ASSOCIATION FOR IMPROVEMENTS IN THE MATERNITY SERVICES

Submission to the UN Special Rapporteur

Since 1960, AIMS has been the leading advocate for improvements in UK maternity care. We have national and international links and a membership of over 700 midwives, health visitors, obstetricians and lay people. Collectively, our volunteers have decades of experience researching, advocating on and campaigning for improvements in UK maternity care. Importantly, we also support women directly to navigate the maternity system. We use our knowledge, influence and experience to instigate policy change at local and national level.

We run an email and telephone helpline which provided support to more than 400 women during 2018/19. We also have a large network via our volunteers and members, who engage with mothers, health care providers and others on social media and at meetings. We provide information on our website and in a series of books. This information is produced to help women to make informed decisions about their care, and to challenge misinformation.

Question 1:

Please indicate whether in your country there are cases of mistreatment and violence against women during reproductive health care, particularly facility-based childbirth. If so, please specify what kind of cases and describe your country's response and any good practices, including protection of human rights.

Birth trauma based on mistreatment and violence during facility-based childbirth is a common complaint raised by women who contact AIMS for support or provide their birthing narratives for our online journal (https://www.aims.org.uk/journal). In our experience, obstetric violence can be both direct and structural. With regards to the former, we have supported women who have been sutured without anaesthesia, physically restrained during birth, subjected to vaginal examinations without informed consent and verbally humiliated and abused. Words used by women to describe their traumatic births include terms such as 'brutal', 'barbaric', 'torture', 'like rape', and 'dehumanised'. Their experiences often include feeling 'helpless', 'ignored', 'invisible' and 'not listened to'. First time mothers tell us about how shocked and degraded they felt at the treatment they received and the way their autonomy was overruled, while mothers approaching subsequent births come to us seeking a way to avoid this mistreatment happening to them again.

What we also see is structural violence, particularly as our maternity system has become highly medicalised and interventions such as caesarean section and induction of labour have become more routine. One way in which this occurs is via women being forced or coerced into complying with care pathways, which often include invasive, intrusive and painful interventions. Other forms of structural violence include the expectation of women to birth on their backs, often with their legs in stirrups for no clear reason, and the overuse of continual fetal monitoring, both of which are a form of indirect restraint and can cause labour to be more painful, and birthing to be more difficult. What women report to us, and what is apparent in both academic and grey literature, is that once one form of intervention is used, it can often lead to a 'cascade of interventions'. A common example is the use of Syntocinon for augmenting labour, which can lead to the need for an epidural, resulting in a difficult birth requiring a forceps delivery. The UK's high rates of episiotomy and instrumental deliveries also leave many women with severe perineal injuries, incontinence and sexual dysfunction. Further,

there is little postnatal support in our healthcare system for remedying the mental and physical traumas caused by such abusive structural violence.

While we are aware of an effort by some within the NHS to ensure more physiological 'normal' births - such as attempts to improve hospital environments, the establishing of birth centres and the provision of home birth services - in our experience such services are not offered as routine. Birthing at home or in a midwifery led unit is often something women have to fight for, even if they are low risk, and women who are not categorised as such will usually have to be very assertive. As our maternity system becomes more medicalised however, it appears that the definition of 'low risk' is being interpreted much more narrowly meaning fewer women are finding it easy to access these services.

A key consequence of this violence is our nation's growing problem with birth trauma, which can include emotional, psychological and mental health problems, some of which can lead to diagnoses of Post-Traumatic Stress Disorder and Post-Natal Depression. Some women, their partners and families suffer without a diagnosis and are unable to return to the health service for support due to its role in their trauma. AIMS has been aware of this for many years and we have supported numerous women who have experienced this. AIMS frequently publishes articles on the aforementioned issues, but we would draw your attention to three editions of our journal in particular:

- When Birth Becomes Trauma (2019) Vol.30, No.4 https://www.aims.org.uk/journal/index/30/4
- Birth Trauma – What makes birth traumatic and how can we help? (2007) Volume 19, No.1 https://www.aims.org.uk/journal/index/19/1
- Failure in Expectations: it's all your fault! (2002) Vol. 14, No.4 https://www.aims.org.uk/journal/index/14/4

Question 2:

Please specify if full and informed consent is administered for any type of reproductive health care and if these include childbirth care.

In AIMS' experience there are two branches of consent in maternity care: informed consent to a medical procedure or intervention, and informed *refusal* of a medical procedure or intervention.

With regards to women providing informed consent, we are aware that while this is a central aspect of ethical maternity care and a legal requirement, it is not always practised in UK childbirth facilities. We hear reports from women about blatant violations in the form of non-consensual vaginal examinations. We also hear of women not being fully informed about the advantages and disadvantages of certain procedures. This happens from the first encounter with the health services, with the assumption that women will automatically accept all antenatal testing, through to birth. We are currently seeing the prevalence of this with regards to induction of labour, which is usually presented as routine with limited discussion about any alternative or what the procedure entails. From our discussions with women we also sense that within the hospital environment, consent to one procedure is presumed to be consent to any further procedures that follow the initial agreement.

Linked to this is informed refusal. Legally, pregnant women are not required to undergo any medical procedure and they can decline all maternity care. However, threats in the form of for example, social services referral, coercion, the deliberate distortion of facts and the withdrawal of services are ways in which our maternity system

violates informed refusal and pressurises some women into submitting to interventions that they do not want. This way of obtaining agreement to interventions erodes women's trust in the maternity services, violates their right to bodily integrity and does not meet the requirement of informed consent.

Question 3:

Please specify whether there are accountability mechanisms in place within the health facilities to ensure redress for victims of mistreatment and violence, including filing complaints, financial compensation, acknowledgement of wrongdoing and guarantees of non-repetition. Please indicate whether the ombudsperson is mandated to address such human rights violations.

In this country, law, policy and professional guidance prohibits violence against women within the maternity setting. On paper therefore, it would appear that there are adequate accountability mechanisms to provide redress to women who have experienced obstetric mistreatment and violence. The reality however is very different.

AIMS frequently supports women to file complaints about the treatment they have experienced within the maternity system. One disadvantage to women is that the notes made by maternity professionals are often considered as providing the 'truth' as to what happened during the birth and antenatal and postnatal appointments. This documented 'truth' is frequently very different to a woman's version of events, or that of her birth companions. Consequently, complainants often find it difficult to challenge the 'official' version of events. We have also found that when women complain to their maternity providers, the institution's response is usually to devalue the woman's experience. In our view, maternity providers tend to deny the abuse or defend it, as opposed to thoroughly investigating the situation.

The Public Health Services Ombudsman (PHSO) is required to investigate complaints of incidents occurring within the healthcare setting, including those within the maternity system. The problem complainants experience however, is that they must first complain to the Trust in which the incident took place. Not only can this be a draining and distressing experience for women, but it also precludes the opportunity for the actions of a hospital to be immediately and independently investigated. A further issue is also that the PHSO has a strict time limit of one year from the date of the incident for the woman to make a complaint. This is extremely discriminatory as during the first year of a baby's life, all mothers are challenged by time, energy and the demands of a newborn. For those who experienced mistreatment and obstetric violence, this will also be coupled with the mental anguish of coming to terms with their trauma, and in many cases mental illness related to that trauma.

Other organisations set up for receiving and addressing complaints are similarly ineffective. The Patient Advice and Liaison Service (PALS) for example, is not independent enough to thoroughly and effectively investigate complaints. Equally, the Care Quality Commission (CQC), although the health and social care regulator, does not have the power to investigate individual complaints.

One avenue some women have attempted to pursue as a way to seek redress for the abuse they have suffered is to complain to the police. Legally, any physical obstetric violence is not only bad medical practice, but also

potentially a criminal offence. In our experience of supporting women who attempt this route, the police refuse to get involved even when the abuse is blatant, for example, physical restraint and forced vaginal examinations.

What this suggests to us is that problematically maternity providers are free to operate outside of the criminal law.

As explained in question 1, much of the violence that takes place within the UK system is structural. Abusive practices are often considered normal and routine. As a result, if a woman complains of a forced vaginal examination for example, as our society views birth as a highly medicalised event, her pain and trauma are considered necessary or lacking in consequence within the bigger picture of the 'emergency' of childbirth. Such ingrained cultural perspectives silence women and prohibit them from ensuring their right to bodily integrity is respected.

Question 4:

Do your health systems have policies that guide health responses to VAW and are these in line with WHO guidelines and standards on this issue?

While maternity providers will usually have policies in place to support women experiencing violence from outside of the healthcare setting, for example, domestic abuse, the reality is that care within the NHS is fragmented. The consequence of this is that women may see ten or more health carers during their pregnancy and birth, therefore developing a successful relationship with a professional is often difficult if not impossible. Additionally, with limited opportunity to engage fully with a woman over the duration of a pregnancy, health carers will struggle to adequately recognise signs of abuse.

In response to both mistreatment and violence within the maternity system, and the ability of carers to recognise it when it occurs outside of that system, AIMS believes that the provision of continuity of carer would greatly improve the experiences of pregnant women. Not only will this aid the recognition of abuse that women may be experiencing outside of their maternity care, but it will also strengthen the relationship between a woman and her health care practitioner. AIMS argues that a health carer who has an existing relationship with a pregnant woman would be less likely to undermine her autonomy, mistreat or abuse her. Further, she would be better aware (than in a fragmented model of care) of that woman's individual needs, limitations, fears and expectations - an understanding which can only be built with a continuing relationship - thus diminishing the chance of informed consent being eroded or violated.

Concluding Comments:

AIMS would be pleased to assist the Special Rapporteur with any additional information she may require to complete her report. Our submission is a very brief overview of the considerable knowledge and experience we have in supporting women to challenge mistreatment and violence within the UK maternity system. For any further assistance, please contact:

Debbie Chippington Derrick
Chair of Trustees
Debbie.chippingtonderrick@aims.org.uk