Response to the Care Quality Commission consultation on changes to the ways the CQC regulates, inspects and monitors care services

(A) About Birthrights

Birthrights is a charitable organisation devoted to improving women's experience of pregnancy and childbirth by promoting respect for human rights. Our board members include senior lawyers and healthcare professionals with expertise in maternity issues.

Birthrights provides free legal information and advice on human rights and the law relating to childbearing women, offers advice and training to professional caregivers and campaigns on respect for women's rights in childbirth as fundamental human rights that maternity care providers are legally obliged to respect and fulfil.

We have an interest in the standards that the CQC sets for monitoring maternity services insofar as they relate to protection of women's human rights. We are particularly concerned that the CQC has robust standards in place for assessing whether or not hospitals are guaranteeing respect for women's dignity and human rights during ante-natal, intra-partum and post-natal care.

We append at the end of this response the Birthrights' factsheet on human rights in maternity care, which provides an overview on the relevance of human rights in the maternity context.

(B) Women's experiences of maternity care in the UK

"*A woman's relationship with her maternity providers is vitally important. Not only are these encounters the vehicle for essential lifesaving health services, but women's experiences with caregivers can empower and comfort or inflict lasting damage and emotional trauma. Either way, women's memories of their childbearing experiences stay with them for a lifetime and are often shared with other women, contributing to a climate of confidence or doubt around childbearing*." White Ribbon Alliance, Respectful Maternity Care (2011)

There is a growing body of evidence that paints a disturbing picture of disrespect in maternity systems within wealthy nations.[1] While the UK's maternity system generally ensures safe outcomes for mothers and babies, stories of disrespect in childbirth – ranging from procedures performed without consent to verbal abuse and bullying – are worryingly common. Caring and respectful interpersonal relationships can make the difference between positive and traumatic birth experiences, which have lasting impacts for the mother that can be measured in poor post-natal

[1] Bowser and Hill, Exploring Evidence for Disrespect and Abuse in Facility-based Childbirth (USAID, 2010).

outcomes, including post-natal depression, post-traumatic stress disorder[2] and even suicide, which remarkably is the leading cause of pregnancy-related death in the UK.[3].

The basic principles of respectful treatment are too often neglected in large-scale healthcare facilities – a problem highlighted in the recent NHS Mid Staffordshire Trust report.[4] Since Birthrights launched in January 2013, many women have sought our advice about disrespectful care. Their complaints commonly centre on performance of medical procedures without consent, poor communication (including rudeness, objectification, the use of threatening language, shouting, labelling and stereotyping) and physical abuse during labour. Women have approached us after they felt bullied by referrals to social services for declining medical treatment, which may not have been necessary (a common complaint is forced administration of prophylactic antibiotics).[5] Midwives have reported serious concerns to us about the impact that low staffing levels are having on the ability to provide respectful care in over-stretched maternity units.

As evidence has repeatedly shown, a critical factor affecting women's experience of childbirth is the nature of the support that she receives from her professional caregivers.[6] An overriding concern for women and healthcare professionals is the ongoing failure to provide continuity of carer, despite the Department of Health's public commitment to guaranteeing every woman a named midwife.[7] It is well-known that continuity of carer has a positive effect on maternal and foetal outcomes[8] and yet NHS Trusts continue to fail to provide continuity of carer, which has serious knock-on impacts on women and their babies.

A core aspect of human rights in maternity care is the ability to make choices about how, where and with whom to give birth. The right of women to decide the circumstances in which they give birth has been recognised by the European Court of Human Rights as a fundamental aspect of the right to autonomy protected under Article 8 of the European Convention on Human Rights.[9] The state is under a positive obligation to ensure 'a legal and institutional environment that enables her

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[2] Rates of post-natal depression and PTSD related to experiences of childbirth are rising. See Alder J, Stadlmayr W, Tschudin S, et al. (2006) Post-traumatic symptoms after childbirth: what should we offer? *Journal of Psychosomatic Obstetrics Gynaeco*logy 27(2):107-12.
[3] J Drife, "Why mothers die", *JR Coll Physicians Edinb* (2005) 35 332.
[4] A number of maternity-related cases were investigated in the Mid-Staffordshire inquiry.
[5] See e.g. the 2012 Scottish ombudsman report into the threats made to a mother who declined intra-partum antibiotics: http://www.spso.org.uk/webfm_send/4289.
[6] See, eg, Eliasson M, Kainz G, von Post I (2008) Uncaring Midwives. *Nusing Ethics* 15(4): 500-11; Hodnett Ellen D., Pain and women's satisfaction with the experience of childbirth: A systematic review. *American Journal of Obstetrics and Gynaecology* 186, S160-172.
[7] In recent research undertaken by the Women's Institute and NCT, 88% of women in England and Wales who gave birth between 2008-12 had not met the midwife who cared for them in labour. National Federation of Women's Institutes, NCT (May, 2013) *Support Overdue: Women's experiences of maternity services*.
[8] See McLachlan HL, Forster DA, Davey MA, et al. (2012) Effects of continuity of care by a primary midwife (caseload midwifery) on caesarean section rates in women of low obstetric risk: the COSMOS randomised controlled trial. *British Journal of Obstetrics and Gynaecology* 119(12):1483-92.
[9] *Ternovszky v Hungary* [2010] ECHR 67545/09.

choice'.[10] But women are routinely denied choice in maternity services. Hospital trusts operate restrictive policies that prevent women deemed 'high-risk' from accessing facilities and women are sometimes put under pressure to accept certain medical interventions which may not be based on sound evidence.[11] Women's choice of pain relief may be denied without good reason. Many NHS Trusts refuse to guarantee women the choice of home birth on the grounds of staff shortages and women who have been offered a home birth are frequently informed in labour that there is no midwife available to attend them at home.[12] Women seeking elective caesareans frequently struggle to obtain support for their choice. The recent amendments to the NICE guidelines are often misunderstood by midwives and doctors, who may refuse to provide a caesarean on request despite the NICE expectation that women should have access to this service.[13]

Birthrights is aware of particular concerns in the healthcare community surrounding the respectful treatment of pregnant refugee and asylum-seeking women.[14] In particular, the overseas visitors charging regime may lead to women being harassed for payment which it known that they cannot afford. Obstetricians have told us of a worrying rise in the maternal deaths amongst women from ethnic minorities in London,[15] which they attribute in part to failures to communicate effectively with women who may not speak English.

(C) Taking dignity into account in the CQC standards

We believe that human rights have a critical role to play in healthcare. While the focus of human rights in the NHS is often on end of life care, human rights values are similarly fundamental to women and their partners' experience of maternity care. The principal human rights value of dignity – rightly at the forefront of the CQC's discussion of human rights in the consultation – encompasses the twin ideals of respect and autonomy. Respectful care and respect for autonomous choice are essential to women's maternity experiences. They are also grounded in the legal obligations placed on NHS Trusts by the Human Rights Act 1998 to respect individual's rights under the European Convention on Human Rights and in particular, the right to private and family life protected by Article 8 of the Convention (see appended factsheet on the meaning and relevance of these rights).

The CQC's human rights impact assessment states that the CQC intends to take a more intensive approach to the inspection of high-risk maternity services. We welcome this approach: in our

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[10] Ibid, [24].
[11] See Bewley and Foo, 'Are Doctors Still Improving Childbirth?' In Ebtehaj et al (eds), *Birth Rites and Rights* (Hart 2011).
[12] The legality of this practice is questionable in light of the decision in *Ternovszky v Hungary* [2010] ECHR 67545/09.
[13] Hull, 'NICE says a planned caesearean section should be offered to women who request it', (7 August 2013) *BMJ* http://www.bmj.com/content/347/bmj.f4649/rr/656733.
[14] See the recent research on treatment of asylum-seeking women: Medical Justice (2013) 'Expecting Change: the case for ending the immigration detention of pregnant women' and Refugee Council/Maternity Action (2013), 'When Maternity Doesn't Matter: Dispersing pregnant women seeking asylum'.
[15] http://www.nhs.uk/news/2012/04april/Pages/midwife-numbers-london-pregnancy-deaths.aspx

experience, it is often women who are deemed high-risk who are at risk of receiving poor care. Less regard may be given to the need for such women's informed consent, they may be treated more roughly and their privacy more easily compromised. Women from ethnic minorities and refugee or asylum-seeking women often have higher risks in pregnancy and childbirth. These women may not speak English and may have experience previous traumatic experiences, including FGM and sexual abuse. They are therefore often most in need of respectful care that takes account of their personal needs and choices, but they may be less able to access that care and more vulnerable to abuse by healthcare providers.

The CQC has identified one potential standard for assessment of maternity care in the consultation – the frequency of fourth degree tears. We understand the clinical utility of this standard and agree that it gives an indication of potential poor quality clinical care. However, we are keen that the CQC's focus in maternity care is not simply based on clinical metrics. We urge the CQC to develop sensitive means of assessing how women's dignity and human rights have been respected during their care.

We suggest the following areas that the CQC might explore in their human rights based approach to assessment of maternity services:

- Choice of birth setting: do Trusts offer the full-range of birth services, including birth centre and home birth? Is access to home birth services contingent on staffing levels? Do healthcare professionals understand the NICE guidelines on elective c-sections and make this option available to women who request it?
- Continuity of midwifery support: do Trusts provide continuity of carer ante-natally and during the intra-partum period? Have women met the midwives who care for them in labour before the birth? How many midwives attend a woman during the course of her labour? Are women left alone during labour at a time when they want support?
- Communication: do health professionals introduce themselves to women and their partners? Do women feel comfortable asking questions of healthcare professionals? Do women feel that healthcare staff listen to them?
- Translation services: are midwives and doctors able to access an independent (i.e. professional, non-family member) translator for women who do not speak English? Do they have confidence that non-English speaking women understand the information that is provided to them?
- Privacy: are women able to labour in a private space with the capacity to shut the door? Do women feel their bodily privacy is respected, particularly when transferring between rooms/wards?
- Informed consent: are women given a choice about medical interventions, such as induction, or are they told what they must do? Do healthcare professionals always obtain consent before performing examinations? Is accurate and objective information given to women about each medical intervention? Is information presented in a supportive and non-coercive manner?
- Choice of birth partner: is this limited by hospital policy? Are women allowed to choose the number and identity of their partners (including swapping partners during labour)?

- Provision of pain relief: are there hospital policies prohibiting access to pain relief, including use of water, during childbirth? Are these policies justified by reference to clinical factors, or on health and safety/staffing grounds?
- Post-natal care: are partners able to remain with women overnight when women request it? Are women able to access sufficient food and drink on post-natal wards? Are women supported to feed their babies in the manner they choose? Are women able to obtain sanitary products and nappies on request?

(D) Conclusion

Birthrights is currently conducting research into women's and midwives' experiences of dignity and human rights in childbirth. We would be happy to share that research with the CQC when it is completed in Autumn 2013.

We are grateful for consideration of our response and we would be very happy to contribute to any future discussions with the CQC on the role of human rights in healthcare.

Birthrights

9 August 2013

HUMAN RIGHTS IN MATERNITY CARE

SUMMARY

Human rights law gives pregnant women the right to receive maternity care; to make their own choices about their care; and to be given standards of care that respect their dignity as human beings.

WHAT ARE HUMAN RIGHTS?

Every human being has human rights.

Human rights protect your dignity, your privacy, your equality and your autonomy (your control over your own life).

Human rights require public bodies to treat you with dignity, consult you about certain decisions and respect your choices.

WHERE DO HUMAN RIGHTS COME FROM?

Human rights in Europe are protected by the European Convention on Human Rights. The Convention sets out the minimum rights that all European countries have to respect.

In the UK, the European Convention rights have been incorporated into law by the Human Rights Act 1998. This means that if a person thinks they have been denied their rights under the Convention, they can bring a legal claim in the UK courts.

The UK has also ratified the Convention on the Elimination of Discrimination against Women, which prohibits pregnancy-related discrimination and requires the provision of healthcare for pregnant and lactating women. The Convention influences the UK courts' interpretation of the law but it is not possible to bring a legal claim under the Convention.

WHY ARE HUMAN RIGHTS RELEVANT TO MATERNITY CARE?

The fundamental human rights values of dignity, privacy, equality and autonomy are often relevant to the way a woman is treated during pregnancy and childbirth.

Failure to provide adequate maternity care, lack of respect for women's dignity, invasions of privacy, procedures carried out without consent, failure to provide adequate pain relief without medical contraindication , giving pain relief where it is not requested, unnecessary or unexplained medical interventions, and lack of respect for women's choices about where and how a birth takes place, may all violate human rights and can lead to women feeling degraded and dehumanised.

HOW DO HUMAN RIGHTS APPLY TO MATERNITY CARE?

Under the Human Rights Act, all UK public bodies must respect the rights set out in the European Convention. Public bodies include all NHS institutions, such as hospitals, Primary Care Trusts, NHS Trusts and Clinical Commissioning Groups.

This means that public bodies must respect human rights when making decisions. It also means that caregivers working in public bodies must respect human rights as they go about their work.

DO I HAVE A RIGHT TO RECEIVE MATERNITY CARE?

Yes. All pregnant women in the UK have a right to receive maternity care.

Although the European Convention does not explicitly guarantee a right to healthcare, Article 2 protects the right to life and requires the state to provide access to basic life-saving health services, including maternity care.

Overseas citizens may be charged for maternity care in some circumstances, but care must be provided regardless of whether the patient can pay the charge. See our factsheet, Foreign Nationals and Maternity Care.

DO I HAVE A RIGHT TO MAKE CHOICES ABOUT MY CARE?

Yes. Women have the right to make their own choices about how they manage their pregnancy and birth.

Article 8 of the European Convention guarantees the right to private life, which the courts have interpreted to include the right to physical autonomy and integrity.

The right to autonomy means that a woman's consent must always be sought before performing any medical procedure on her. Failure to obtain consent violates Article 8, and may also violate the prohibition on inhuman and degrading treatment under Article 3.

Failure to provide sufficient, objective and unbiased information for a woman to make an informed choice will also violate Article 8. See our factsheet, Consenting to Treatment.

The European Court of Human Rights has held that the right to private life includes a right for women to make choices about the circumstances in which they give birth, including whether to give birth at home (*Ternovskzy v Hungary* (2011)). See our factsheet, Choice of Place of Birth.

The right to make choices about childbirth includes the right to refuse any medical care at all. See our factsheet, Unassisted Birth.

DO HUMAN RIGHTS GUARANTEE STANDARDS OF CARE?

Yes. All women are entitled to care which respects their basic dignity, privacy and autonomy.

Article 3 of the European Convention prohibits inhuman and degrading treatment. If caregivers fail to provide care which is needed to avoid preventable suffering – such as pain relief – then this can amount to inhuman or degrading treatment.

Article 8 of the European Convention, as interpreted by the courts, requires public bodies to respect dignity and autonomy.

Article 14 of the European Convention prohibits discrimination and entitles women to equal treatment in their maternity care. This makes it unlawful for NHS organisations or individual caregivers to discriminate against pregnant women on irrelevant grounds such as disability, race, religion, immigration status and national origin.

DO HUMAN RIGHTS PROTECT AN UNBORN CHILD?

No. Unborn children do not have separate legal recognition under the European Convention or in the common law of England and Wales.

Women are free to make choices against medical advice and cannot be forced to accept treatment which is said to be in the unborn child's interest. See our factsheet, Consenting to Treatment.

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

Consent that is given on the basis of such a threat is not given freely and the health professional may be legally liable for battery and violation of Article 8 of the European Convention if they perform the intervention and they know, or should know, that consent has not been freely given. See our factsheet, Facing Criticism.

WHAT IF YOUR RIGHTS HAVE BEEN VIOLATED?

Birthrights provides a free and confidential legal advice service for women and healthcare professionals seeking advice about human rights in pregnancy and childbirth. You can contact us by email: info@birthrights.org.uk.

If you are unhappy with your care, you can make a complaint to the relevant healthcare provider. For advice on complaints, see our factsheet, Making a Complaint about your Maternity Care.

If you wish to seek financial compensation for ill-treatment, you will usually be advised that a negligence claim should be brought, rather than a claim under the Human Rights Act, and you will need to contact a solicitor specialising in medical negligence law.

Disclaimer: Our factsheets provide information about the law in England and Wales. The information is correct at the time of writing (January 2013). The law in this area may be subject to change. Birthrights cannot be held responsible if changes to the law outdate this publication. Birthrights accepts no responsibility for loss which may arise from reliance on information contained in this factsheet.