.

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“*It’s something to work towards because I think we all need to be trauma informed*”

Trauma-informed care is a broader way of framing care that “*attends to the context of care and the nature of all staff members’ interactions with all clients and each other*”. Trauma-informed care is built on an assumption that any woman accessing maternity care may have experienced trauma; recognises the presence of trauma, acknowledges the impact of trauma and aims to aid recovery and avoid re-traumatisation.⁷⁴ Professionals spoke about aspects of care that better supported women who have experienced trauma, but the majority had had no formal training.

They said the continuity of carer model was vital for them to be able to provide safe and respectful support. They said this applied to both women with a known history of trauma and women who needed the time and the opportunity to build trust before

⁷² Birth Companions (2016). *Birth Charter for women in prisons in England and Wales*. Citing Buckley, S (2015). *Hormonal Physiology of Childbearing: Evidence and Implications for Women, Babies, and Maternity Care*. Washington, D.C.: Childbirth Connection Programs, National Partnership for Women & Families.

⁷³ Sperlich, M, Seng, JS, Li, Y, Taylor, J and Bradbury-Jones, C (2017). ‘Integrating trauma-informed care into maternity care practice: Conceptual and practical issues’. *J Midwifery Womens Health*, 62(6), 661-672.

⁷⁴ Cuthbert, C and Seng, J (2015). ‘What is trauma informed care and why is it important?’, in Seng, J. and Taylor, J (eds.) *Trauma informed care in the Perinatal period*. United Kingdom: Dunedin Academic Press, 13-23.

disclosing trauma and discussing their needs. Birth planning was given as an example. They said taking time and building trust enabled midwives to have open and honest conversations about choices, and to support women to develop multiple personalised plans, so they felt empowered and supported whatever happened during labour.

Training and confidence

—
“Other midwives just don’t ask because what are they going to do, they don’t want to know the answer. Sometimes you don’t even ask how are you because actually if they start crying ... your clinic is over.”

Midwives suggested that colleagues without training, or the confidence to recognise and support women who disclose trauma, are less likely to ask women about their experiences. This was thought to be partly because of a lack of confidence in what midwives should do with ‘difficult’ information. It was also thought to be because it

involved the development of particular skills in asking tricky and direct questions. Additionally, it was thought to be partly for practical reasons. This is discussed further in theme five (specialist midwives and continuity of carer).

Specialist professionals working with women in temporary accommodation, who often had a history of trauma, said they felt trauma was not always recognised by other non-specialist colleagues who were not looking out for it in their day-to-day work: *“I say to them, ‘We meet the families because they’re in a certain address. You’re meeting them out there. You just need to recognise it’”*. Non-specialists said they needed support upfront to build confidence and competencies in trauma-informed practice: as Sperlich et al note: *“Women won’t disclose in clinical settings unless they know that providers are competent to hear disclosures and that some form of help is available”*.⁷⁵

Specialist professionals felt that there was a need for more training for students and early career professionals: *“Students should be geared up more towards being able to spot [trauma] and be thinking about it.”* Midwives recognised that current curricula include training in complex needs, but that this was often midway through the programme and did not specifically include trauma-informed care. They felt more focus needed to be placed on ensuring that student midwives revisited that aspect of training close to the end of their course, so they were prepared for practice: *“If you’re not turned on to that way of thinking [about potential traumas and complex needs] then you’re not picking it up.”*

We welcome the focus in the Nursing and Midwifery Council’s draft Future Midwife Standards on knowledge, understanding and ability to advocate for *“women and newborn infants who are made vulnerable as a result of factors including social exclusion, poverty, legal status, mental health, disability, violence, sexual exploitation, or clinical circumstances.”*⁷⁶

⁷⁵ Sperlich, M, Seng, JS, Li, Y, Taylor, J and Bradbury-Jones, C (2017). 'Integrating trauma-informed care into maternity care practice: Conceptual and practical issues'.

⁷⁶ Nursing and Midwifery Council (2019). *Future midwife: standards of proficiency for midwives [Draft - January 2019]*.

The need for ongoing training for other professionals, such as obstetricians, in identifying and supporting women with trauma, and in trauma-informed care, were also flagged by healthcare professionals in this research. A key part of trauma-informed care was thought to be joined-up services, so that women don't have to re-tell and re-live the trauma multiple times.

Removal of infants

The professionals commented that a lack of support services could be traumatising for women. The midwives were particularly critical of the lack of recognition of the

“It reinforces to them that they have no value... It's like saying, 'Actually, you only mattered up to the point you were pregnant. You're almost like a vessel and then once the baby is out, we are not worried about you anymore.’”

support needs of women whose infants are removed by social services. One midwife described being asked to do a postnatal check on a baby that had been removed: *“And I said... where's the mother, and they were like, oh no don't worry the baby's been removed from the mother. And I was like, no I want to know where the mother is, you know because she needs postnatal care... it didn't even occur to them to make the referral.”*

This is very worrying and represents a possible breach of the woman's Article 2 rights in relation to access to healthcare and Article 3 rights to be free from inhuman or degrading treatment (treatment which could cause severe mental or physical suffering).

Interviewees said they felt services fail to recognise that the removal of an infant is an enormous trauma for the mother. They observed that often no additional support is provided, and a mother frequently loses the support of services she is already accessing, or might have accessed if she had care of her baby. One midwife described seeking support from the bereavement team for a woman whose baby was removed: *“And they said, no we don't deal with that... but it's an equivalent loss for her.”* In their peer research, Birth Companions and Revolving Doors Agency identified the need for support for women who were at risk of having their baby removed, or experience separation, providing the equivalent to that offered by bereavement teams.⁷⁷

“Health visitors don't want to know because you haven't got your baby. Perinatal [mental health] services don't want to know because you haven't got your baby.”

Midwives had seen the same falling away of support for women who experienced a stillbirth: *“All the services that she was engaging with very well, just stopped.”* One

⁷⁷ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages.*

midwife was still being contacted by the mother a year after the birth: *“I really was at that stage the only person left.”*

This lack of support is disrespectful and adds an additional layer of trauma at a time when a woman should expect kindness, empathy and support. It is also dangerous. The MBRRACE report into maternal deaths 2014-6 found that for a number of women who died *“pre-existing mental health conditions were exacerbated when their child was removed”*. It also noted: *“Maternal suicide is the third largest cause of direct maternal deaths occurring during or within 42 days of the end of pregnancy”* and the leading cause of direct maternal death in the year following pregnancy.⁷⁸

Yet midwives in our study commented that women who have had children removed – or sometimes who are bereaved – are often discharged with no follow-up support and just the expectation that they will present for a six- or eight-week postnatal check with a GP. MBRRACE specifically noted one case where *“The final act of removal of her children, without providing additional support and risk management for her, was the act that likely led to her death [by suicide]”*.⁷⁹ The risks of discharging women without support should not be underestimated and all women’s right to safe and appropriate care (Article 2) must be upheld.

Professional trauma

The specialist professionals described how they feel they ‘hold’ trauma for the women they care for: *“It’s containing the worry actually... which is quite difficult. I think when you’ve got a lot of cases like that, that hold a lot of worry and concern [it]... can be quite a challenge.”* Specialist midwives said they provided a “safe space” in which women could express their emotions, but that it could be “exhausting”, particularly when women are not engaging with any other services. They said it was difficult to let go of feeling responsible for women and their outcomes. One midwife said: *“It’s very hard to separate yourself from what’s going on with them.”*

“[There’s] a lot of stress and worry... I can’t switch off after work... I have to be quite disciplined not to check my phone on days off and because they can contact another midwife on my team should they need to, and I think you end up feeling really responsible for the women, knowing that they are in these kind of very vulnerable situations.”

Some specialist midwives had access to restorative supervision, aimed at supporting midwives with the emotional impact of their work and providing reflective discussion.⁸⁰ However, they said it was very easy not to make time for this, when juggling what they felt was an overwhelming caseload. In contrast, the FNP nurses reported having weekly supervisions.

Other midwives did not have reflective or restorative supervision but said they would value it. One of the non-specialists talked about having been unable to access support

⁷⁸ Knight et al on behalf of MBRRACE-UK (2018). *Saving Lives, Improving Mothers’ Care*.

⁷⁹ Ibid.

⁸⁰ NHS England (2017). *A-EQUIP: A model of clinical midwifery supervision*.

or supervision from a Professional Midwifery Advocate⁸¹ when she needed it. The non-specialists commented that it was often difficult to find the time to engage even in informal reflection with colleagues when working in hospital wards dealing with acute care situations.

Some professionals talked about the difficulty of discussing issues which arise in their work with women with complex needs, because of a general lack of understanding amongst colleagues: *“I didn't talk to many people about things because by the time I'd explain the complexity, I was exhausted and fed up because they didn't get it.”* Others said they ended up providing support for colleagues, as well as for the women in their care.

Midwives and other professionals working with women with severe and multiple disadvantage need supportive management (discussed further in theme five) and time and access to restorative supervision to develop and maintain resilience and recognise secondary trauma.

“You can find yourself, as a midwife, supporting other people [in the team] as much as you are supporting the women you are looking after.”

Theme three: Asylum and immigration

Women's experiences

A third of the women who took part in our research indicated that they were current or recent asylum seekers.⁸² Many issues raised by these women are similar to those discussed under other themes. However, women who were asylum seekers had less understanding of how maternity care works in the UK and were offered fewer choices than other women. They were living in more unstable housing situations and were less likely to be offered the support they needed than other women in this research. While these findings reflect a small number of interviews, they are in line with research by other organisations, in particular Maternity Action, the Refugee Council⁸³ and the Equality and Human Rights Commission.⁸⁴

None of the women said they had been charged for their maternity care. However, as below, the midwives' focus groups all discussed the impact of NHS charging policies on them as healthcare professionals. Forthcoming research from Maternity Action will

⁸¹ Professional Midwifery Advocates (PMAs) have replaced Supervisors of Midwives. The PMA role includes supporting midwives “through a process of restorative clinical supervision, personal action for quality improvement, and preparedness for professional revalidation”: *ibid.*

⁸² Women were not explicitly asked about their immigration status.

⁸³ Refugee Council and Maternity Action (2013). *When Maternity Doesn't Matter: Dispersing pregnant women seeking asylum.*

⁸⁴ Equality and Human Rights Commission (2018). *Research report 112: The Lived Experiences of Access to Healthcare for People Seeking and Refused Asylum.*

also highlight the frustrations and concerns of midwives in relation to NHS charging, particularly in terms of access, risks and safety.⁸⁵

Of the four women who identified themselves as current or recent asylum seekers, at least two had been trafficked to the UK. One explicitly stated she had been trafficked for sexual exploitation and another described working as a prostitute to pay off debts. One said she had suffered childhood trauma. At least three were pregnant unexpectedly.

One had received no antenatal care before she arrived in the UK seven months pregnant. Another said she had only attended some of her antenatal care and a third described finding it difficult to keep track of, and attend, her antenatal appointments. All four women described being socially isolated during their pregnancies. Two described being alone during labour, two had friends or roommates with them. One woman had children living in her home country as well as the baby born in the UK.

Unstable maternity care

Overall, the women in this group seemed to have had worse experiences than the others, particularly in relation to their experiences of maternity care and stability of housing. Three described unstable housing situations, with one woman having to share a bedroom both in late pregnancy and after her baby was born. Housing moves meant that two women had to change maternity providers during pregnancy; in one case the woman was unable to register with the new hospital Trust before she went into labour, as she had only been in her accommodation for a few days.

One woman said she had been living with a person who was “*not nice*” before she had her baby and did not want to return. She said the hospital put pressure on her support services to find somewhere to live so they could move her off the ward because “*they need the space for another person*”.

Whilst other women also faced housing challenges, the women who were asylum seekers tended to be less settled. One described three moves during her pregnancy and the first months of her baby’s life. She said one of those moves might have been avoided had the hospital allowed her to stay a couple of additional days. As a result, these women found it harder to access continuity of carer and maintain longer term support.

The Equality and Human Rights Commission recommended in 2018 that the Government “*Review current Home Office accommodation and dispersal policy and practice to ensure that healthcare needs, especially of disabled people and pregnant women, are met in the provision of asylum accommodation*”.⁸⁶ This seems particularly important if asylum seekers are to benefit from the ambitions around safety and continuity of maternity care set out in the NHS Long Term Plan.

⁸⁵ Maternity Action (forthcoming 2019) research on midwives’ views on charging for NHS maternity care.

⁸⁶ Equality and Human Rights Commission (2018). *Making sure people seeking and refused asylum can access healthcare: what needs to change?*

Knowledge of UK maternity care

Three of the four women who were asylum seekers said they had not been given information about what maternity care they could expect in the UK. Three also said they were not offered any antenatal education. Even when they were engaging with antenatal care, they described the interactions as being focussed solely on routine checks: *“When I go to the hospital they just checked the baby every time, that was it.”*

Unless they found a midwife who asked about them as a person, women described their care as functional rather than supportive. This was also true for women who said their midwives were aware of their situation. One woman, who shared her background during the interview, said she had found it difficult to talk about her past and what had happened to her: *“I was just pretending all was fine.”*

“I just went to the hospital, did a visit and then just went back home, I didn’t feel less afraid and I didn’t necessarily feel that I was getting any support as such.”

Midwifery support

All the women talked about the importance of social and midwifery support and having *“someone to talk to”*. However, only one of the four – a woman who started her maternity care at seven months gestation – received any continuity of carer. This compares to over half of the women interviewed overall. The one woman who did have some continuity described the midwife as *“my saviour”* in labour. One other woman said she really appreciated a midwife who treated her in a friendly manner during her antenatal care, compared to her other midwives who *“don’t talk to you... even she greets you when she sees you ‘oh hello, how are you today?’ Even before she starts her work, she would ask after... everything about you, if you’re okay, how’s your pregnancy, how is the baby, she’s very good”*. This midwife saw the woman two to three times.

“The midwife was standing there but I wished someone was holding my hand, telling me it was going to be fine, don’t worry, but the midwife was just standing there waiting for me to... waiting for the baby to come.”

Women said they lacked the support to feel comfortable to talk about their lives or to ask for practical help. One said through her interpreter: *“She would have liked them... to have spoken to her, talked to her about the baby, or the baby coming into her life... she would have like some maybe guidance or... for them to have facilitated maybe the practical aspect of the whole process.”⁸⁷*

One woman described how she was treated: *“I don’t call it kindly, I’d just say I was treated nicely, like the normal way you would treat a person, not like there was anything out of the ordinary”*, whilst others felt support and treatment had varied.

Two women said they wished they had received more midwifery support during labour, particularly as they lacked family or friends to support them during the birth. One described catching her own baby during her water birth: *“I don’t know whatever*

⁸⁷ This quote is from a woman who used interpretation during her interview. Some interpretation was given in the first person, some in the third. It is reported verbatim as transcribed.

she was doing, I was having the baby then she was on the computer. I pushed myself, the baby came...into the bath. Then I quickly raise up the baby.”

Dignity and autonomy

Only one woman said she felt she had received the support to make the choices that were right for her. Three women said they didn't think their pain was taken seriously: *“Probably because they see a lot of that everyday so it's a normal pain so like there's nothing special there.”* Or they felt unable to access pain relief, as one woman said: *“I was constantly asked to wait.”* The interpreter continued: *“The pains, they were enormous, and they were telling her to do something but in fact they had the means to help her.”* In one case, the failure to provide pain relief may have been exacerbated by the failure to provide interpreting services (discussed below), leaving the woman unable to articulate her needs and at greater risk of experiencing fear and anguish: *“She was in a lot of pain so she was screaming and saying I'm in pain.”*

One woman, who had already had a baby in another country, said she would have spoken up about her choices if she had understood that she could: *“I thought about asking them but I just thought in my mind, and maybe this is the... the way it's been done over here.”* Another said she was completely unable to communicate her choices because there was nobody to translate for her: *“She asked all the time for an interpreter but they never provided... she was merely told that this hospital does not provide interpreters.”* She said that apart from being asked initially by the GP whether she wanted a vaginal birth or an elective Caesarean section, she was presented with no other choices about her birth and felt that she had *“no other option”* than to do as she was told throughout her labour. Because she could not communicate, she says she was unable to access the care and support she needed. She also said she would have complained about this later, had she known how.

Complaining about experiences of maternity services was thought to be particularly unusual for women who are seeking asylum: it was noted by Birth Companions participants that women in this situation are less likely to make complaints even when processes are accessible, because they do not wish to draw attention to themselves. Any reticence to complain is likely to be exacerbated for women who do not have a regularised immigration status.⁸⁸

Practical support

Three women said they had needed assistance with practical matters – for example help with forms to enable them to access support payments. However, they said that help had not been forthcoming. One woman reported losing belongings when she moved between hospital rooms, because there was no one to help her carry her bags. Another described being discharged with her newborn wrapped in a hospital towel, because she didn't have any clothes or equipment for the baby. She said it would have been nice to have had an item of new clothing, to reflect that *“something special has happened to me”*. Several women talked very positively about the support and practical assistance they had received from charities and other support organisations: in one case, the woman would have had no clothes for her infant without such support.

⁸⁸ This project did not knowingly speak to anyone with irregular immigration status, but Maternity Action's 2018 research *What Price Safe Motherhood*, examining the impact of NHS charging on women's maternity care, did.

Professionals' experiences

As mentioned above, none of the women we interviewed said they had been charged for their maternity care – or expressed concerned about charges. However, among the midwives we spoke to, this topic provoked strong views. They expressed significant discomfort about having to deal with NHS charging and were particularly concerned about the impact on undocumented women and women without regularised immigration status.

The midwives described deep unhappiness with NHS charging policies overall and specifically with their own perceived role in 'policing immigration'. They considered it outside their remit as healthcare professionals, and in direct contravention of their role as maternity care providers. Other healthcare professionals have raised similar concerns, for example in the 2018 joint statement from the Royal Colleges of Paediatrics and Child Health, Obstetricians and Gynaecologists, and Physicians, and the Faculty of Public Health, which described NHS charging as "*a concerning barrier to care*" and called for charging to be suspended pending "*a full review of their impact on individual and public health*".⁸⁹

NHS charging and access to care

The midwives said they felt powerless, because they were obliged to explain the charging policies to women, but they knew that some women would then avoid maternity care as a result. Some midwives said women were "*scared to keep coming back*" for maternity care because they feared NHS charges. They said some women booked in, but then didn't return for any further maternity care before they went into labour. This finding reflects those of the 2018 Maternity Action research into the impact of charging policy on pregnant migrant women in the UK.⁹⁰ Some women were suspected of having booked under false names to avoid charging.

The midwives also said they thought charging was likely to be a false economy. They cited the case of a woman who had been trafficked to the UK, but who, on being told she would be charged, then disengaged with maternity care. They said she later re-presented in premature labour, resulting in an emergency Caesarean section. The infant required intensive follow-up care and the mother needed inpatient treatment for a mental health crisis.

A 2018 systemic review found that maternal mental health, mortality and preterm birth were worse for migrant women compared to women in the host country. Asylum-seeking and refugee women had worse outcomes within that group, something the authors described as "*a double burden of inequality for one of the most globally vulnerable groups of women*" requiring urgent attention and "*strategies to overcome barriers to accessing care*".⁹¹ It seems perverse, therefore, to enact policies such as charging, which are likely to deter women from fully engaging with their antenatal care.

⁸⁹ Royal College of Physicians (2018). *Royal colleges support suspension of NHS overseas visitor charges pending review* [online, 20 December].

⁹⁰ Maternity Action (2018). *What Price Safe Motherhood*.

⁹¹ Heslehurst, N, Brown, H, Pemu, A, Coleman, H and Rankin, J (2018). 'Perinatal health outcomes and care among asylum seekers and refugees: a systematic review of systematic reviews'. *BMC Medicine*, 16, 89.

Maternity care is deemed ‘immediately necessary’ and therefore not subject to upfront charging. Yet successive research projects have identified the fear of charging as a significant barrier to women accessing maternity care.⁹² Deterring women from seeking care jeopardises their Article 2 Convention rights to safe and appropriate maternity care.⁹³

Information-sharing

Midwives expressed significant unhappiness at being required to act as a conduit of information about a woman’s immigration status and eligibility for non-charged care. They described attempts to avoid asking for this information where possible: “*If someone tells me they’re a British citizen I will not question it*”.

However, the midwives talked of some Trusts using computerised booking systems, which required them to seek information from women and note whether they had recourse to public funds. They felt this mandatory question fails to take into account the complexity and fluidity of many women’s immigration status and their entitlement to uncharged NHS maternity care over time, and places the responsibility of recording a woman’s immigration status on midwives rather than on Overseas Visitors Managers (OVMs).⁹⁴ The midwives we spoke to said they had received little or no training in either immigration policy or NHS charging.

There was some suspicion among the midwives that racial profiling was being used to identify women liable for charges. The complexity of immigration rules and entitlements was perceived to be a real challenge for both women and professionals.

Our focus groups took place after the suspension of the NHS Digital data sharing Memorandum of Understanding with the Home Office.⁹⁵ Nonetheless, midwives said they felt uncertain and uncomfortable about how and what information might be shared as a result of immigration enquiries. They said they were unsure whether women understood that information might be shared. They felt this compromised the midwife-woman interaction, making it hard to build an open and trusting relationship. They said consequently they were less likely to be able to support a woman to make the right choices for her, and they worried that a woman might be deterred from seeking care or being open with a midwife if she felt her information might not be held in confidence.

The midwives also talked of what they saw as inappropriate engagement from Overseas Visitors Managers (OVMs), for example, OVMs knocking on the door during an antenatal appointment or while a woman was in labour. They said the approach of OVMs often left women distressed, with the midwives acting to try to protect them from untimely intrusion.

⁹² Maternity Action (2018). *What Price Safe Motherhood*; Equality and Human Rights Commission (2018). *Research report 112: The Lived Experiences of Access to Healthcare for People Seeking and Refused Asylum*.

⁹³ British Institute for Human Rights, Birthrights and Royal College of Midwives (2016). *Midwifery and Human Rights: A practitioner’s guide*.

⁹⁴ This is explored more fully in Maternity Action’s (2018) *What Price Safe Motherhood*.

⁹⁵ The Memorandum of Understanding enabled sharing of non-clinical data between the NHS and the Home Office for the purpose of tracing immigration offenders and vulnerable people who may be at risk. It was suspended in May 2018 and terminated awaiting results of a consultation in November 2018: Digitalhealth (2018). *NHS Digital confirms end of patient data sharing with Home Office* [online, 14 November].

Additional support needs

NICE recognises that “*Pregnant women who are recent migrants, asylum seekers or refugees, or who have difficulty reading or speaking English*” are a group of women dealing with “*complex social factors*” who require additional support to ensure access to appropriate good quality maternity care.⁹⁶ Despite this, in our small sample, the women who were asylum seekers found it harder to access the care and support they needed, had worse experiences of care and poorer (in some case very little) support for making decisions about their care than the other women interviewed. The midwives said they felt ill-equipped to support women’s access to maternity care under the NHS charging regime.

These findings add to the evidence (collected by other organisations such as Maternity Action, the Refugee Council, Doctors of the World and the Equality and Human Rights Commission) of the inconsistent and intrusive application of charging policies, and of the impact that charges might have on both women’s access to maternity care and woman-midwife interactions.

The findings raise significant questions about whether women’s Article 2 rights to access to healthcare and Article 8 rights to private and family life are being upheld, especially when set alongside other challenges they were facing, such as frequent dispersal and language barriers. They also raise questions about whether women’s rights to equal access to healthcare under Article 14 are being supported.

In 2018 Maternity Action called for NHS charging for maternity care to be suspended because of the risks of maternal and infant morbidity and mortality and the impact on pregnant women’s mental health.⁹⁷ The same year, the Equality and Human Rights Commission recommended that the Government should provide “*free and full access to all family planning services and pregnancy and maternity services, regardless of immigration status*”. The Commission also set out recommendations for the Government to ensure that people seeking and refused asylum should be provided with accessible information about the rights to access healthcare and to “*Ensure that healthcare services are able to provide professional interpreters to help people seeking and refused asylum to navigate unfamiliar healthcare systems, facilitate clear communication between patient and doctor, and ensure informed consent for any treatment*”.⁹⁸ We support these timely recommendations.

Theme four: Housing and hardship

Women’s experiences

Almost all the women who took part in this research were living in temporary, unstable or unsuitable housing. Many women described unsuitable housing as a central problem in their life, causing and/or exacerbating mental health problems and jeopardising access to care.

⁹⁶ National Institute for Health and Care Excellence (2010). *Clinical Guideline CG110 Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors*.

⁹⁷ Maternity Action (2018). *What Price Safe Motherhood*.

⁹⁸ Equality and Human Rights Commission (2018). *Making sure people seeking and refused asylum can access healthcare: what needs to change?*

As described in theme three (asylum and immigration), three of the four women who were asylum seekers described insecure housing situations and multiple moves. One woman had to share a bedroom in late pregnancy and after her baby was born where she “*didn’t have any space*”.

Health impacts

Other women also described feeling “trapped” in unsuitable, dirty and cramped accommodation. They said supporters – such as midwives, mental health workers, health visitors and advocates working for charities – petitioned for a move to more suitable housing. However, they said, the perception was that “*they [housing] don’t*

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“The thing is, we are human beings, first point, if you are in this condition, like we can’t afford our own place, we depend on them.”

want to do nothing, no one will do nothing.” Housing seemed to sit outside any multi-agency support that women were otherwise receiving and seemed at times to be unresponsive to letters from professionals advocating for women to be given accommodation that met their needs.

The lack of control over their accommodation, and the physical experience of having to share a room or a dirty bathroom, were deeply distressing to some women. They recognised that their situation meant they had little choice, but that did not diminish the effect on their mental health: “*The best way I can describe it... it feels like a prison sentence.*”

Case study: disability, housing and access to care

One woman said she was trapped in her flat for ten months, due to mobility problems that were made worse by an accident early in her pregnancy. She said she had “*little or no access to the outside world*” and was unable to wash properly at home as she could not shower without help. Her specialist midwife did visit her at home, but she said she had to rely on the hospital transport team to access hospital-based care. However, she says the transport teams did not always arrive with enough crew members to help her leave the flat, even though her midwife would order a large team: “*How many times I missed my scans.*”

As discussed in theme one (choice and consent), this ultimately limited her choices around labour and birth, because she was too afraid that she would go into labour alone in her flat to choose anything other than an induction. She said her housing situation made her feel suicidal: “*Experience was so horrible.*” Multiple professionals, including social services and her mental health team, attempted to intervene to secure more suitable accommodation but: “*Housing did not see me as a priority.*” Only once her landlord said he would evict her did the Council pay attention, she said, and even then, she had to appeal before she could secure a move.

This raises concerns about whether the Local Authority was meeting its duties to reduce the disadvantage she was suffering due to her disability or to meet her needs under the Equality Act 2010. It also calls into question whether the Trust was meeting its Article 14 Convention duties to ensure non-discrimination in access to healthcare, given the problems with the hospital transport team, which seem to have prevented her accessing care, or exercising her Article 8 rights to make choices about her care.

Moves during pregnancy

Some women had been living in what they understood to be ‘temporary’ housing for many months, or even years, when they spoke to us. Several described moving or being moved during pregnancy or in the postnatal period; for two women, this involved moving out of the area in which they were receiving their maternity care. Women who move out of area – often by some distance – then have a choice to make: whether to continue their maternity care with a known service, and sometimes with known midwives, but at the expense of travel time and cost; or to move to a new service in their new area and start from scratch building a new relationship with carers. This is likely to be a harder decision for women who have been receiving specialist care or continuity of carer, which may not be available at a new Trust.

The potential disruption in maternity and/or postnatal care could jeopardise women’s fundamental right to safe and appropriate care under Article 2 (right to life). The same issues arise for other services women may have contact with – especially those based on long-term therapeutic relationships or ongoing medical care – as discussed further below and highlighted by Shelter.⁹⁹ One woman we interviewed had moved back to live with her mother for support after the birth, but found that her postnatal care did not transfer smoothly to the new Trust. In the end, she moved home to return to her old team, away from her family support.¹⁰⁰

Safety concerns

Housing also affected the ability of some women to find a safe place for their early labour; one woman described being sent away from the hospital, but not asked whether she had anywhere safe to be. She then had to call an ambulance and “*almost [had her baby in the ambulance] because it was so close.*” Birth Companions staff and volunteers said they had supported a number of women who had to experience early labour in the street, or elsewhere in the hospital. They said the women either felt unsafe in their housing, couldn’t afford to travel home and back to the hospital again, or had left their accommodation in the expectation of being rehoused with their baby after it was born.

It seems that these women had often not been asked, and didn’t feel confident or safe enough to say, that they had nowhere else to go. These examples raise serious questions about whether women’s fundamental rights to safe, appropriate and dignified maternity care (Articles 2 and 8), including in early labour, are being upheld.

Postnatal and neonatal care

The distance between home and hospital – and the travel costs to cover that distance – could also have an impact on a woman’s care after she had given birth. One woman said she was only able to stay on the neonatal ward with her newborn, after explaining she could not afford the travel costs to visit more than once a week after she had been discharged from the postnatal ward. A neonatal nurse found her

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“*She’s seen my situation and she was like ‘I’ll go and talk to someone, and she got me a room...I was like ‘that’s absolutely amazing’.*”

⁹⁹ Shelter (2016). *Home and away: The rise in homeless families moved away from their local area.*

¹⁰⁰ See also *ibid.*

somewhere to stay on the neonatal unit and the midwifery administrative team ‘unofficially’ provided her with leftover meals or ordered food for her when they could. She described herself as “*really lucky*”, but it should not be down to luck whether a woman is able to visit her newborn who is receiving specialist medical care. In another case, an FNP nurse described a couple being criticised for not visiting their baby more when they were unable to travel to the hospital regularly because of lack of transport options.

The right to a family life is fundamental. However, Bliss, the charity for babies born premature or sick, found that “*one in seven neonatal units are unable to provide any, or only very limited facilities or support to families with infants on the unit. 40% of neonatal units have no or very limited kitchen facilities*” and “*Fewer than one in five NICUs have enough overnight rooms for parents of critically ill babies*” (2016).¹⁰¹

Provision of accommodation for parents is a core part of the Bliss Baby Charter for family-centred care (2015).¹⁰² In addition, in 2014, Bliss found that parents had to spend an extra £282 a week when their sick or premature baby was in hospital – over £2000 for the average stay¹⁰³ – a sum likely to be vastly out of the reach of the women who took part in this research.

The National Maternity Review Better Births (2016) also stated that “*neonatal services should include accommodation and assistance for parents*” to actively take part in their baby’s care.¹⁰⁴ We reiterate this call. To fail to do this could be a breach of women’s Article 8 rights to a private and family life.

Professionals’ experiences

All the professionals recognised housing as a major issue, of central importance to the women they were supporting. Housing was described as a “complete nightmare”. Only in rare cases were housing services included within a woman’s multi-agency support team and housing was often described as being separate and difficult to access or influence.

“No one takes ownership... It’s not a safeguarding issue. It’s not a social services issue. It’s not a midwife’s issue. It’s not a health visitor’s issue. It’s not a GP’s issue.”

The professionals talked of writing letters to intervene on behalf of women in their care. However, they said they felt the letters had “*no impact*” unless a woman had “*clear medical needs*”, and even then it was not always sufficient to influence a change in housing. “*You are as powerless as the poor woman in the hostel to affect any change in this area.*”

Some of the healthcare professionals said they felt social workers had more impact.

¹⁰¹ Bliss (2016). *Families kept apart: barriers to parents' involvement in their baby's hospital care.*

¹⁰² Bliss (2015). *Bliss Family Friendly Accreditation Scheme: Helping to make family-centred care a reality on your neonatal unit.*

¹⁰³ Bliss (2014). *It's not a game: the very real costs of having a premature or sick baby.*

¹⁰⁴ National Maternity Review (2016). *Better Births.*

Health visitors said they found that some women could focus on their worries about housing to the exclusion of other factors. They said they sometimes had to be honest with women about where it was most effective to focus their energies.

The professionals recognised that there are very significant pressures on housing stock, particularly in the areas of London where they worked: *“There’s no housing.”* The London Housing Strategy acknowledges the magnitude of the problem: *“How to provide all Londoners with a decent and affordable home is the greatest challenge facing our city today.”* It says a *“shortfall in homebuilding meant that by 2016 there were only around 3.5 million homes in London. If housing growth had kept pace with population growth since 1997, there would have been around 4.2 million.”*¹⁰⁵

Inappropriate and unsafe housing

The professionals described the inappropriate and unsafe accommodation in which some women were housed. Examples included:

- accommodation where women with disabilities could not manage the stairs with their baby
- women who had left violent relationships being housed in accommodation blocks where domestic violence, or threatening behaviour, was frequent and re-traumatising
- women with children being housed in buildings with stringent rules governing children’s play or access to laundry facilities (with some families having to do laundry in the middle of the night)
- building rules saying that women and families would be referred to social services or evicted for breaking the rules.

The professionals also talked of temporary housing that had no behaviour standards or rules to ensure residents’ safety, as well as housing where visitors were not permitted, or where landlords unlawfully told women that health professionals were not allowed to visit. They described private housing as *“very difficult”* and landlords as *“exploitative”*, particularly for women who are undocumented and *“cannot make any fuss”*. Similarly, housing for women seeking asylum was described as *“awful”*, with women feeling unsafe leaving their rooms.

For women provided with housing by statutory bodies, Article 8 rights to a private and family life may be engaged if housing is either not provided or is not suitable to the extent that it interferes with private or family life.¹⁰⁶

Impact on maternity care

The professionals talked about how women’s care might be affected if they were moved by housing services between boroughs. The difficulty of maintaining continuous, holistic care across borough boundaries when women *“don’t belong to anywhere”* is discussed further in theme six (navigating multiple systems and services). Like the women we spoke to, they also mentioned travel time and cost, and the risk of women disengaging from care.

¹⁰⁵ Greater London Authority (2018). *London Housing Strategy*.

¹⁰⁶ Shelter Legal (2019). *Human rights challenges* [online].

At the same time, professionals recognised that in some cases, women were choosing to remain in poorer quality housing in an area they knew, rather than move to better accommodation in a new area away from their support network.¹⁰⁷ The professional interviewees felt it was not always clear whether women understood the risk of being considered to have become intentionally homeless, if they declined housing elsewhere.

Housing was described by midwives as being available only at the point when a woman was *“literally on the street”*.

Some midwives talked about

discharging women in time to be at the housing office for 9am, newborn and belongings in arms, to access

accommodation. They wished it was

possible for women to be seen by housing services whilst they were on the ward. This raises serious questions of safety for the woman and the child, as well as being undignified, unfair and disrespectful.

“It doesn't matter that you're still bleeding, that your stitches hurt and your milk is coming in. You need to go and present there.”

“[Some women] go to hospital to have their baby with what they own... not knowing where they are going to go afterwards.”

Many midwives and Birth Companions staff and volunteers also talked about women being moved just before their due date or being ‘stuck’ on the postnatal ward because they had no home to be discharged to. They described the enormous stress women experienced in both situations.¹⁰⁸ Women who are moved shortly before their due date

“can't just settle and they can't nest” because they are having to adjust to being in a new area, often away from their support and maternity care. In the cases of asylum-seeking women, professionals described how the Home Office often only arranges accommodation after the baby is born: *“It's taken more seriously if you like because there's a very vulnerable child, a vulnerable baby involved.”*

The caregivers we spoke to said women are often moved multiple times shortly after giving birth, which might risk disrupting postnatal care both for the woman and for her baby.

One midwife described the particularly distressing case of a woman who had just had a stillbirth. She then lost her housing allocation, because she would no longer have her baby with her: *“I have to go in and tell her that now. I have to go and tell her that the place she was going to go, where she would have had a fresh start, now doesn't exist because her baby has died”*. This jeopardised the woman's rights under Article 8 to a private and family life.

¹⁰⁷ The impact of losing support networks as a result of out of area moves is described in more detail in Shelter's (2016) *Home and away: The rise in homeless families moved away from their local area*.

¹⁰⁸ We are grateful to Crisis for highlighting the role that Local Housing Allowance may play here: pregnant women without dependents qualify for a lower rate of Local Housing Allowance than women with dependent children. Women without dependents will only qualify for a shared room rate (for a woman under 35) or a one-bedroom property (for women over 35) until their baby is born. Additional payments to allow women to move into a two-bedroom property before her baby is born are discretionary and vary between local authorities.

We welcome the ongoing roll-out of community hubs under Better Births, to bring multiple services together, and note NHS England's vision that these should include local authority services. We also welcome the commitment to local Integrated Care Systems as the vehicle for delivery of the NHS Long Term Plan. Genuine integration across the full range of health, local authority and voluntary sector services has the potential to address some of the issues described by women and professionals.

Theme five: Specialist midwives and continuity of carer

Women's experiences

More than half of the women interviewed said they had received some continuity of carer during their antenatal care. Two of them said they had also seen a known midwife during labour and childbirth. What was understood as 'continuity' was not tightly defined ahead of the interviews: women were asked whether they generally saw the same midwife or different ones. Women's experiences varied – some always saw different midwives, while a few always saw the same person for each appointment. Three quarters of women (nine) said they saw the same person at least some of the time. The three women who said they saw a different midwife each time were all asylum seekers.

None of the women reported experiencing full continuity of carer as it is described in the NHS Long Term Plan, which sets out an ambition for *"most women [to] receive continuity of the person caring for them during pregnancy, during birth and postnatally... This will be targeted towards women from BAME backgrounds and those living in deprived areas."*¹⁰⁹

Antenatal continuity

Our research found a higher proportion of women receiving some antenatal continuity of carer than might have been expected. This might in part reflect the complexity of their needs. Birth Companions volunteers reported that the women they support tend only to receive continuity of carer if they are *"in a really extreme situation"*, when they then reach the threshold for support from a specialist team or midwife. At least five of the women, who had continuity of carer, had midwives from teams that specialise in supporting women with particular medical or social needs. Two of this group had care from teams specialising in their medical conditions, rather than social complexity.

Our findings (alongside those of the Birth Companions and Revolving Doors Agency¹¹⁰) strongly support the case for continuity of carer for women facing severe and complex disadvantage, in line with the NHS Long Term Plan goals.

Trusting relationships

In our analysis, women are described as having experienced continuity of carer if they saw one midwife for the majority of their antenatal care, with whom they had the opportunity to build a relationship.

¹⁰⁹ NHS (2019). *The NHS Long Term Plan*.

¹¹⁰ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

One woman who experienced this model of care found it difficult to trust a male midwife within her care team, commenting: *“If it’s a woman it would be more better then.”* Services need to be sensitive to the needs of women who do not feel safe being supported by a male caregiver.

This exception aside, all the other women who had this model of care talked very positively about their experiences, particularly the opportunity to build a relationship of trust with their midwife. They appreciated feeling supported to speak freely about their lives and to be better understood as a person. They said their midwife *“showed empathy”* and *“listened”*, enabling them to *“talk to them about anything”*. This chimes with other data on the benefits of continuity of carer and relationships of trust for women facing complex needs, in terms of their experiences of pregnancy and birth, access to other services, and maternal and infant outcomes.¹¹¹ Continuity of carer is associated with women feeling more in control and able to make choices and exercise their rights.¹¹²

“I had a really trusting relationship with [my midwife] ... I was able to be really honest with her.”

Specialist care

As in the Birth Companions and Revolving Doors Agency research,¹¹³ a few women commented explicitly on the value of the specialist care they received. Some described specific additional support being put in place by midwives who understood their situation. One woman described being given help to access additional (private and charity-provided) support to help her with parenting. Another said her midwives took care to make her hospital stay as good as possible, recognising difficulties she had at home. A third woman, who was cared for by a multi-disciplinary team, said she felt that continuity meant she knew she had *“Every base covered... They were like, ‘you know that you’ve got our numbers to call us any time’.”*

Lack of continuity

One woman (an asylum seeker) who didn’t have any continuity of carer said that she had found her maternity care very hard to engage with: *“My antenatal care was different places, go to this place, send me to this place... It wasn’t a good thing for me because I’m very difficult to move to place, I will be late, they will postpone the dates and things like that.”* Another said she had not attended all her appointments.

¹¹¹ McLeish, J and Redshaw M (2019). 'Maternity Experiences of mothers with multiple disadvantages in England: A qualitative study'; Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*; Homer, C., Leap, N., Edwards, N. and Sandall, J (2017). 'Midwifery continuity of carer in an area of high socio-economic disadvantage in London: A retrospective analysis of Albany Midwifery Practice outcomes using routine data (1997–2009)'; Raymont-Jones, H, Murrells, T and Sandall, J. (2015). 'An investigation of the relationship between the caseload model of midwifery for socially disadvantaged women and childbirth outcomes using routine data - a retrospective, observational study'; Beake, S, Acosta, L, Cooke, P and McCourt, C (2013). 'Caseload midwifery in a multi-ethnic community: The women's experiences'. *Midwifery*, 29(8), 996-1002.

¹¹² McCourt, C and Stevens, T (2006). 'Continuity of carer – what does it mean and does it matter to midwives and birthing women?'. *Canadian Journal of Midwifery Research and Practice*, 4(3), 10-20.

¹¹³ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

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“It’s better for you to have just one person. It’s no good to have different one... explain over and over again.”

The women who did not have continuity of carer said they would have preferred it. As described in theme two (trauma and dignity), this is particularly true for women with a history of trauma, where repeatedly having to re-tell and re-live their experiences may be re-traumatising.

When asked what one thing would have improved their care, two women specifically stated continuity of carer and better communication: *“You can never know what is best for somebody unless you talk through to them and hear what their views are.”*

Other women described missed opportunities to talk about their needs and the issues in their lives: *“No one asked me.”* This was particularly notable in the cases of the asylum-seeking women, who mostly did not have any continuity.

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“I wished I could talk to someone... have a conversation with someone, just someone that I wanted to know what I was going through at the time.”

A few women said they felt judged at times, in situations with caregivers with whom they had not built a relationship. One woman, who had her baby whilst serving a prison sentence, said some of the maternity team *“treated me like a criminal. I didn’t really matter.”* In contrast to previous experiences in the community, she said having a baby in prison meant *“there was completely no respect, no regard.”* Another woman said she felt that a sonographer spoke to her *“really harsh[ly]”* when she brought her mother for support instead of a partner.

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“I could tell that the lady was judging me you know.”

She said the sonographer’s tone changed when she read her history of abuse in her notes: *“And then she was like the loveliest person in the world. But... you shouldn’t be judging people just by what you see.”*

Positive engagement

In some cases, continuity of carer and specialist care helped to maximise engagement with antenatal care. One woman said her midwife facilitated both her appointments at home and transport to appointments in hospital. Another said: *“They always called me if I missed an appointment.”*

Rights-respecting care

Good experiences of caregivers were not solely associated with continuity of carer, although there was a strong correlation between the two. Women said they appreciated midwives who listened to them, took their concerns seriously and tried to meet their needs. Both women and midwives emphasised the importance of kindness, openness, honesty and equality. One woman’s comment about professionals that they should: *“Just everybody be kind and helpful,”* mirrors almost exactly the words of a midwife, who said professionals should: *“Just be nice and treat everyone the same.”* Both reflect the findings of Birth Companions and Revolving Doors Agency that

“Compassion and a non-judgemental approach made a tangible difference to women; indeed, kindness (or lack of it) could shape people’s experiences profoundly.”¹¹⁴

Continuity of carer is a major strand of Better Births, the NHS Long Term Plan and a vital component of ensuring that women receive *Montgomery*-compliant personalised care. Continuity of carer enables a woman to receive safer, dignified, equal and respectful care that is responsive to her needs and supports her as an informed decision-maker. It is fundamentally aligned with rights-respecting care. We welcome the focus in the NHS Long Term Plan on rolling out continuity of carer to women from BAME communities and those living in deprived areas.

Professionals’ experiences

Continuity of carer was seen as vital, with one of the FNP nurses calling it: “The key, it’s the real key.” The professionals, especially those working in specialist roles, talked about the competencies, skills and working arrangements that were required to be able to provide genuinely personalised support for women. All the specialist professionals described working in continuity models, providing stability in women’s lives and building trusting and, in some cases, “long term therapeutic” relationships. Specialist midwives mainly provided antenatal and postnatal continuity, but not during childbirth itself.

Midwives were seen as being “*the key... a way in*” to provide wider support. One professional said: “*Often women can really see the value in midwives. I think they can understand what our job is.*”, helping midwives to establish positive relationships. Birth Companions and Revolving Doors Agency noted that there is a “*significant opportunity in the perinatal period to offer women help with the issues they face in relation to trauma (past or current) and other complex social needs – if these are identified.*”¹¹⁵

“There is no way that you would be able to understand the layers of that person and their communication needs, their social needs, their support needs – how they’ve managed their condition, how they live their life unless you have seen them [on] multiple occasions.”

Pressures on midwives

However, continuity models can create greater pressure for midwives to hold a woman’s needs: “*that’s the thing, as a midwife..., we’re trying to so hard to fix things during a pregnancy. You have got this short window of time where women are suddenly engaged*”. Specialists said they spent considerable time co-ordinating across multiple services (see theme six: navigating multiple systems and services), re-organising appointments and supporting women to access care and support where they had disengaged. Birth Companions staff and midwives said this was partly due to

¹¹⁴ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages.*

¹¹⁵ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages.*

difficulties women experienced keeping track of all the things going on in their lives, and partly because women were often trying to juggle multiple rounds of appointments and may, for example, prioritise housing over maternity.

“You end up feeling really responsible for the women, knowing that they are in these kind of very vulnerable situations.”

Some of the midwives said that in the longer term, women sometimes found it hard to break ties with them. They described women seeking their support with child protection proceedings a year after childbirth: *“There’s a limit to what you can do to support that person at that point, I*

think, that’s hard, it’s hard, cause you want to.” As described in theme two (trauma and dignity), specialist midwives talked of finding it very hard to manage the *“stress and worry”* about the women they support, and of having had to learn discipline to avoid being contactable by women – and other midwives – day and night.

Professional autonomy

The midwives talked about the importance of professional autonomy and flexibility to fully meet women’s needs. They said flexibility meant being able to structure work weeks based on the individual needs of the women in their caseload, for example *“go[ing] to somebody’s house, when they’re not showing up and you’re really worried about them”*, spending time meeting with other services, or simply giving a woman enough time and space to talk about what she needs to share. One summarised: *“The care can be more successful, because you can tailor it to the woman’s needs.”*

Midwives said they sometimes had to remind women about appointments both with them and with other services, but specialists were able to allow for extended appointment times. However, the hours midwives were commissioned to work were not deemed sufficient by professionals in many, if not all cases, and as a result, specialist midwives were working: *“Extra hours every single week.”*

The midwives said they thought it was vital that they had managers with an *“understanding of the complexity of our job”* and *“of the demands that are on you”*. Some midwives also talked about management understanding that they had to work in a more flexible way than other teams – for example, carrying out home visits, in circumstances where other professionals might not. Midwives and other specialists also said they needed access to, and time for, reflective supervision, as discussed in theme two (trauma and dignity).

Skills and confidence

Specialist professionals spoke particularly about the skills sets and confidence they needed and had developed – often through experience – during their practice. They talked about the importance of being direct and honest with women, and *“not being afraid to ask that question”*.

Others talked about the importance of learning to *“listen... to understand, rather than listening to answer”* and learning to *“sit with some uncomfortableness”*. They said it was

“One of the massive changes in my practice is that I ask some amazing questions much more directly than I ever would have in the past.”

important not to *“shy away from difficult conversations”*. Women in Birth Companions and Revolving Doors Agency’s research noted how important it was to be asked *“more*

consistently and in more detail about their home situations, in order to understand better the range of difficulties they faced and the help they might need”.¹¹⁶

Some midwives were concerned that non-specialist colleagues were “often not given that training or time to meet the needs of the unexpected things that come through the door”. Specialist midwives, who provided continuity of antenatal care, but not necessarily during labour, talked about the importance of documenting women’s care plans, so that in labour, the women were able to receive continuity of care, if not carer. They said women were less likely to feel judged, if their midwife in labour understood their history.

“If that midwife has got access to your very kind of detailed history... you can say, okay, so this is the bigger picture of what's happened into this woman, she's not just a headline, she's not just a substance misuser, she's not just a woman who's had her children removed, she's not just somebody who suffers from mental health, there's always something else that's going on and no midwife should ever care for a woman with her judgment skewed by any of those things but its far less likely to happen if you can provide somebody with the full picture of what's been happening with that woman.”

Nevertheless, specialist midwives said that colleagues can “panic a bit when they know that it’s one of your women” and had to be reassured that “that’s okay, there’s a plan, you know, I don’t need to come in”. In some cases, they said they felt their colleagues made comments about a woman’s behaviour, because she was under specialist care. They thought that if another woman under ‘standard’ care behaved that way, it would not be noticed.

The specialists said they thought all midwives should have training on working effectively with specialist teams caring for women experiencing severe and multiple disadvantage. They felt it was important to enable all midwives to support women in accessing dignified, personalised and equal treatment. This echoes the

findings of Birth Companions and Revolving Doors Agency¹¹⁷ and would further support all midwives to work as champions for human rights and advocates for women’s choices and needs, as outlined in the recent Nursing and Midwifery Council draft proficiency standards for midwives.¹¹⁸

¹¹⁶ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

¹¹⁷ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*: Recommendation 7: “Maternity teams should receive mandatory training in order to understand and better meet the needs of women with multiple complex social factors within a trauma-informed framework. Specialist organisations, such as Birth Companions, can deliver this training or work with maternity services to develop in-house training.” Recommendation 8: “Within a framework of meeting the needs of women with complex social factors, training should include delivering meaningful routine enquiry; understanding the impact of trauma; supporting the needs of women who have experienced abuse; ensuring respectful care; ensuring confidentiality is maintained and meeting the needs of women with specific religious or cultural backgrounds.”

¹¹⁸ Nursing and Midwifery Council (2019). *Future midwife: standards of proficiency for midwives [Draft - January 2019]*.

The midwives said they thought there were significant risks attached to not having the right skills and confidence. Relationships of trust between women and their caregivers were thought to be fragile by professionals. In one example, a non-specialist midwife was described by a specialist professional as making a referral to social care without informing the woman, because the midwife was feeling *“overwhelmed with the number of issues”*. Despite a lot of effort, the specialist team was unable to rebuild the relationship with that woman. In other cases, specialists talked about having to walk a narrow line trying to build a supportive relationship, whilst making the necessary referrals to other services, something that could be seen as *“betraying their trust”*.

“I offered everything I could possibly offer but it was never going to be enough because we’d already broken our trust with her.”

Knowledge and time

As discussed in theme two (trauma and dignity), professionals raised concerns about risks if models of care and midwifery skills did not support midwives to ask about, recognise and respond to histories of trauma. This is applicable to all midwives, not only those working in specialist roles. The professionals said that part of this involved having the confidence to recognise the woman, not the trauma or the headline.

“We just see the single story, teenage mum, pregnant 17 year old or whatever but there is so much more... There’s a rich...but sometimes traumatic tapestry that makes them and that’s who they are and you cannot be a health professional, you can’t work with people unless you can see this and when I was first qualified I didn’t see that rich tapestry.”

Midwives felt that existing models of (non-specialist) care do not always support the development of a trusting relationship. Both specialists and non-specialists said they thought it was extremely difficult to meet women’s needs in a regular clinic setting, and that in the time and structure allotted to appointments, midwives were *“never going to scratch the surface”* and so, women’s needs were *“going to go unnoticed”*.

They said making referrals and contacts with other support services could take significant amounts of time: *“I think a lot of the time unless you’ve got the time... you just don’t do it.”* Some specialists did run clinics themselves, but they said these had very high ‘did not attend’ rates. Clinics that enabled women to access midwifery and other (for example, obstetric) care during one visit were described as popular with women. However, the example cited by one midwife had ceased, because of restructuring of the Trust’s service delivery. Midwives who worked in a clinic setting, which supported some continuity, said that might still not be enough to build the trust needed for women to disclose difficult circumstances or trauma: *“It takes a long time to get the social information out of some of the women... she only brought it up when it was an emergency.”*

Often, for women not receiving specialist care, they only disclosed their needs in labour: *“It’s then too little too late to give them that support”*. Professionals felt this was exacerbated by problems with data sharing across agencies, discussed further in

theme six (navigating multiple systems and services), and by staffing levels across all aspects of maternity care.

Postnatal care, a period when many women value continuity and support,¹¹⁹ was described by one interviewee as “*a car crash*”. It was highlighted as an area where staffing pressures made it very difficult to respond to women’s needs in a timely and personalised way.

Flexible service delivery

The professionals said they felt some aspects of service delivery needed to be more flexible to accommodate the needs of women facing severe and multiple disadvantage. Some specialists said their own professional flexibility allowed them to meet women ‘where they were’. However, many other aspects of maternity services were not structured in this way. For example, some services would discharge a woman automatically after she had missed two appointments, regardless of her situation.

Some women found it difficult to commit to appointments for maternity care, such as ultrasound scans, and one midwife said: “*Wouldn’t it be nice if there was just like, a little pocket of appointments that were set aside for the vulnerable women where you could just say, right, actually today, we need to...*” provide care for these women on site, when they were there. In some cases, there was provision for rescheduling appointments to suit women, but this was subject to gatekeeping by the receptionists.

These findings underscore the importance of continuity of carer for upholding the rights of women facing severe and complex disadvantage during pregnancy, childbirth and postnatally. Rights to respectful care, dignity, autonomy and equality appear to be reinforced when women have the time and space to build trusting relationships with their midwives, and midwives have sufficient autonomy and flexibility to pursue personalised care plans. We welcome NHS England’s drive towards continuity of carer and the achievements of many Trusts in implementing this model. Our findings illustrate how valuable continuity of carer is both for women and for midwives, but also reflect the RCM’s calls for sufficient investment and staffing levels to implement it.¹²⁰

The importance of specialist midwives also reflects the previous recommendation from Birth Companions and Revolving Doors Agency that: “*The number of specialist midwives and teams who work with women experiencing disadvantage (including domestic violence and substance misuse) should be expanded to meet current and predicted future need*”.¹²¹ While investment upfront would be required, the long term cost-effectiveness and benefits in improving health outcomes for women and infants should be considered.

¹¹⁹ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

¹²⁰ Royal College of Midwives (2018). *Position Statement: Midwifery Continuity of Carer (MCOC)*.

¹²¹ Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

Theme six: Navigating multiple systems and services

Women's experiences

Many of the women we interviewed were managing contact with multiple support services, which could be challenging, confusing and costly. Services ranged across the NHS (including obstetric care, existing healthcare teams, or specialist maternity services such as gestational diabetes), housing, children's social care, and perinatal mental health and counselling. Three women were actively engaged with mental health services, six had engagement with children's social care during pregnancy and one when her baby was a few months old. Four women described physical health conditions that affected their maternity care, and four women had pregnancy-related conditions, some of which involved multiple appointments.

Some women did not have access to services they felt they would have found helpful: a woman who gave birth in prison said she would have liked to have mental health or counselling support; another woman was not offered any additional support through the NHS, despite a history of trauma.¹²²

Multiple appointments

The women interviewed said they needed to be very organised to keep track of multiple appointments and that they found this very challenging. They said travel costs and logistics made the problem worse: “[Travel is] very expensive”, and they said it was not always possible to align appointments. One woman said she had to take her older child with her to appointments which sometimes lasted several hours.

“I stopped my treatment because it was getting so hard for me to attend all the appointments... I lose track, then I start again and I lose track.”

These barriers impact on continuity and effectiveness of treatment for women's physical and mental health needs, and it is concerning that some women described withdrawing from treatment and support as a result. This raises serious questions about whether the challenges arising from complex, fragmented local systems are undermining the rights of women facing severe and multiple disadvantage to receive safe and appropriate maternity care (Article 2), and to equal treatment (Article 14).

¹²² Whilst not raised by the participants in this research, the Birth Companions and Revolving Doors Agency research identified the need for earlier and more co-ordinated access to specialist mental health services: Birth Companions and the Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

Case study: fragmented support

One of the asylum-seeking women described a stressful experience when she went into labour and had to leave her older child with a stranger living in the same building, because she said ambulance staff refused to let the child ride with her.

She had very recently moved to a new area and it seems that no transfer of support or emergency provisions had been put in place, despite her clear need. *“I was leaving her with a total stranger because that was the only person available at the time...it wasn’t like she was even willing to take her...so all the time I was in labour, I was thinking about my daughter.”* She said that the midwives caring for her didn’t know she had had to leave her daughter behind: *“I guess there was a lot of confusion, because they didn’t have any of my details, so they had to sort that out.”* She also said she had felt unable to tell them about the situation. *“I wished I could talk to someone... just someone that I wanted to know what I was going through at the time.”*

The woman said she believed that appropriate support would have been put in place had more time been available. However, the fact remains that she was moved very late in pregnancy, apparently without any direct transfer of support, and without adequate information about what support to request in the new area. As a result, she ‘fell through the cracks’ and was only ‘picked up’ after going through a distressing experience. This raises serious concerns about respect for her Article 8 right to a private and family life, and to Article 14 rights to non-discrimination as a result of her status as an asylum seeker.

Children’s social care

Some women described being afraid of children’s social care: *“I was so scared of social services... all you heard they take your children away from you.”*¹²³, although a number reported positive experiences of support despite their initial concerns. No women in our cohort had their children removed from their care. One woman described the application process for a prison Mother and Baby Unit as *“very frightening”* and said she did not feel well informed: *“All I could hear from the other inmates [was] ‘oh, you can’t get to keep your baby, your baby will be in social care’.”* She said she was afraid that social care was being considered as an alternative, despite having a supportive family in the community.

The fear of having a child removed appears to have put women off engaging with social care support. Another woman feared being referred to social care because of her mental ill-health and felt obliged to engage with mental health treatment as a result. In some cases, women described finding it difficult to build a relationship with their social worker. One woman with a

When I want to talk she doesn’t allow me to talk, she does it, they say mum you don’t have a choice, you don’t have a choice”.

¹²³ Women in the Birth Companions and Revolving Doors Agency research felt similarly: “Although the role of social services was most frequently discussed, fear of services in general and being scrutinised had an impact on how women viewed maternity services. This affected women’s ability to articulate their feelings, choices or concerns during their care by maternity services.” Women feared scrutiny and judgement if they asked for help: Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

history of trauma requested a female social worker since she was “*not comfortable*” talking to the male social worker, and says she was told: “*It does not really matter, a man can be better than a woman*”.

Nonetheless, most women spoke positively about the input of social care to their lives once a relationship had been established. Two said that social workers had helped them find activities and groups to attend with their children.

All women have the right to safe and appropriate maternity care (Article 2) and to equal treatment (Article 14), so women facing severe and multiple disadvantage deserve additional support to ensure they do not fall through the cracks between services. Specialist midwives can play a very important role, helping women to navigate services and advocating for their needs. However, not all women who would benefit have access to these services. Other options for support are discussed below, including better multi-agency working, support from case-workers or navigators and the co-location of services.

Professionals’ experiences

The professionals from all groups talked of the difficulties they had in navigating, and supporting women to navigate, multiple services. They said this was especially hard when supporting women facing severe and multiple disadvantage, as they frequently had to move home. This meant that the multiple services crossed the boundaries of different NHS and local authority areas. As explained in theme four (housing and hardship), women who are offered, or are moved to, housing in a new area often have to decide between continuing maternity care and other support with known services (at the expense of travel time and cost) or face “*start again care*”.

“Part of our role is to kind of hold some of that I think for people and try and help them just like push them in the right direction, you can’t solve it for them but to help them make a... manageable plan.”

The midwives recognised the pressures the women described: “*I couldn’t balance that amount of stuff, so I think we really need to be mindful of trying to... limit women’s appointments as much as possible.*” They said they often felt they were trying to “*hold it all together*” for the women. They also said that many of the issues could be improved with more time and resources for different professionals and services to work together to plan care for, and with, the women.

Co-ordinating with other services

All the professionals described the challenge of providing holistic support for a woman in their care, while co-ordinating with other services. They said information was not always shared between services: “*If we’re out of the loop with each other, it’s really difficult for that woman.*”¹²⁴ They said it was hard to “*know where responsibility lies*”

¹²⁴ The Birth Companions and Revolving Doors Agency researched found similarly that “Women with multiple disadvantages often need multi-agency support and the effectiveness of their joint working

when many services were involved, but that the services needed to keep the woman at the centre of her care, recognising her individual needs and the challenges involved in engaging with multiple agencies. For example, some professionals described the difficulties of trying to support a woman to attend appointments with other services: *“She wouldn’t come to appointments, because she couldn’t read... I [would]...escort her...[but]...our system won’t do that”.*

Postnatal care

Postnatal care was highlighted as an area of particular challenge by health visitors, who described liaison with midwives as “poor”. They said this was especially concerning because most postnatal contact happened in clinics, not in women’s homes. They also said there were barriers to accessing information about women’s needs from Trusts, so they worried about the consequent risk of not getting a good overview of women’s situations. This highlights questions of safety, similar to those identified in Birthrights’ previous work on the experiences of disabled women, which found that *“some women felt that it was not worth raising any issues or concerns with care providers because they may never meet them again and because the visits were so short.”*¹²⁵

“We’re not giving them the message, if you give them a ten or fifteen minute appointment at a clinic, that we’re interested in them or any of their issues.”

IT and data systems

IT and data systems were frequently mentioned by the healthcare professionals interviewed. They said there were different systems for midwives, GPs, A&E, mental health teams and social workers, and sometimes for the same teams in neighbouring areas. As a result, they said they were often unable to get an overall picture of a woman’s life and needs, which could be a challenge when midwives were trying to make clinical decisions about risk.

Midwives were concerned this problem could be exacerbated by the current move to electronic maternity care records,¹²⁶ adding additional layers to already complicated systems. A few midwives raised concerns about the accessibility of electronic maternity care records for women with limited or inconsistent access to the internet or smartphones, and women with limited English.

Midwives also described struggling to speak to other professionals, such as social workers, GPs and mental health specialists, because of work patterns, pressures on time and location.

made a difference to the experiences of the women we spoke to”: Birth Companions and Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

¹²⁵ Hall, J, Collins B, Ireland J, and Hundley V (2018). *The Human Rights & Dignity Experience of Disabled Women during Pregnancy, Childbirth and Early Parenting*.

¹²⁶ Electronic maternity care records are being rolled out as part of the Maternity Transformation Plan. NHS England’s ambition is to provide 100,000 women with access to their electronic record by October 2019. For more information see NHS Digital (2018). *Electronic maternity care records – what women want?* [online, 3 December].

The need for better joined-up systems is recognised in both the recommendations of the 2018 MBRRACE report into maternal mortality¹²⁷ and the NHS Long Term Plan. The Long Term Plan recognises that *“the burden of managing complex interactions and data flows between trusts, systems and individuals too often falls on patients and clinicians”* and prioritises improving digital services so they work better for both groups.¹²⁸ Our findings support the aim of improving digital services, while recognising the practical challenge of achieving data integration, given the multiple systems in use across different NHS Trusts and other services. This may require standardisation of some electronic systems to ensure cross-agency and cross-boundary join up. This work should also take into account challenges women may face accessing and using digital technology.

Cross-boundary working

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“You think, I know what she should have but I can’t get it for her because she’s out of area’... You can’t magic up a team that doesn’t exist.”

The professionals said that working across borough boundaries presented particular challenges, because of the variation in services by area.¹²⁹ In some cases, women were accessing ‘out of area’ care specifically so they could be cared for by a specialist team. The professionals said finding contacts and

making referrals could take significant amounts of time. This was possible for specialists with more time within their role but was thought to be extremely difficult for midwives who were seeing women within a regular clinic structure.

Women who gave birth outside the area in which they lived were thought to be at particular risk of missing specialist care in the postnatal period. Midwives described making contact with the Trust in the new area *“to try to find out who the midwives and health visitors are in that area, so, hopefully, they can have an enhanced 28 days [service]”*. Some specialist midwives described situations where safeguarding information was not passed on from the Trust delivering the antenatal care to the postnatal Trust. This was thought to be particularly problematic in relation to women with moderate needs *“who perhaps are not... at the top of the ladder of safeguarding concerns”* and who may not access specialist midwifery care.

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“I get quite a lot of postnatal women who just appear and I then have to run around and try and sort out what’s going on.”

These examples raise concerns about whether women’s rights to safe and appropriate care (Article 2) throughout pregnancy, birth and postnatally are being upheld. Work is

¹²⁷ This highlighted the importance of services developing “clear protocols and methods for sharing information, both within and between agencies, about people at risk of, experiencing, or perpetrating domestic violence and abuse” and the need for “intra-operability of systems to support information sharing through electronic records”: Knight et al on behalf of MBRRACE-UK (2018). *Saving Lives, Improving Mothers’ Care*.

¹²⁸ NHS (2019). *The NHS Long Term Plan*.

¹²⁹ Similarly, the Birth Companions and Revolving Doors Agency research found that women’s experiences of support services varied widely depending on which Borough they were living in: Birth Companions and the Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*.

currently underway with the Pan-London Safeguarding Midwives' Network to explore options for improving postnatal cross-boundary care transfers.¹³⁰

Thresholds for support

Midwives described the challenges for women in getting support from services, when the thresholds for accessing those services varied. This meant women might disclose traumatic experiences but not subsequently be able to access support: “[she]... didn't hit that threshold, what do I do with her?”. Early intervention was described as “so hard to get”; an issue likely exacerbated by the significant cuts made since 2010 to support services for young families, such as Sure Start children's centres and family support services.¹³¹ Support fell off during the transition from children's to adult services, particularly for those with no recourse to public funds: with professionals reporting that, once women reach eighteen (or are believed to be eighteen), access to social care, education and other services is removed, regardless of need.

Social care

Social care referrals posed a particular challenge for midwives trying to build and maintain trusting relationships with women: “Social care are ‘the baddies’...the people that have the power to take babies away and that's just the perception of women.” Midwives said this perception was especially prevalent amongst women, particularly young women, whose families have experienced multiple generations of social care involvement. Human rights advocacy can offer an opportunity to break this cycle. The Mother and Child Project trained advocates to support women to exercise their Article 8 rights, which improved women's engagement with social care professionals, and outcomes for women and their children.¹³²

Midwives described differences between boroughs in the thresholds to access social care and said assessments could feel rushed. They felt that at times women needed more support and advocacy. The health caregivers said they thought social care worked best when professionals from different agencies had the time to work together to plan support and care around the particular woman.

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“She's going to hear what she's heard all her life – that she's no good, that she can't do it, that she's not good enough.”

They said that, as part of this, it was important to see situations from the woman's perspective: “We don't look through their eyes and see what they see.” In some cases, professionals felt all the pressure was on the woman to make changes to protect her child, regardless of the broader circumstances and the role of

other adults around her: “it's often very woman blaming and actually, very focussed on what Mum hasn't done when actually, what brought her there?”

We recognise that our study did not manage to recruit social workers, so this section represents the views of midwives, health visitors and FNP nurses supporting women who are engaged with children's social care. However, our findings echo The National Commission on Domestic and Sexual Violence and Multiple Disadvantage: “The

¹³⁰ Personal communication, Tamsin Bicknell.

¹³¹ Action for Children, National Children's Bureau and The Children's Society (2016). *Losing in the long run: Trends in early intervention funding*.

¹³² Mother and Child Project (n.d.). Mother and child project [online].

failure to understand trauma and the impacts of domestic and sexual violence can lead to services responding in such a way as to blame women or view their response to trauma as evidence of mental ill health manifesting as behavioural problems, rather than a signal of deep distress and a normal reaction to the fear and trauma of abuse.”¹³³

Responding to women’s needs

Professionals were concerned that women’s needs in this context were not being met adequately. One midwife described how she referred women to adult social care to receive support, only to have them passed straight onto children’s social care. Another midwife described how an undocumented migrant was ineligible for much of the funded support available. This ultimately led to her baby being removed from her care. In a third case, a woman’s complicated history of mental illness, learning difficulties and previous child removals was perceived as a barrier to her being eligible for, or being offered, any targeted support.

“At that point the adult social services team stepped back and let children’s services take over and without putting any care in place for the woman.”

The focus groups identified a specific lack of social care support for women with older children who didn’t have childcare during labour or for healthcare appointments. Birth Companions staff commented that childcare arrangements were rarely put in place ahead of a woman’s labour, meaning older children were often left on the ward waiting for emergency foster care whilst their mother laboured. In another complex case described by a midwife, a woman struggled to access urgent, potentially lifesaving medical treatment, because no service would take responsibility for supporting her with her childcare needs. This raises serious questions about whether her Article 2 Convention right to safe (and in this case potentially lifesaving) care was being upheld and why social care services do not appear to work proactively with women to plan for childcare during inpatient stays, so they have equal access to maternity care.

Mental health support

Some of the midwives said that women’s mental health needs were not always understood in social care proceedings: *“There’s a lack of understanding with what having a mental health diagnosis means”*, which could lead to unpredictable outcomes for women: *“Depending on the [child protection] Chair you get on the day, at that conference, it shapes the whole way that goes.”* In addition, the midwives felt that women could be at risk of additional scrutiny if social care was involved, particularly for women with known mental health issues: *“They have to be on their best behaviour all the time, because otherwise somebody will write something about them.”*

¹³³ The National Commission on Domestic Violence and Sexual Assault (2019). *Breaking Down the Barriers*.

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“We want an awareness, but what we don’t want is a stigma attached to that and then the way that we treat them makes them feel even more under the spotlight. It’s such a hard balance.”

In one case, a woman was described as reaching out for mental health support but was referred instead to children’s social care. Professionals felt this could reinforce perceived stigma and increase the risk that women will ‘borough hop’, avoid care or fail to disclose their mental health history to avoid social care referrals, posing risks to both women’s and infants’ health: *“They then present*

late and then we’ve missed other things obstetrically and then they’re really unwell”.

The National Commission on Domestic and Sexual Violence and Multiple Disadvantage also found that: *“Many women described the fear of losing their children as a huge barrier to seeking support. This was particularly true for women who used substances and/or who experienced mental ill-health, who feared their situation would be “used against them.”*¹³⁴

The professionals worried about what they said was limited access to mental health support. FNP nurses described the difficulty for women of moving from “proactive” Child and Adolescent Mental Health Services (CAMHS) to adult mental health services with a “two strikes and they’re out” approach to appointments. Gaps were also identified for women with moderate mental health needs, which deteriorate during pregnancy (and who may not be eligible for Improving Access to Psychological Therapies (IAPT) services), and in mental health outreach: *The only way to get an immediate mental health assessment is crisis and it takes a suicide attempt basically”.*

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“Either you’ve got mild to moderate symptoms and your only option is IAPT... it’s a very good service but it’s so strict... if anyone has ever had suicidal thoughts or has ever self-harmed then they are excluded... then we have a perinatal mental health team... work with women who have very severe mental health instances... there’s just these two ends of the spectrum and nothing for the women in the middle”.

The professionals said they felt they needed ways to seek easy re-referrals, particularly where women had not attended after an initial referral, in order to acknowledge the reality of women’s lives. A recent report for charities working with women facing multiple disadvantage similarly observed that missed appointments led to cases being closed and that: *“Non-engagement is therefore seen as a refusal of services, not a common symptom of mental health, trauma and complex needs, when sometimes attending appointments can feel overwhelming and frightening”.*¹³⁵

The 2018 MBRRACE report into maternal deaths and morbidity stated that *“Mental health services should work to minimise barriers to care for women in pregnancy and the postnatal period, recognising the need for lowered thresholds and direct access for*

¹³⁴ The National Commission on Domestic and Sexual Violence and Multiple Disadvantage (2019). *Breaking Down the Barriers*.

¹³⁵ Sharpen, J (2018). *Jumping through hoops: How are coordinated responses to multiple disadvantage meeting the needs of women?* London: AVA, MEAM, Agenda and St Mungo’s.

maternity and primary care professionals".¹³⁶ The NHS Long Term Plan commitment to expand access to perinatal mental health care, especially for women with moderate to severe needs, could provide a crucial opportunity to improve access.

However, careful liaison with women about their needs is essential. For example, one proposal in the Long Term Plan for "maternity outreach clinics" would integrate maternity, reproductive health and psychological therapy services.¹³⁷ One professional in this study was aware of plans to co-locate these services within children's centres; however, some professionals noted that the women they support, particularly younger women, could be uncomfortable accessing children's centres, as they feared being judged.

The NHS Long Term Plan ambition to create integrated community-based health and care provides a timely opportunity to develop and commission services that meet the needs of women facing severe and multiple disadvantage. Joining up care across different services and local boundaries could help deliver truly woman-centred care throughout pregnancy, birth and the postnatal period.

This chimes with the ambition in Better Births for Local Maternity Systems to bring services together. Some Clinical Commissioning Groups and Local Authorities in London have already moved towards integrated commissioning across the range of health and care services, such as Tower Hamlets which now has joint senior roles, teams and governance in place.¹³⁸

Care-co-ordinator or navigator roles in other sectors may provide useful examples of models to facilitate or augment the integrated support of perinatal women. The National Commission on Domestic and Sexual Violence and Multiple Disadvantage recommends that "*services should work collaboratively to break down service silos and offer person-centred, holistic support for women from diverse backgrounds, including through one-stop-shops, and co-location of professionals. Where this is not possible, 'navigator' models, where individuals or teams support service users to navigate systems, should be developed to support survivors to access available services.*"¹³⁹

NHS England's commitment to social prescribing, where link workers help people – often with complex needs – to access and navigate community services, also demonstrates the benefit of person-centred, integrated models.¹⁴⁰

¹³⁶ Knight et al on behalf of MBRRACE-UK (2018). *Saving Lives, Improving Mothers' Care*.

¹³⁷ NHS (2019). *The NHS Long Term Plan*.

¹³⁸ Tower Hamlets Together (2018). *Integrated Commissioning in Tower Hamlets* [online].

¹³⁹ The National Commission on Domestic and Sexual Violence and Multiple Disadvantage (2019). *Breaking Down the Barriers*.

¹⁴⁰ "Social prescribing works for a wide range of people, including people: with one or more long-term conditions; who need support with their mental health; who are lonely or isolated; who have complex social needs which affect their wellbeing.": NHS England (n.d.). *Social prescribing* [online].

Removal of children

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“We don’t think she’s in the threshold for adult services so what’s going to happen, she’s either going to get pregnant... she’s going to be exploited... and what have we got for her? Nothing, nothing, she’s just left flailing around, surviving.”

Theme two (trauma and dignity) described the lack of support for women whose children are removed by social care, and in some cases, women who experienced a stillbirth. In some cases, midwives felt they were the last professional left supporting a woman, when other services cut off support because of a perceived lack of engagement. Midwives could not do this, even though it is not mandatory to present for maternity care.

Two midwives described going “on my own to homes that are not safe, just to make sure the woman is okay.” Yet even extended specialist midwifery postnatal care ends at 28 days post-birth, leaving women without specialist input but a hope they will present for a six-to-eight-week check with a GP, at a point where they are already extremely vulnerable.

The evidence suggests there are short and long-term safety risks associated with this loss of support. The 2018 MBRRACE report into maternal deaths noted that “On too many occasions the mother was forgotten once services were appropriately reassured that her child was safe”. It also outlined a possible increase in the proportion of women living with multiple disadvantage who died by suicide in 2014-2016, noting that “the number of women who avoided, or disengaged from, care in the time leading to their deaths is striking”.¹⁴¹ In some of the cases described above, women were not offered any care at all; a significant failure to safeguard women at a very distressing time in their lives.

Sharpen et al found that “Women who had had their children removed felt as though services (in particular statutory social care services) abandoned them after the removal and that the grief and loss they felt was not acknowledged. This often led to internalised shame, guilt and a sense of not fulfilling societal expectations of what it means to be a woman (i.e. a mother, a care-taker and a home-maker). This became yet another form of trauma and could lead to more issues relating to mental ill health and substance misuse”.¹⁴²

This lack of support may violate their rights to safe and appropriate maternity care (Article 2), to respect and dignity during pregnancy, childbirth and postnatally (Article 3), to a private and family life (Article 8) and to equal treatment (Article 14). A human rights approach reminds us that women are human beings, not means to an end; that women’s health and lives matter just as much as their babies’.

The professionals we spoke to felt that “as a society, we let those women down” and that women return to “risky behaviour” because “what else have they got?”. This is supported by evidence on recurrent care proceedings: in their research, Broadhurst et

¹⁴¹ Knight et al on behalf of MBRRACE-UK (2018). *Saving Lives, Improving Mothers’ Care*.

¹⁴² Sharpen, J (2018). *Jumping through hoops: How are coordinated responses to multiple disadvantage meeting the needs of women?*

al found that around one in four women who had a child removed reappeared in a subsequent child protection hearing within seven years (one in three teenagers).¹⁴³

Our evidence reiterates questions by Broadhurst et al as to whether Local Authorities are meeting their “*obligations to women to prevent recurrent proceedings*”.¹⁴⁴ It calls into serious question whether Local Authorities are meeting their obligations to support adults and promote individual wellbeing under the Care Act 2014, as well as the Human Rights Act 1998. Current models of support, such as the Pause project, are not universally available, have limits on who they will accept, and there is not always alternative support available for women who choose not to take long acting reversible contraception (LARC).¹⁴⁵

All services must ensure women facing severe and multiple disadvantage are valued, respected and supported, to prevent the tragic consequences outlined in the 2018 MBRRACE report.

¹⁴³ Broadhurst, K, Alrouh, B, Yeend, E, Harwin, J, Shaw, M, Pilling, M, Mason, C and Kershaw, S (2015). 'Connecting Events in Time to Identify a Hidden Population: Birth mothers and their children in recurrent care proceedings in England', *The British Journal of Social Work*, 45(8), 2241-2260.

¹⁴⁴ Ibid.

¹⁴⁵ Pause (2019). *Creating space for change* [online].

Conclusion

Our research highlights the human rights issues experienced by women facing severe and multiple disadvantage during pregnancy, birth and postnatal care. Common themes were expressed by both the women themselves and the professionals who cared for them. In many cases, we heard of experiences which suggest that women's rights to safe and appropriate care, to autonomy and dignity, to a private and family life, and to equal treatment are not being protected. We also heard many examples of good practice, particularly where continuity of carer or specialist midwifery were in place, supporting women to “hold it all together” through and beyond their maternity care.

Although the sample group for our research was small, the rich stories echo many findings from other organisations about the particular barriers encountered by pregnant women already facing severe and multiple disadvantage. Birthrights and Birth Companions are committed to addressing these issues in our own organisations, and in partnership with each other and with wider stakeholders.

This year, Birthrights will review our existing factsheets and resources on women's rights in childbirth, to improve their accessibility and reach. Birthrights will work with Birth Companions' team of women with lived experience of disadvantage to co-design new products. Birthrights will also feed the examples and experiences from this research into our training for frontline healthcare professionals, to support their understanding and response to women facing disadvantage.

Birth Companions will work to ensure that the voices of women with lived experience can help inform and shape service improvements in many of the areas highlighted in this report – particularly in relation to housing, trauma, and temporary or permanent separation from children. We will work with Local Maternity Systems and commissioners to explore better ways to help the most disadvantaged women navigate multiple services, and support ongoing work to unlock the full potential of increased continuity of carer.

We know NHS England, the Royal Colleges of Midwives and of Obstetricians and Gynaecologists and other partners are equally committed to ensuring all women receive safe, respectful and personalised maternity care. We welcome the focus – in the maternity transformation programme and the NHS Long Term Plan – on achieving this goal, and we look forward to working together to reach it.

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