Birthrights submission to inform the Women's Health Strategy

Introduction

Birthrights is the UK charity that champions respectful care during pregnancy and childbirth by protecting human rights. We want all women and anyone giving birth, however they identify, to have a positive experience of maternity care. As a human rights charity, inclusion is core to our ethos. We want everyone to have access to safe, appropriate healthcare that meets their needs and recognises the specific barriers and structural discrimination faced by some, such as women of colour, those experiencing multiple disadvantage and LGBTQ+ people.

For Birthrights, this means care that is grounded in human rights. Every woman has the right to easily access care that is safe and personalised to them. Every woman has the right, protected in law, to have a two way dialogue about all reasonable options for treatment or intervention, the right to say yes or no, and the right to have their decisions respected. Every woman has the right to be treated with dignity and respect throughout their maternity journey and indeed throughout life, which is why we wholeheartedly welcome the Government's decision to take a whole life course approach to women's health. This approach must also recognise and address the intersectional ways in which people experience structural disadvantage and discrimination in healthcare throughout their lives. It is our belief that such an approach will lead to better care for women throughout their lives, including better maternity care.

A human rights based approach to women's health

For many women, pregnancy is the first time they have had any significant interaction with health services, and as such, will inform their whole experience of engaging with health services thereafter. Others may have already have had positive or negative interactions with health or other statutory services, which will foreshadow their interaction with maternity professionals.

However, in all cases, this intense focus around pregnancy can in itself send the message that a woman is not important in her own right, but because she is gestating another human being. Issues such as smoking and obesity, which from a public health perspective are best addressed before pregnancy, suddenly come under the microscope. Many women contacting Birthrights report feeling judged for not conforming to healthcare professionals' expectations in a number of respects, for example by being a smoker, or by being overweight, or wanting different care from other women. This can lead to disengagement from maternity services. Furthermore, once a woman has given birth, this intense focus quickly evaporates and women are often left to deal with the physical and mental aftermath (which can last for years) without adequate advice or treatment to regain and maintain optimum health.

Recent developments, such as funding the six week postnatal check for women and greater investment in both perinatal mental health services and postpartum physiotherapy, are all positive steps in the right direction. However, a whole life course approach could go further to support women to value and take charge of their own health, because health services are taking an interest and are there to support them at every stage of their life. It has huge potential to identify potential issues early on and to prevent them occurring, rather than treating them after they arise, saving the NHS money and increasing the quality of life for millions of women. It is a once in a lifetime opportunity to address the patriarchal past, correct historic underinvestment in women's healthcare, and show that we truly value the health and wellbeing of half of the population.

To make this a reality we need all girls and women to:

- Be able to access balanced, evidence based information from the NHS
- Be able to access services at a time and a place that meets their needs, having been co-designed with service users. This includes accessing contraception, abortion, sexual health services and cervical smears
- Be treated by staff who will listen to them and treat them with respect, and that are culturally safe
- Be empowered to make informed choices about their care
- Be able to access services that are holistic, with seamless referrals, so that emerging issues are addressed early and women do not fall between the gaps

If this was the expectation and experience of all girls from the outset, women would be more informed and empowered consumers of maternity care and health care more generally. Research shows that having a positive relationship with care givers and feeling in control of decisions are primary determinants of a positive birth experience[1] . This is turn is likely to reduce the burden of birth trauma. A life course approach underpinned by a human rights based approach would also ensure that women are well set up to live a healthy and fulfilled life post their child-bearing years, knowing that they can continue to access care that meets their needs throughout the menopause and beyond.

We fully support the approach set out in the Royal College of Obstetricians and Gynaecologists' report "Better for women",[2] underpinned by education to ensure women understand their rights to received balanced information, to be treated with dignity and respect, and that is inclusive and culturally safe, and to give fully informed consent in a healthcare context.

Issues resulting from our work

Research

Research into health conditions must include a diverse and representative range of participants. One of the main problems of inequality is the lack of inclusion of Black and Brown people in research and clinical trials:

"Unless all ethnic communities are included in research, the medical profession will never be able to develop culturally competent diagnostic tests and services - and therefore can't deliver equity in healthcare."[3]

Women's health issues must receive adequate attention and funding, including support for co-design of research, and to ensure that research is tackling the issues that are most important to women and girls.

Information giving which take a life course approach

Our work on maternal request caesarean in particular, but also with women with invasive placenta conditions, has highlighted that there is often a mismatch between women wanting to take a life

[1] Cook K, Loomis C. The Impact of choice and control on women's childbirth experiences. J Perinat Educ. 2012;21(3):158-168. doi:10.1891/1058-1243.21.3.158
[2] https://www.rcog.org.uk/en/news/campaigns-and-opinions/better-for-women/
[3] Professor Gurch Randhawa quoted in Lilian Anekwe, 2020, Ethnic disparities in maternal care

course approach to their own health by considering the long term impacts of decisions, and healthcare professionals focusing on more short term outcomes.

For example, women who have suffered urinary or faecal incontinence (or both) afterwards tell us they had no idea that this could happen as a result of birth and are angry that they weren't told about this. To make matters worse, the support received to address these issues is often poor or women are too embarrassed to seek it out. Healthcare professionals on the other hand view such complications as a rare occurrence, and are reluctant to "scare" women even when a woman's risk of complications is increased. Women who develop placenta accreta or related conditions where multiple caesareans are a factor, also do not feel adequately warned.

It is vitally important that maternity professionals fully understand the impact of what happens during birth, not only in the first few weeks but many years down the line, so that they are able to advise women accordingly. Gynaecologists who pick up the pieces often despair that women are not given more useful advice during the perinatal period.

It is also vital that information provided to women and girls is accessible and appropriate to their personal needs. This is a particular issue for women with no or limited English, and for those who have accessibility requirements. In the absence of appropriate interpreting and communication support services, women are unable to make informed decisions about their care, and healthcare professionals are unable to discharge their legal requirements in relation to informed consent. This is discussed further in relation to maternity care in the submission from Birth Companions.

Public health issues

Issues such as smoking, obesity, and mental health must be addressed primarily and holistically at the population level, whilst recognising the need for specialist services as well. This approach will have the greatest public health benefit but should also reduce the pressure pregnant women are made to feel that they carry sole responsibility for the health of the child, and having a short, defined and often inadequate window to address any "problems" they may have. Using maternity care as a means to tackle public health issues results in time limited appointments where the discussion is all about "risks", with little time to discuss what is important to the woman in question. If not done sensitively, it also risks relationships of trust breaking down (or failing to be established in the first place), if women feel under surveillance about their choices and behaviour. This is discussed further in the submission from Birth Companions, in relation to women facing multiple disadvantage. The importance of relationships of trust and women-focussed care must be central to all policy and practice decisions which may impact maternity care.

In addition, a life course approach recognises that risks to women after birth and not just during pregnancy (suicide is the leading direct cause of death for women in the year after birth[4]). There is an urgent need to invest in co-ordinated support for all woman and families *after* the birth of a baby. Specialist support is needed following the loss of a baby and particularly following the removal of a baby where women receive very little support at all. (The specialist support needs of women separated from their baby is discussed further in the submission from Birth Companions.)

More broadly, addressing public health issues requires a co-ordinated approach which recognises and addresses inequalities and social determinants of health. The provision of holistic and joined-up support for women across health and other statutory services is vital, particularly for those facing

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4 https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2020/MBRRACE-UK_Maternal_Report_Dec_2020_-_Ex_Summary_v10.pdf

multiple disadvantage and complex life circumstances. This is discussed further in the submission from Birth Companions.

Women's health in the workplace

Although at the edge of our remit, we are aware that pregnant women struggle to get adequate support at work whether that is a risk assessment to modify their duties, or a clean and comfortable room to express milk. There is also lack of understanding of the support needs of women who have experienced miscarriage, stillbirth or the death of a baby. The needs of women who are party to a surrogacy arrangement, or are involved with social services or have had a baby removed from their care are also little understood. Women in unstable or zero-hours employment face barriers to accessing basic rights, such as time off for maternity appointments.

The needs of menopausal women are possibly even less catered for.

Once again a whole life course approach, would normalise the concept that women have different needs at different stages of their lives that need to be properly catered for, rather that swept under the carpet.

Reproductive rights

We understand that reproductive and sexual health services are likely to be addressed under the Government's Reproductive and Sexual Health strategy. However these elements are essential to a comprehensive women's health strategy and we urge the Government to ensure both strategies work seamlessly together.

Birthrights has signed an open letter[5] urging the Government to ensure women continue to have access to early medical abortion at home as they have during the pandemic. Given the overwhelming evidence that women are highly satisfied with the service, that it is safe and encourages earlier access to abortion, the decision would seem to be easy to make. And yet as the situation regarding access to abortion in Northern Ireland also shows, there are still some who believe there is a moral imperative to ensure these services are difficult to access. This attitude has no place in modern health services.

All women's health services should be easily accessible without any moral strings attached. Birthrights has also been involved in cases around access criteria to IVF treatment, where contrary to NICE guidance, commissioners have felt able to ration access to IVF around their own moral judgements about who might make suitable parents. Recent research by BPAS highlights how CCGs ration IVF based on whether women are in a stable relationship , their sexual orientation, whether they smoke and their Body Mass Index amongst other criteria[6]. We have also witnessed cases where sterilisation has been withheld, despite it being the informed choice of the woman requesting it.

Risk counselling in relation to health decisions must be responsive to women's individual needs and life circumstances. For example, access to medication should not be conditional on a requirement to 'consent' to certain forms of contraceptive, where this is not wanted or required by the woman in question.

The Government must ensure that all reproductive services are easily accessible, non-judgemental, non-discriminatory and driven by women's needs.

[5] https://www.bpas.org/media/3471/telemedical-abortion-care-open-letter.pdf
[6] https://www.bpas.org/media/3369/bpas-fertility-ivf-postcode-lottery-report.pdf

Trauma-informed care

According to national crime statistics[7] around 1 in 5 women has been the subject of a sexual assault since the age of sixteen. Our research with women facing severe and multiple disadvantage also highlighted the impact of trafficking, the experience of seeking asylum, and domestic violence to name just a few of the traumatic circumstances many women face. Women may not always disclose their experiences to healthcare professionals.

It is therefore essential that all women's health practitioners are aware of the potential for them to cause further harm even if unintentionally, and practise in a trauma-informed way[8]. This is discussed further in the submission from Birth Companions.

Addressing inequalities

Evidence shows time and again that disrespectful and dehumanised care is experienced most acutely by groups that already face structural disadvantage.

The MBBRACE report in 2020 showed that Black women are four times more likely to die around the period of pregnancy and birth, with Asian women twice as likely to die, compared to white women. Similarly, Black and Asian women are significantly more likely to experience a stillbirth or neonatal death than their white peers. This clearly shows that maternity services are safer for some women, birthing people and babies than others. Black and Asian women are also at higher risk of illness during pregnancy, which has been brought to the fore in the pandemic: Black pregnant women are eight times and Asian women four times more likely to be admitted to hospital with Covid-19.[9]

Birthrights is currently convening an inquiry into the maternal outcomes and experiences of Black, Brown and Mixed Ethnicity women and birthing people, led by an expert panel of people with lived experience, maternity professionals and birth workers, human rights and clinical negligence lawyers, research and inquiry specialists, and equalities and anti-racism campaigners. The call for evidence is ongoing and has received 200 submissions to date. Early findings include:

- Most people reported they did not feel safe at some point during their care
- Being ignored or disbelieved is a strong theme, especially late in pregnancy or in labour, in relation to pain and to concerns about their own or their babies' safety, in many cases leading to serious injury for women and/or neonatal complications
- Being seen as a nuisance or a "pest" for asking questions about care, even when this related to specific conditions with high miscarriage or other risks
- Racial stereotypes leading to denial or delay of pain relief, with significant physical and psychological trauma – Asian women seen as "precious" with low pain thresholds, Black women told "girls 'like me' should be stronger"
- Failure to listen to concerns or recognise complications due to skin colour e.g. jaundice in Black babies

[7] https://www.crimesurvey.co.uk/en/index.html

[8] https://www.england.nhs.uk/wp-content/uploads/2021/02/A-good-practice-guide-to-support-implementation-of-trauma-informed-care-in-the-perinatal-period-February-2021.pdf

[9] NHS England, 2020, NHS boosts support for Black and ethnic minority women

- Distress and trauma from failure to respect religious or cultural needs e.g. male healthcare professionals doing intimate procedures, overhearing maternity staff complaining that "people like me" causes issues e.g. needing Halal suitable milk
- Overt racist or other discriminatory language, microaggressions and assumptions rooted in racial stereotypes leading to disrespectful care and distress
- Not being told about options, lack of choice, and feeling coerced into interventions.

"I am British Bangladeshi and English is my first language, but I think there is a stereotype of Asian women in my area that we are tame, quiet and compliant people who have no voice and will be obedient. I have a condition that can cause miscarriage if it is not managed well and monitored, so I felt unsafe when my questions about this weren't answered. It felt like maternity professionals are not used to being challenged by brown women."

"At one appointment, I was kept waiting for several hours to see a consultant, only to be told everyone had gone home, despite me asking three times when I will be seen. When I challenge this I am spoken to at the same time by three white staff who say it is my fault for keeping hold of my notes and that I am aggressive. I am scared to deliver in this hospital. […] I feel my race means I am seen as less, other, expected to endure more. It led to me being called aggressive by someone who has never before met me – three white staff against one lone black vulnerable female."

"With the birth of my first child, I felt my voice was ignored. My expressions of pain and exhaustion were diminished with comments about how I didn't look like I was in that much pain and how a girl "like me" should be stronger than that. I was told people "like me" don't need epidurals. I laboured for three days, I was unable to keep food down or sleep at all for 48 hours. I was begging for an epidural and shaking with the effort of trying not to push. When I got my first midwife back after several shift changes she was appalled I had been left to continue struggling and had a consultant informed and epidural scheduled within an hour of taking over my care."

The testimony received so far by the inquiry is deeply concerning, but there are examples of rights-respecting and culturally competent care – where "amazing" healthcare professionals listened, were compassionate, and made sure individual needs could be met without judgement or invasive curiosity.

Addressing inequalities must run through a whole life course approach. This ranges from addressing the vast disparities in maternal and neonatal outcomes for Black and Brown women and those living with multiple disadvantage, to recognising the inequality in experiences of care for women. In our research with Birth Companions[10], three quarters of participants from disadvantaged backgrounds described times in their maternity care where their choices were not respect or they were not supported to give informed consent. One quarter described explicitly non-consented care, and experiences were worst for the women in the most disadvantaged circumstances. As further outlined in the Birth Companions submission, addressing inequalities also requires safe and holistic support across health, social and other needs (such as housing) to be available during and beyond maternity care. It also requires an absence of NHS charging for maternity care in order to ensure asylum seeking women are not discouraged from receiving care.

Addressing inequalities also requires services to ensure they are meeting their legal requirements around equality: in our research on the maternity experiences of disabled women, only 19% thought that reasonable adjustments had been made for them. Maternal medicine centres should assist in ensuring that women with more complex health needs are able to access multidisciplinary care;

[10] https://www.birthrights.org.uk/campaigns-research/severe-disadvantage/

however health services also need to be able to respond appropriately and sensitively to basic needs within individual services.

Services will be more responsive to the needs of marginalised women when they are supported to be involved in the design and development of services and in research which shapes care. Service user voice involvement in maternity and women's healthcare needs to be inclusive across the diversity and range of women using services. This is discussed further in relation to Maternity Voice Partnerships in the submission from Birth Companions.

We welcome the opportunity to submit evidence to the DHSC and look forward to reading the Women's Health Strategy in due course.

About Birthrights

Birthrights champions respectful care during pregnancy and childbirth by protecting human rights. We provide advice and information to women and birthing people, train doctors and midwives, and campaign to change maternity policy and systems.
We are a charity, independent of government and the NHS.

https://www.birthrights.org.uk/

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