Birth Companions is a specialist reproductive health charity led by and for women. The organisation was founded in 1996 to support pregnant women and new mothers in Holloway Prison. Since then we’ve developed an expertise in the needs and experiences of women in the most difficult and disadvantaged circumstances during pregnancy and early motherhood, in prison and in the community.

The women we support face a range of difficulties which can often make the birth of their baby a time of anxiety, stress and hardship. These can include being in contact with the criminal justice system, involvement with social services, immigration issues, insecure housing or homelessness, financial difficulties, mental ill-health and a history of domestic violence or sexual abuse. Birth Companions provides advocacy, antenatal and early parenting education, one-to-one, group and peer support programmes, and birth partner services. We work with women during their contact with the maternity, criminal justice, social services and immigration systems. Many of those we work with go on to join our Lived Experience Team; a group of over 40 women who are committed to drawing on their experiences to inform our work and the work of other organisations in order to improve the care provided to others.

Time and again our work has shown that with the right support cycles of disadvantage can be broken and the futures of mothers and their babies can be improved.

More information about our services and our work to shape policy and practice is available on our website at www.birthcompanions.org.uk

Introduction

We welcome the focus on tackling inequalities in the Women’s Health Strategy, and its recognition of the need for gender-specific and holistic care. The inequalities highlighted in so many reports on women’s reproductive health, along lines of deprivation, disadvantage and ethnicity, have not been adequately responded to for far too long.

The latest MBRRACE reports on maternal mortality rates and rates of stillbirths and neonatal deaths during 2016-18 show significant and growing inequalities in outcomes:

- Women living in the most deprived areas are almost three times more likely to die in pregnancy, birth or the year after birth. As the level of deprivation increases, the risk of dying increases. 37% of the women who died lived in areas ranked at the very highest index of multiple deprivation, compared to 7% in the least deprived area.

- One in five (20%) of the women who died were known to social services – an increase from 12% in 2012-14. As the report states, “Involvement with social services is an indicator of the otherwise largely invisible levels of need and adversity experienced by many of the women who die”.

- These inequalities are widening. The number of women who are known to be experiencing multiple disadvantages when they die has increased by a third since the last report, from 6% to 8%.

- Babies born in the most deprived areas are at an 80% higher risk of stillbirth and neonatal death compared to those living in the least deprived areas.

These stark figures are rooted in the wider determinants of health including poverty, insecure and inappropriate housing, mental ill-health, domestic and sexual abuse, trauma and experiences of racism. This data relates to deaths before the outbreak of COVID-19, and it is clear that the pandemic is intensifying these issues and escalating levels of need across the country.

Work is underway to address the inequalities experienced by Black, Asian and other minority ethnic women and their babies; work that is greatly needed. But the other disparities outlined above, the consequences of deprivation and the social determinants of health, also require urgent attention. These inequalities have been known about for years, they are avoidable and they are unacceptable. Evidence shows that our health and social care systems do not know enough about the social determinants of
health\(^1\) and are ill-equipped to respond to the complexity of many women’s needs during pregnancy and the year after birth\(^2\).

It is vital that this strategy dovetails with the work underway on violence against women and girls, and the planned strategy on sexual and reproductive health. But it is also vital that it is tied into work in other spheres too – work in the criminal justice system through the National Concordat on women in contact with the criminal justice system\(^4\), for example, and the current review of children’s social care\(^5\). Only by working within and across systems in this way can we hope to address the full range of factors that impact on the health and wellbeing of women and girls.

Our submission focuses on a number of key points:

- The impact of the wider determinants of health on the lives of girls and women across their life course;
- The impact of key systems on women’s health and wellbeing, and that of their children; in particular the maternity system, the criminal justice system, the social services system, and the immigration system;
- The barriers to women’s engagement with health and care services, including the impact of bias, judgment, stigma, and fear associated with social services involvement;
- The central importance of a trauma-informed approach;
- The importance of engagement with women with lived experience;
- The risks and opportunities associated with the critical first 1001 days (from conception to a child’s second birthday).

We have explored these points in more detail under each of the relevant themes. Much of our evidence draws on recent research conducted with partners at Birthrights and Revolving Doors in two reports – Holding it all together\(^6\) and Making Better Births a reality for women facing multiple disadvantage\(^7\) – and our work in the criminal justice system including our Birth Charter\(^8\), the accompanying Birth Charter Toolkit\(^9\), and A Window of Opportunity, focusing on women in contact with the CJS in the community\(^10\).

**Responding to the themes**

1. **Placing women’s voices at the centre of their health and care**

It is important that the strategy explicitly recognises and responds to the fact that not all women have an equal opportunity to make their voice heard; and that not all women’s voices carry the same level of weight with those who may hear them, as a result of structural, institutional and interpersonal bias.

The women we work with are often excluded from information and decision-making about their health and care. On an interpersonal level this is frequently as a result of judgment and stigma stemming from their involvement with the criminal justice, social services or immigration systems. Women also experience exclusion from information and decision-making because of structural inequalities related to their ethnicity, social isolation, poverty, housing status, cultural differences, language and literacy issues, and digital poverty. In seeking to place women’s voices at the centre of their health and care,

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\(^3\) Making Better Births and reality for women with multiple disadvantages, Birth Companions and Revolving Doors Agency https://www.birthcompanions.org.uk/resources/6-making-better-births-a-reality-for-women-with-multiple-disadvantages.
\(^4\) Ministry of Justice (2021) Concordat on women in or at risk of contact with the Criminal Justice System. Online: www.gov.uk/government/publications/concordat-on-women-in-or-at-risk-of-contact-with-the-criminal-justice-system
\(^5\) https://childrenssocialcare.independent-review.uk/.
we must understand and address the barriers that prevent women voicing their questions and concerns, and being heard in the right way.

Stigma and judgment are themes that regularly appear in the research we conduct among women facing deprivation and disadvantage in the community and in prison, presenting real barriers to women’s sense of agency and the capacity to make their voices heard. In our recent work with Clinks, exploring women’s experiences of pregnancy and early motherhood while serving a community sentence or under probation supervision after leaving prison, midwives expressed clear concerns about the impact of CJS involvement on women’s antenatal and postnatal care needs. “Women may delay booking with a maternity unit once released from prison. They feel that midwives may judge them. They are not trusting of ‘professionals’. This means they can miss out on opportunities for scans, screening tests etc.” (midwife)

“Stigma around offending colours the opinion of agencies, particularly statutory agencies, who are risk averse”. (midwife)

“If you have a health care team that don’t judge, clients have gone on to have healthier pregnancies”. (voluntary sector agency)

“I have a lot of years of experience so have seen some cases work out well and others not so well. It all depends on how well a woman is able to engage in the work and that can depend on whether she feel the added judgement and shame from professionals in power. If she is empowered she will often go far and be honest when things become challenging and so showing she is able to ask for support to look after herself and her child”. (voluntary sector agency)

Almost half of midwives recalled situations where they felt a woman’s community sentence requirements or probation license conditions had or risked a negative impact on her maternity care. They also identified bail restrictions or licence conditions impacting on women’s ability to attend normal healthcare locations, court dates that were scheduled around their expected delivery date and cases where effective forward planning was hindered by uncertainty as to whether they would remain in the community.

In our research with Birthrights (Holding it all Together11) 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.

Women who took part in our peer-led research with Revolving Doors12 told us they feared and distrusted services, including maternity services. They often felt unable, or scared, to make their choices clear to health professionals. This had an impact on how they engaged with services, and on their care. Women interviewed in this research were not always able to make their needs known. This fear of services manifested in different ways and for different reasons, but was often related to fear of having their baby removed or to a fear that if they disclosed a problem (for example a mental health need) they would be subject to high levels of scrutiny rather than support.

Our research has highlighted the importance of asking women about their situations and needs in a trauma-informed way, rather than waiting for women to voice things themselves. Despite progress in the duty to inquire about domestic abuse, and the duty to refer in order to prevent and relieve homelessness, women have told us they felt professionals should have asked them 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. In particular, they wanted to be asked about domestic violence and abuse, and the wider context of drug use in the home or family, and they recommended professionals should not assume they were fine if they looked well. “Nobody actually asked, ‘Is anyone in the house using?’ If anyone had actually said, ‘Is everything alright at home?’ You know, just a question like that, I would probably say, ‘No, it’s been a bit hard, you know.’”

Several women had similar reflections: "I was going through this domestic violence, but when I went to the hospital for my, what’s it called, my scans and stuff. It would have been nice if the midwives had asked me, ‘is there anything you need to talk about?...[...]....If the midwives take time to just, try and

11 Ibid
https://www.birthcompanions.org.uk/resources/6-making-better-births-a-reality-for-women-with-multiple-disadvantages.
find out a bit about your life. A bit about your history. You know? Because some women, they look like they’re the happiest people in the world, but actually, you don’t know what they’re going through, you know?”

It is clear from our research and frontline practice that women want to understand the processes affecting their choices and value being included in decision-making. One pregnant woman who hoped to keep her baby and regain custody of her toddler was asked how involved she felt in her care plan: “I actually do feel rather involved. They asked me what I wanted to do. I’ve told them, and we are working towards it, so I am actually really happy with that. I feel really confident going into next year as well.” Another woman said: “My voice was heard, you know, they took my issues to heart”. It was clear from the interviews that women facing multiple disadvantage were often distrustful of services, but there was potential to mitigate this by supporting women to understand choices and processes better and include them fully in decision-making.

Trauma-informed care holds the key to addressing many of these issues, allowing women to feel safe and supported to make their voices heard. The adoption of trauma-informed approaches across the healthcare system and beyond, in related systems such as the CJS, immigration and social services, will be crucial to establishing relationships of trust and ensuring services work in a holistic, safe and compassionate way around women. This, paired with commitments to whole-systems models and multi-agency working can deliver considerable value, so long as the woman remains at the very centre of her care and does not become a bystander to the assessments and decisions made by others.

Birth Companions has seen time and again the value of navigator roles and advocacy services in helping women negotiate the complex nature of their health and care, bridging the gaps between systems and services in order to improve outcomes.

As well as considering the ways to build greater opportunities for women to make their voices heard in the course of their care, it will also be important to invest in the networks and forums that support this. Maternity Voices Partnerships (MVPs) are a valuable source of insight for Local Maternity and Neonatal Systems. In order to equip them to tackle inequalities, and avoid reinforcing existing imbalances, they must be committed and resourced to engage the views of seldom heard women. It is not enough to simply ‘reach out’ to groups who may be underrepresented. Work should be done to ensure the work of MVPs is trauma-informed, safe, respectful and supportive, and that women are supported to overcome practical barriers to participation, for example by paying travel costs and providing language support.

Working to increase representation of women experiencing disadvantage

In 2019/20 Birth Companions ran a project with North Central London Local Maternity and Neonatal System (NCL LMNS) to understand how the needs of women with complex social factors were being addressed in the LMNS. As part of this project Birth Companions staff and members of the charity’s Lived Experience Team worked with four Maternity Voices Partnerships (MVPs) to build effective, trauma-informed and sustainable representation of women facing multiple disadvantage. Work included:

- Helping MVPs identify and solve challenges to better engagement
- Training to embed trauma-informed and co-production principles
- Facilitating shared learning
- Supporting women with lived experience to engage with opportunities such as 15 Steps events.

Birth Companions is continuing its work with NCL LMNS.
2. Improving the quality and accessibility of information and education on women’s health

Language barriers are a major factor limiting many disadvantaged women’s access to information relating to their healthcare. We see the impacts of this in maternity care on a regular basis.

In our research and in the course of our frontline service provision we see issues in securing appropriate, safe and supportive interpreting services. Some of the women interviewed for our research in East London13 were not sure of what they were being asked or advised to do as a result of a lack of interpreting services. One woman had a probe inserted for a vaginal examination during labour, with no explanation beforehand. Another recounted that no one explained the caesarean section birth procedure to her, or helped her to understand the forms: “Told to sign forms, didn’t really know what it was about.”

Where interpretation services are not available, women have looked to family or friends for help with translation. This is not always appropriate, especially with maternity assessments and conversations. One woman only had her 14-year-old son to help her communicate, which she found difficult. 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.”14

Language support is important not only for women who speak no English, but also for women with some English, who are unable to express themselves fully; women who can “just about explain themselves”; yet language support is not prioritised for women in this situation. As a result, women have attended our specialist antenatal classes with very basic questions, such as “Could you tell me how pregnant I am?” even after engagement with maternity services.

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.”16 Similar issues arise for women with other language and communication needs, for example disabled women.17

It is concerning that language support in maternity care varies considerably from Trust to Trust. The findings of our research with Birthrights illustrate the risks stemming from inadequate provision, 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; or examples of women suspected to have been trafficked being ‘supported’ by unrelated adults providing informal interpretation. Furthermore, there were examples of concerning practical issues arising from the current system: “You can never get an interpreter [for birth] because even if you book someone you’re only ever allowed to book someone for four hours and nobody labours for four hours”). There is a clear need for sufficient provision of accessible information and language support, including interpreting services for all women who need or may benefit from this.

Considering other issues relating to the accessibility of information, it is also vital that information and education relating to health care is made available in systems that pose barriers to ready access, including prison custody and immigration settings. We refer you to the submission of Women in Prison for further detail on the circumstances relating to healthcare information for the former.

While such systems (criminal justice and immigration) impose specific restrictions on women’s capacity to seek information freely, the wider impacts of digital exclusion should also be recognised. As remote forms of healthcare and other service delivery increase, catalysed by the impacts of the pandemic, and focus shifts towards digital communications and record keeping, such as digital maternity notes, there is a risk existing inequalities may be entrenched and exacerbated. Efforts to ensure women can access information and services in a timely and appropriate way must include assessing and addressing any

issues with access to technology, adequate funds for data, and reliable internet provision, otherwise disadvantage will be perpetuated.

Digital provision can make some things easier, including ease of translation and the ability to engage with women in their own homes rather than in hospital settings, which some women can find intimidating or triggering. However, these gains must be balanced against the primary need to establish and maintain relationships of trust, safety, and understanding which rely on face-to-face contact.

3. Ensuring the health and care system understands and is responsive to women’s health and care needs across the life course

We support the life course approach to women’s health. For those leading complex lives, amidst disadvantage and deprivation, a life course approach will take into consideration not only the changes in girls’ and women’s bodies and health needs as they grow older, but the social determinants of health that shape their whole lives from before birth.

Multiple disadvantage during pregnancy and early motherhood usually has its roots in women’s previous experiences, and the structural inequalities that shape their lives. We know that women who have experienced significant trauma and abuse in the past are more likely to face a lifetime of mental and physical health problems, poverty, discrimination and continued abuse. The inequalities that arise from women’s unequal status in society through factors such as race, gender, immigration status and poverty reinforce and amplify the difficulties they face. Their reproductive health should be seen in this wider health and social context.

During the course of our work at we see the impacts of trauma and adverse experiences in childhood and how these affect women’s health and wellbeing throughout their lives. We welcome the work done in recent years to embed trauma-informed care in the perinatal period. This work must continue in order to ensure the systems women engage with protect those whose experiences may make them particularly vulnerable at this particular point in their lives. Equipping universal health systems such as maternity with the tools to work effectively with women with the most complex needs through a commitment to safety, dignity, and compassionate, non-judgmental care will benefit all women.

Through our research and practical work with women we hear about and observe the impact of life course involvement with systems. For example, we hear how past contact with the care system impacts on women’s engagement with statutory services.

Improving the health and care of infants need not come at a cost to the mother. Holistic, early and preventative family support, as recognised by the recently published early years review, lies at the heart of improving outcomes for women, babies and children, and for improving the health of our society as a whole. As women move through their perinatal journey, we often see their needs come into sharp focus at the point of pregnancy. However when attention shifts post-birth to the needs of their newborn child, this can leave some women without the care and support they need. This is particularly acute where that newborn is removed from their care as a result of social services involvement.

The lack of specialist support provided to mothers experiencing or at risk of separation from their infant is notable and shocking. Professionals interviewed for our Holding it all Together report were particularly critical of the lack of recognition of the 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

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23 Ibid
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.”

If families are not supported to stay together where that might be possible, and if women are not supported to deal with the trauma of separation, cycles of disadvantage will be perpetuated, with more children experiencing the care system and more women involved in recurrent care proceedings.

In the course of our work in the criminal justice system we see the health and care needs associated with pregnancy or early motherhood ignored, complicated or put at risk by the nature of that system, despite the existence of gender specific standards for women’s care and best practice guidance. Our recent research with Clinks found less than half of voluntary sector professionals felt probation services take sufficient account of the needs and circumstance of pregnant women and new mothers, and almost half of midwives recalled situations where they felt a woman’s community sentence requirements or probation license conditions risked a negative impact on her maternity care. For more on the healthcare issues relating to women in contact with the CJS we refer you to the submission from Women in Prison.

Issues are also presented in women’s contact with the immigration system, with particular risks and barriers created by no recourse to public funds, poor housing, and charging for healthcare. We would refer you to the submission from Maternity Action for more detail on this.

In adopting an approach to health and care that is truly rooted in women’s life course, it is vital that the wider determinants of health are factored in at every stage, and the impact of all systems on women and girls’ health are recognised. Building capacity for services to recognise and respond to the complexity of women’s lives, and a commitment to delivering services through whole systems, multi-agency working is central. These should be enabled through cross-governmental commitments to ‘health in all policies’.

Services across the health and care system should develop specialist pathways, co-produced with women with lived experience, for working with women who experience deprivation and disadvantage, including specific pathways for those at risk of separation or separated from their child.

There is much evidence to support the value of care co-ordinator or navigator roles in helping women who health and social inequalities to negotiate complex services and systems of care during the perinatal period. This role, working alongside appropriately resourced, dedicated teams in each service (safeguarding midwives, pre-birth and newborn teams in local authority social services, women’s teams in probation, pregnancy, mother and baby liaison officers in prison, etc.) holds the key to bridging dangerous gaps within and between systems and allows women to be placed at the very heart of their care. Voluntary sector agencies are ideally placed to provide roles of this kind, as they can overcome some of the barriers to engagement related to statutory services.

Integrated Care Systems will have a key role to play in supporting multi-agency responses to women’s health and care across the life course, and meaningful engagement with specialist voluntary sector

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organisations – particularly those led by and for women, and those led by and for women from racially
minoritised communities – should be emphasised in all ICSs to support scrutiny and co-production.

4. Maximising women’s health in the workplace

N/A

5. Ensuring research, evidence and data support improvements in women’s health

Building the evidence base on the social determinants behind health inequalities must be a priority for all.

The inequalities highlighted by the MBRRACE reports\(^{31}\) require urgent further investigation, to better understand the links between the wider determinants of health and maternal deaths. This research should be extended to explore inequalities in the prevalence of serious incidents or poor outcomes in perinatal care, as well as maternal deaths.

The quality of maternity and social care data should be improved to support research of this kind, as well as local population analysis and responsiveness. Maternity and social care systems should embed systematic data collection on a comprehensive range of complex social factors in a woman’s life, tracking the impact these have on outcomes for her and her baby. This data should be used to drive positive changes that narrow inequalities and ensure all women have access to appropriate, safe and respectful care.

Data on the number of pregnant and postnatal women in contact with the criminal, family justice and immigration system and their health outcomes should also be a priority to ensure that issues created by/ experienced within these systems are scrutinised and services adapted accordingly.

Work with these datasets should be matched and supported with co-produced and peer-led research with women facing deprivation and disadvantage in the perinatal period, including involvement with the systems described above.

The successes of local place-based models and the value of flexibility as set out in the Integration and Innovation Bill are laudable. Work should be done to ensure that best practice in pockets such as work by specialist midwifery teams, pre-birth teams in children’s social services and maternal separation support projects, is shared and replicated across the country. Regional variation is stark and must be addressed if the fact of where girls and women are born results in inequalities in the care they receive, and their health outcomes.

6. Understanding and responding to the impacts of COVID-19 on women’s health

This public health emergency has exposed stark health and social inequalities, and highlighted the precariousness of vulnerable women’s lives. The impact of the pandemic on statutory services, particularly on the amount of face to face contact practitioners have with families, has reduced opportunities to establish and maintain the relationships of trust that are key to identifying and responding to women’s complex issues.

The pandemic has brought into sharp focus the extent and impact of deeply entrenched health and social inequalities. This is particularly true for women who live in the poorest areas of the country and

\(^{31}\) Ibid
those who are from Black, Asian or minority ethnic communities, who are disproportionately affected physically, psychologically and financially.\(^\text{32}\) \(^\text{33}\) \(^\text{34}\) \(^\text{35}\)

These inequalities are wholly unacceptable. It should not have taken a pandemic to draw attention to them, as their existence and impact have been known for decades, and have been getting worse. They must now be addressed with ambition and urgency at national, regional and local levels. The response must combine listening to women and acting on their concerns, and developing the evidence base to understand better the intersecting impact of inequalities on the lives of women and their families.

All those delivering services should take some time to learn from what necessity has taught us in the fourteen months. The relative successes of remote working should not be allowed to tip the balance away from investment in face-to-face support. Instead, what we have learnt should help us produce more varied forms of support, informed by women’s own preferences about the way they would like to engage with services.

Both Clinks\(^\text{36}\) and Agenda\(^\text{37}\), among others, have recently published work specific to the pandemic and we would support their submissions to this consultation, drawing on that evidence.


\(^{\text{33}}\) Health Foundation (2020) Emerging findings on the impact of COVID-19 on black and minority ethnic people

\(^{\text{34}}\) IFS (2020) The mental health effects of the first two months of lockdown and social distancing during the Covid-19 pandemic in the UK

\(^{\text{35}}\) MBRRACE (2020) MBRRACE-UK Perinatal Confidential Enquiry: Stillbirths and Neonatal Deaths in Twin Pregnancies
https://www.npeu.ox.ac.uk/mbrrace-uk/reports.


\(^{\text{37}}\) Agenda (2021) Voices from Lockdown