Holding it all together

Executive summary

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

birthrights | birth companions

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.

Trust for London
Tackling poverty and inequality

Trust for London is an independent charitable foundation. We aim to tackle poverty and inequality in London and we do this by: funding voluntary and charity groups – currently we make grants totalling around £10 million a year and at any one time we are supporting up to 300 organisations; funding independent research; and providing knowledge and expertise on London's social issues to policymakers and journalists.

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 traumatisation, 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 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-traumatisation 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.

Our research

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

We focused on London, because women facing multiple disadvantage are over-represented in maternal deaths in the capital.[1] This research also complements existing Birth Companions research with the Revolving Doors Agency supporting the transformation of maternity services in North East London.[2] Funding from Trust for London enabled us to build on this existing evidence on women's experiences in London, though the findings are relevant to maternity services across the UK.

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, including: midwives working in specialist roles across public health, perinatal mental health,[3] safeguarding and maternal medicine;[4] midwives not working in specialist roles; specialist health visitors; Family Nurse Partnership (FNP) nurses; and Birth Companions volunteer birth supporters and staff members.

[1] NHS London Clinical Networks (2016). *London maternal deaths: A 2015 review*.

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

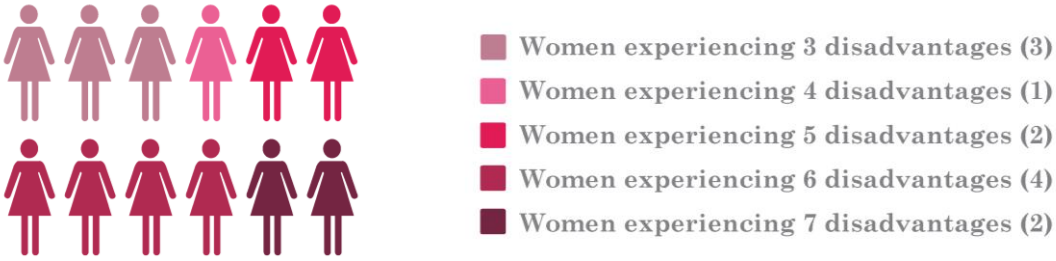
[3] Perinatal mental health refers to mental health problems which arise during pregnancy or in the first year after childbirth.

[4] Maternal medicine midwives support women with pre-existing medical conditions, or medical conditions which arise during pregnancy.

We asked the women to tell us about their experiences of care during pregnancy and early motherhood, and we asked the professionals and supporters to tell us about their work and what makes it easier, or harder, to support these women.[5]

Severe and multiple disadvantage

What do we mean by 'severe and multiple disadvantage'? Understanding women's experiences of multiple disadvantage holds the key to tackling health and social inequalities. In this report, we refer to multiple disadvantage where women experienced three or more complex health or social factors at the same time. **When asked about the disadvantages they faced, all twelve of the women who took part in the research experienced at least three; eight experienced five or more.**



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**
- 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 were **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.

[5] 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 women) by their specific job roles, where relevant, or as "professionals".

Their ages ranged from 19-45 years. 11 women were from Black, Asian and Minority Ethnic (BAME) groups, one was White European.

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,[6] and that their babies are also more likely to die.[7] Women facing multiple disadvantage also experience poorer maternity care, need extra support and trusted relationships to navigate their care,[8] 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.[9] There are inconsistencies in access to services between different geographical areas in London.[10]

Legal and policy context

Human rights are the rights we all share by virtue of being human. In the UK, they are protected by law, which sets out the way we can expect to be treated by Government and all public bodies, such as the NHS. The Human Rights Act 1998 incorporates the rights protected by the European Convention on Human Rights into domestic law. Human rights are also protected by common law. Human rights law requires personalised maternity care that treats women as individuals.[11]

Respect for 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 Better Births recognises.[12] Yet our research highlights particular areas where the rights of women facing severe and multiple disadvantage appear to be under threat.

---

[6] 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.

[7] 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*.

[8] 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 the 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.

[9] 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.

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

[11] For more information see Birthrights' factsheet "Human Rights in Maternity Care".

[12] 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 vision of Better Births (2016) to achieve maternity care that is "*safer, more personalised, kinder, professional and more family friendly*". The recent NHS Long Term Plan (2019) is an important step forward in addressing the needs of the most disadvantaged.[13] It includes a commitment that *"action to drive down health inequalities is central to everything we do"*, with specific pledges on *"enhanced and targeted continuity of carer to help improve outcomes for the most vulnerable mothers and babies"*,[14] increased access to perinatal mental healthcare, and embedding women's voices in work to improve care.

We hope our research adds to the imperative to make these aspirations reality. Our findings demonstrate the value placed by both women and professionals on specialist midwife support and continuity of carer. 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.

[13] NHS (2019). *The NHS Long Term Plan*.

[14] Continuity of carer was not tightly defined for the purposes of the project but is used to refer to care where a named midwife provides and co-ordinates a woman's maternity care throughout the antenatal period, during birth and after the birth. During the research interviews, women were asked whether they generally saw the same midwife or different ones.

Our findings

Our research suggests that in many cases women's rights are not being upheld, in particular, their rights to:

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

Some women we interviewed spoke very positively about the care and support they had received from maternity and other services. Others felt they had received impersonal or patchy care, or at worst described care that raised significant human rights issues.[15]

Overall, the views of both women and professionals on what they identified as core themes were largely consistent, in terms of both positive and negative experiences.

Theme one: Choice and consent

Choice and consent sit at the heart of safe and respectful maternity care, protected by Article 8 of the European Convention (right to private and family life), which the courts have interpreted as the right to autonomy – to decide what happens to your own body.

However, three quarters of the women interviewed described situations where their choices were not respected or they did not feel supported to give informed consent.

Eight women said they had either not known about, or not been offered, choices in their maternity care, or that they had 'not been allowed' certain choices. Seven said they had not understood, or had been confused by, aspects of their care. Professionals commented that many women did not expect choice, and that women could find themselves *"browbeaten"* into compliance by healthcare professionals. Three women described interventions being carried out in situations where, it seems, consent had not been obtained. Professionals described examples where other healthcare professionals had failed to secure consent.

[15] For more information and examples of human rights issues in maternity care see British Institute for Human Rights, Birthrights and Royal College of Midwives (2016). *Midwifery and Human Rights: A practitioner's guide*.

Professionals and birth supporters thought women already dealing with multiple disadvantage were unlikely to access debriefing services or to complain: *"The women who come forward saying "this wasn't ok for me" are the women who've been taught in their lives to expect better."*

Specialist midwives and birth supporters talked about being able to have extra time to discuss choices and build women's confidence to ask questions, to articulate preferences and to give or decline consent. Nonetheless, professionals suggested that some women (for example, younger women or women with mental health conditions) might face particular scrutiny if they declined procedures.

Only two of the twelve women said they had been supported to make a birth plan, and only three described accessing antenatal education. Six expressed birthplace preferences, but none gave birth in the place where they had hoped to.

> *"In particular moments when I needed care and support…I couldn't communicate."*

Midwives and birth supporters raised specific concerns about consent for women who required language support and for women with learning difficulties. One woman we interviewed received no interpretation support at all during her maternity care. Midwives' experience of language support varied widely – some were almost always able to access good quality support, while others had only partial access. Language support for women with limited, rather than no English, was thought to be lacking.

Midwives raised concerns about clinical safety, as a result of the lack of language support or inaccurate interpretation. They also questioned whether the spirit of consent and choice was accurately interpreted at all times. Midwives were concerned that women with learning or cognitive difficulties were not always appropriately identified and supported, particularly where family members were offering support or speaking for them.

If NHS Trusts fail to provide equal access to care which supports and promotes women's autonomy in decision-making, they may be in breach of Articles 8 and 14 (protection from discrimination) of the European Convention.

Theme two: Trauma and dignity

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). The requirement to provide personalised care that respects women's dignity, autonomy and individual needs (Article 8) means experiences of trauma must be taken into account by caregivers.

Six of the women interviewed described recent or childhood experiences of domestic abuse, sexual abuse or exploitation, previous birth trauma or referred to other unspecified historic trauma. It is likely that the incidence of prior trauma described in this summary understates women's experience, as it only includes what they chose to disclose to the interviewer. Some women raised wider issues – such as lack of privacy or support – which they felt compromised their dignity and exacerbated their trauma.

Two thirds of the women described being frightened – *"I thought I was going to die"* – during their most recent birth, when they were not offered or given pain relief, or were left alone or unsupported at a time when they did not feel safe.

Women who did disclose prior trauma to healthcare professionals said this did not always result in support or *"a listening ear"*. Some professionals identified a lack of recognition of the support needs of women whose infants were removed by social services, a very traumatic experience. In one case, a midwife described being asked to undertake postnatal checks for a baby who had been removed by social services, but said that no postnatal care had been arranged for the mother. This example 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).

> *"I was not really comfortable talking about it on the ward but I had no choice."*

Some women found the lack of privacy on the maternity ward difficult, particularly when discussing challenging issues in their lives (this echoes previous research from Birth Companions and the Revolving Doors Agency[16]). This distress could be exacerbated when men were present, especially for women who had recently left situations of abuse or exploitation. One woman described how uncomfortable she was having intimate procedures carried out on the antenatal ward with "*men around"*. Birth supporters reported women finding it *"humiliating"* when visits from social services were overheard on the ward. Yet Article 8 of the European Convention makes clear all women's rights to privacy and dignity should be respected.

Many of the women described the situations in which they lived as very difficult. Some felt unsupported with, or unable to share information about, these circumstances. Others said they were not provided with the physical and emotional support they needed after labour. One described being forgotten about postnatally: she had been taken to see her baby in the neonatal unit, and then left there in a wheelchair unable to move.

Midwives also reported the risk of experiencing trauma themselves. Specialist midwives said they were able to provide a *"safe space"* for women, but that sometimes the responsibility could be *"exhausting"*. They said they needed support in this role. Professionals described the need for trauma-informed care and additional training for healthcare professionals in recognising trauma and complex needs.

Theme three: Asylum and immigration

Article 14 requires that all of the rights and freedoms set out in the European Convention must be protected and applied without discrimination. This makes it illegal to discriminate on a wide range of grounds including 'sex, race, colour, language, religion, political or other opinion, national or social origin, association with

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

a national minority, property, birth or other status'.[17] 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.

A third of the women interviewed said they were current or recent asylum seekers. At least two had been trafficked and sexually exploited. Overall, the women in this group seem to have had worse experiences than the other women interviewed for this report, which raises concerns about whether their Article 14 rights are being upheld.

They commonly lived in insecure housing, which disrupted their maternity care; were particularly vulnerable to social isolation; and had worse experiences of choice and consent during their maternity care, with three women saying they had not been told about what care they could expect in the UK. One had received no antenatal care before she arrived in the UK seven months pregnant. Another woman indicated 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.

> *"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".*

Most described maternity appointments as being focussed solely on routine checks, even in cases where midwives were aware of their background and history of trauma: "*When I go to the hospital they just checked the baby every time, that was it*". Two women specifically described feeling unsupported during labour.

Some women described needing help with practical issues – such as completing forms, keeping track of belongings, finding childcare and clothing – which was not forthcoming. One woman described leaving hospital with her newborn wrapped in a hospital towel as she had no baby clothes.

None of the women we interviewed reported being asked to pay NHS charges. However, the midwives we spoke to expressed deep unhappiness with NHS charging policies and how these left midwives feeling as if they were 'policing' immigration, something they considered beyond their remit as healthcare professionals. Midwives described Overseas Visitors Managers acting in what they saw as an inappropriate manner and interrupting appointments. They worried that, as a result, women were avoiding antenatal care and re-presenting with greater emergency needs in labour.

Similarly, a joint statement from the Royal Colleges of Paediatrics and Child Health, Obstetricians and Gynaecologists, and Physicians, and the Faculty of Public Health, described NHS charging as *"a concerning barrier to care."*[18] We are concerned that deterring women from seeking care jeopardises their Article 2 rights to safe and appropriate maternity care.

[17] For more information, see: https://www.equalityhumanrights.com/en/human-rights-act/article-14-protection-discrimination.
[18] Royal College of Physicians (2018). Royal colleges support suspension of NHS overseas visitor charges pending review.

Theme four: Housing and hardship

Human rights are directly relevant to housing. 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.[19] Our research also found cases where housing directly impacted on women's rights to access safe, appropriate and dignified maternity care.

As previously mentioned, many of the women described living in insecure and unsuitable accommodation. Some described their housing as unclean, unsafe and unsuitable for a baby. One woman talked about being trapped in her flat due to mobility issues and being unable to wash properly at home as she could not access the shower without help. She required specialist transport to access maternity care, which, when booked, did not always arrive. Others described how housing problems caused or exacerbated mental health problems.

Many of the women were in housing officially designated as 'temporary', although a number had been in the same accommodation for months or even years. This temporary housing was described as "*depressing*" and "*like a prison sentence*". Professionals talked about women who had left violent relationships being re-housed in accommodation blocks where domestic violence was frequent.

Midwives said they had little influence over housing describing it as a "*complete nightmare*". Similarly, women perceived housing services as unresponsive both to them and to the professionals involved in their care. One said she wished "*establishments could work together*". Another commented "*no one will do nothing*".

> *"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".*

Professionals described how some women were moved just before their due date and others being 'stuck' on the postnatal ward because they had no home to be discharged to. In one case, midwives described a woman losing her housing allocation after experiencing a stillbirth. Private housing was described as "*very difficult*" and landlords as "*exploitative*" at times.

Professionals described how housing issues have a direct impact on maternity care. Women in temporary accommodation were reported to be less likely to access either continuity of carer or services based on long-term therapeutic relationships, than women living in stable homes. We heard examples of women living in insecure or inappropriate accommodation who were unable to find a safe place to be during their early labour. In these cases, women might not feel confident enough to explain this to a health professional, who also might not think to ask.

The birth companions we spoke to described supporting women who had to experience early labour outside in the street or elsewhere in the hospital, because they had nowhere else safe to go or because travel costs were prohibitive. One woman we interviewed was only able to stay with her newborn on the neonatal ward after she

[19] For more information see Shelter Legal (2019). Human rights challenges.

explained she could not afford travel costs to visit more than once a week and a neonatal nurse found her somewhere to stay.

These examples raise serious questions about whether housing issues are jeopardising women's rights to safe and appropriate maternity care, to dignity, to a private and family life and to non-discrimination.

Theme five: Specialist midwives and continuity of carer

Access to continuity of carer and specialist midwife support can be pivotal to ensuring women have their rights to safe, respectful and personalised maternity care upheld. The positive examples shared by both women and professionals are testament to this.

> *"That's why…midwives are so important because we are the key, it's an opportunity, it's a way in."*

Professionals commented that high quality midwife care offers a significant opportunity to engage women with their maternity care and with wider support services: *"Often women can really see the value in midwives. I think they can understand what our job is."*

No women experienced full continuity of carer before, during and after childbirth, but over half the women had received some continuity of carer during their antenatal care. While continuity was not tightly defined ahead of the interviews, these women all described having a midwife who provided most of their antenatal care, and with whom they built a relationship. One described how her midwife had made sure she was on duty for the woman's birth.

Almost all of those who experienced continuity of carer were very positive, particularly about the opportunity to build a relationship of trust with their midwife and to be better understood as a person. Many women who had some continuity of carer said their midwife *"showed empathy"* and "*listened*", enabling them to *"talk to them about anything"*. Another said her midwives took care to make her hospital stay as good as possible, recognising the difficulties she faced at home. However, one found it difficult to build trust with a male midwife within her care team.

Women who did not have continuity of carer said they would have preferred it: *"it's better for you to have just one person. It's no good to have different one…explain over and over again"*. When asked what one thing would have improved their care, two women specifically stated continuity of carer and better communication. One woman said she appreciated professionals checking the records from her previous pregnancy to inform their care.

> *"You can never know what is best for somebody unless you talk through to them and hear what their views are."*

Five of the twelve women described their midwife in a way that implied they were a specialist midwife. These women also described positive experiences. In two cases women described how their midwife helped them engage with their maternity care by doing home visits; helped to arrange transport for one woman who needed it because

of physical disability; and re-booked appointments for another when she struggled to attend because of work.

Whilst many of the women who saw different midwives for most or all of their care described instances of midwives being *"kind"*, a few described feeling judged: *"they treated me like a criminal"*. Others described missed opportunities to talk about problems that were causing stress because: *"no one asked me"*.

Midwives said they felt that more specialist provision is required across the country. Specialist midwives emphasised the importance of professional autonomy, flexibility and support from managers to meet the different needs of women. They described the importance of developing relationships of trust with their clients, so women can speak honestly and openly.

The value placed on continuity of carer, and specialist support, by both women and professionals, underlines the importance of these models for rights-respecting care. However, professionals also felt that in order to care for all women, midwives in general – not just specialists – needed the skills and confidence to support those with complex needs, enough time in appointments and the knowledge of what to do when women disclose complex needs. These findings reflect the Royal College of Midwives' calls for sufficient investment and staffing levels to implement continuity of carer[20] and the welcome focus on complex needs in the Nursing and Midwifery Council's draft Future Midwife proficiency standards.[21]

Both women and midwives emphasised the importance of kindness, openness, honesty and equality. One woman said professionals should *"just everybody be kind and helpful"* – echoing the words of one midwife, that professionals should *"just be nice and treat everyone the same*". This goes to the heart of rights-respecting care.

Theme six: Navigating multiple systems and services

Both women and professionals we spoke to described how engagement with multiple services could impact on access to and experience of maternity care. 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.

Many of the women interviewed were in contact with multiple support services across the NHS (including obstetric care, existing healthcare, and specialist maternity services, such as for gestational diabetes); as well as across housing services, children's social care and perinatal mental health and counselling services. Some reported that multiple appointments could be hard to manage and travel *"very expensive"*.

[20] Royal College of Midwives (2018). *Position Statement: Midwifery Continuity of Carer (MCOC)*.
[21] Nursing and Midwifery Council (2019). *Future midwife: standards of proficiency for midwives [Draft - January 2019]* which include 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."*

> *"You're a bereavement counsellor. You're a housing support person and all these other things".*

In these situations, specialist midwives described themselves as *"holding it all together*'. However, they pointed out that this specialist care comes to an abrupt end after childbirth – a time many women already find challenging. Even extended postnatal specialist midwifery care ends at 28 days after birth. This means unless women can access specialist health visitor services, there is a gap in care at a time when some feel particularly vulnerable. This is even more of a challenge for women whose care transfers to a new local area after birth.

Poor information sharing between systems and services was described as a significant obstacle to providing full continuity of care. IT systems were often incompatible or inaccessible, and information sharing often dependent on professionals having the time and flexibility to pursue individual personal contacts. Professionals reported that without access to information about a woman's situation, it is difficult to keep the woman safe, provide holistic care and avoid what one professional described as *"start again care"* each time a woman accessed a new service. This is particularly relevant where women are moving between boroughs due to unstable housing, or because their maternity care, social care or health visiting transfers to different teams or Trusts in the postnatal period.

Professionals commented that not all support services were consistently available and referrals were not always accepted. Mental health service provision varied by area, and gaps were identified in the care of women moving from Child and Adolescent Mental Health Services (CAMHS) to adult services, and in the care of women with moderate mental health needs. Children's social care was feared by some women: *"I was so scared of social services… all you heard they take your children away from you"*, although most reported good experiences after referral.

Services did not always respond to women's needs. One midwife said that in some cases, women she had referred to adult social care were actually seen by children's social care. In other cases, women were unable to access the support they needed because of their personal circumstances and the complexities of their needs.

Support was also not always available for women already caring for older children. One woman, an asylum seeker who had been moved very recently, had not been able to get support from social services before she went into labour. This meant she had to leave her daughter with an unwilling new neighbour, because she didn't know anyone else and because the ambulance wouldn't allow the child to accompany her to hospital.

Professionals described little to no support for women who had their baby removed by social services and that: *"as a society, we let those women down"*. They described support services falling away once women no longer had a baby with them. Two midwives described going *"on my own to homes that are not safe, just to make sure the woman is okay"*.

> *"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".*

A rights-based 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'. All services need to ensure that women facing severe and multiple disadvantage are valued, respected and supported.

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.

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).