Submission to the Joint Oireachtas Committee on Gender Equality

AIMS Ireland

4th March 2022

1. Introduction

AIMS Ireland is a consumer-led voluntary organisation that was formed in early 2007 by women following their own experiences in the Irish maternity system. Our mission is to highlight normal birth practices, which are supported by evidence-based research and international best practices, and campaign for recognition of maternal autonomy and issues surrounding informed choice and informed refusal for women in all aspects of the maternity services.

AIMS Ireland offers independent, confidential, non-judgmental support and information on maternity choices and care to women and their families. We assist in complaints and run a private online Birth Healing support group for women following difficult and/or traumatic birth. Our day-to-day contact with service users, consumer interest groups and healthcare practitioners help us stay informed of key issues in maternity care and services which we can then feedback directly to service providers, media, HSE and Government in an effort to improve maternity services on a local and national level.

As service users we are in a unique position to see flaws in service provision which those working in the field are unable to see. Service users are more adept at seeing gaps in provision than those working in their own area of expertise. Only service users navigate the entire system from beginning to end. Their collective experience is the most accurate snapshot of any health service at any given point in time.

2. Gender based violence in maternity care.

There is now a recognised term in the international childbirth literature called "obstetric violence". Obstetric violence is usually defined as the "medical appropriation of women's bodies and reproductive processes during childbirth which causes a loss of autonomy and denies women their rights to make decisions about their bodies and sexuality. It is a form of violence that occurs in healthcare settings which is perpetrated by 'hospital personnel' broadly defined to include nurses, midwives, doctors, trainees, healthcare institutions and training facilities. So, 'obstetric' in 'obstetric violence' refers to the context of facility-based childbirth, and not only to obstetricians."[1]

Specifically, obstetric violence can include any of the following issues:
Denying women their right to practise important cultural rites during childbirth, Physical abuse, Verbal abuse, Emotional and mental abuse, Coercion to gain compliance with medical advice or hospital protocols, Routine provision of interventions that lack an evidence base and without women's informed consent, Ignoring women's requests and refusals, Failure to provide informed consent in any aspect of care[2].

Violence against women in childbirth in Ireland is so normalised that it is often not considered 'violence against women'. Instead, women are routinely told to "get on with it" and "sure look don't you have a healthy baby?". Obstetric violence is enabled greater scope in facility-based childbirth, or childbirth and maternity care

[1] https://www.makebirthbetter.org/blog/obstetric-violence-what-is-it#:~:text=Obstetric%20violence%20is%20usually%20defined,about%20their%20bodies%20and%20sexuality.
[2] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1586344/

where women are reduced to "units of production", to be moved through large under-resourced, understaffed units. Obstetric violence is never "normal" and should not be accepted as normal. It exposes routine facility-based interventions and protocols as harmful human rights violations, and it identifies these practices as a manifestation of violence against women.

It is however important to point out that in general a maternity care provider does not seek to perpetrate violence upon a woman in the maternity care setting, although this does sometimes happen. 'Obstetric violence' is more closely aligned with the school of thought that defines violence in terms of 'violation'[3]. Meaning to infringe, transgress or exceed a norm and it focuses on the victims' perspective not on the care giver's perspective. So, in this context, the focus is not on what the perpetrator intended, but on the consequences of their behaviour as experienced by the person on the receiving end of it. The violation experienced by the victim is the defining feature of 'violence'. This aspect is often ignored in reviewing women's birth stories. In many cases women report to us, that during clinical review, it is not validated, not reflected or acted upon and not understood. The focus of clinical and medical reviews from the care givers perspective takes precedent, and that view is to ensure that no legal liability rests with the care giver. Unacknowledged obstetric violence results in birth trauma, antenatal anxiety on a second baby, postnatal anxiety and depression and in severe cases PTSD.

We feel that Obstetric Violence should be added to the other forms of gender-based violence cited in CA Recommendation 37.

3. Informed consent and informed refusal as Gender based violence in Childbirth

Women have consistently and repeatedly raised the issue of lack of informed consent and informed refusal in our childbirth services issue with AIMSI over the last 14 years. We included questions related to consent in many of our surveys and this has also featured in other surveys such as the Public Consultation[4] carried out for the National Maternity Strategy and the recent Maternity Care Experience Survey. 'Informed consent' and 'informed refusal' are both factors which generally define informed consent. Issues with respect to consent in maternity care settings identified by women are the following:

1. Consent is mostly sought; however, it is often not informed. Education is required as to what informed consent is both for health care professionals and service users, as the impact of realising that consent was not informed at a later stage can be devastating emotionally for a woman or pregnant person.
2. Informed consent is most frequently not given during late labour and childbirth itself. Many women also report lack of informed consent with respect to artificial milk substitutes being given to their babies.
3. Informed consent is cited on women's medical records as being sought and given when it was not sought or given. This can be particularly devastating emotionally when women are requesting their notes to understand why their repeated refusal of a procedure was not heard.
4. Informed consent is particularly difficult to obtain with respect to medical induction. This is an area that women and pregnant people consistently report not receiving informed consent, not being able to make an informed refusal and in many cases feeling coerced and forced into the procedure. Women regularly cite that they are being frightened into the procedure by being told in no uncertain terms that their babies will die if they do not comply. Coercion is a serious form of gender violence against women.
5. Women report very little autonomy and support for informed refusals. Guidelines for informed consent and informed refusal in pregnancy are contained within the HSE's National Consent Policy,[5] but women frequently report these are often not adhered to.

[3] https://www.makebirthbetter.org/blog/what-does-violence-mean-in-obstetric-violence

[4] Keilthy, P., McAvoy, H. and Keating, T. (2015) Consultation on the development of a National Maternity Strategy. Institute of Public Health; Dublin, Ireland.

[5] HSE National Consent Policy: Section 7.10 Refusal of treatment in pregnancy p45

The consent of a service user is required for all health and social care interventions in pregnancy in accordance with Section 1.4 of this Policy. Section 1.4 Consent in Irish law p21

It is a basic rule at common law that consent must be obtained for medical examination, treatment, service or investigation. This is well established in Irish case law and ethical standards. The requirement for consent is also recognised in international and European human rights law and under the Irish Constitution.

6. Extreme forms of not recognising women's rights to make an informed refusal or to receive informed consent are apparent in court proceedings where healthcare workers seek High Court powers to force a procedure. For example, in 2016 a woman (Ms B) was taken to an emergency sitting of the High Court at 40 weeks gestation by her maternity hospital seeking powers to sedate her and then carry out a forced c section, as she had refused this procedure. Ms B won her case.

The AIMS Ireland "What Matters to You" survey (2014/5 n=2832), revealed that informed consent and informed refusal rates amongst respondents were both disappointingly low. Examples women cite within the maternity services of when the opportunity for informed consent or informed refusal is not given

•Due dates – medical personnel decide on which date is "the due date" even though women may know exactly when they conceived. A fixed due date will have implications for induction, which in turn has implications for maternal morbidity and the increased rate of c sections and increases the potential for birth trauma due to being "silenced" or "not heard".

•Induction – medical personnel decide on what date a woman must submit herself for induction even though she may not want to be induced. Induction "dates" vary between HCPs. Different HCPs in one hospital may have different limits on how far a woman can be "allowed" to go past her "due date". For example, in one large Dublin maternity hospital this can vary from term to 5 days to 7 days to 10 days to 12 days to 14 days to expectant management

•Sweeps – these are sometimes given routinely at the HCP's discretion without informing the woman that such an intimate procedure is being undertaken. Women may have consented to an internal examination (a diagnostic procedure), but not to a sweep (an inductive tool). Many women report that they only found out by reading their notes that they had been given a sweep. This huge physical and emotional violation again has consequences for postnatal well being

•AROM (Artificial Rupture of Membranes) Women report feeling pressurised into having this procedure because their labours are not keeping up with the clock. This procedure carries risks not often discussed with women before the procedure is agreed to or carried out. This was a procedure implicated in a case in Cavan where baby Conor Whelan died following a forced AROM against his mother's will rather than the c section she was begging for. "Whelan and her husband Andrew, from Ballyjamesduff, said their son died after her membranes were ruptured against her will and following a delay in carrying out the section". [6]

•Active Management of labour – is often carried out routinely in many hospitals and women who do not want to avail of it find that negotiating a refusal can be very difficult.

•Use of EFM (Electronic Foetal Monitoring) - the use of EFM / CTGs has been investigated by a Cochrane review and the review found that even for high-risk women CTGs have not yet been shown to improve outcomes for mothers or babies. The National Obstetric Guidelines for Ireland also state that there is no evidence to support a 20-minute admissions trace, yet many women report that it is very difficult to refuse EFM in Irish Maternity hospitals.

•Use of syntocinin – there are known risks associated with the use of syntocinin both for mother and baby, yet women report that it's very difficult to refuse this drug in a hospital setting. Syntocinin has been implicated in over stimulation of the uterus and in disorganisation of baby behaviours in the first hours following birth. It impacts initiation of breastfeeding and also mother baby bonding.

•Maternal position during labour and birth – all the evidence shows that labours in which women mobilise and do not adopt a supine position are faster and easier for women, yet many women report that they have to adopt positions that suit the care provider whether it's to facilitate the HCP's preference or whether it's to facilitate technology the HCP wants to use

Examples reported to AIMSI include the following:

"In the hospital and with the doctor unless I refused the procedure it was assumed that I would go ahead with it. I was told that it was happening, not asked if I wanted it to happen."

"The tests they did were as far as I was told compulsory and results were just told to me and options were not discussed it was their way is best. When we questioned it we were told we were putting our babies life in danger."

"I felt that I could not say no to anything. ."

[6] http://www.irishtimes.com/news/crime-and-law/courts/coroner-s-court/inquest-into-death-of-cavan-baby-finds-medical-misadventure-1.2799705

"I refused plenty, but they weren't put as questions. Statements like "we're just going to" or "ok, so now we'll" had to be responded to quickly with a NO, you won't, and that wasn't always "heard". Lack of informed consent in maternity care forms a part of gender based violence and as such should be included in CA Recommendation 37.

4. Choice in maternity care

One of the major issues underpinning the obstetric violence experienced by so many women and pregnant people in Ireland in their maternity care journey is that 99% of women and pregnant people are essentially forced to go into care settings that are facility-based and not community based, not because there is no other choice.

This complete lack of investment in community-based settings has without a doubt also contributed to the damaging and severe restrictions placed on users of maternity care during the Covid 19 pandemic. Large birthing facility-based care settings in busy General Hospitals are not solely women and pregnancy centred; they are focused on a wide variety of acute and chronic care. Therefore, the same general visiting rules were applied to pregnant labouring and birthing people as were applied to any other patients. Partners became "visitors" rather than and integral component in maternity care and maternity based experience. More community-based settings could have reduced so much trauma, difficult experiences and infection concerns for the approximate 130,000 people who gave birth during the pandemic.

Women should have choice in the way maternity care is received. In Ireland, despite the recommendations of[7] the National Maternity Strategy, women continue to have extremely limited choices in terms of the care providers and of their care settings. Ireland has a safe maternity care system, but a maternity care system that is heavily focused around medicalisation of childbirth. Our rates of C birth and medical induction have soared over the last years; in and of itself considered a factor in obstetric violence.

The rate for First Time mothers giving birth by caesarean (January – November 2021) in Ireland is available by individually dissecting the 19 Maternity Safety Statements month by month. It is not possible to see all of the data on one website or to make direct easy comparisons. Some units have not complied for months in the publication of these statements and others are impossible to find. well over 40% in many units (Galway 43.1%, Sligo 42%, Portuncula 47.1%, CUMH 41.7%), the rate of medical induction for first time mothers in Ireland over the same time period is also well over 40% in many units (CUMH 46.8%, Letterkenny 47.7%, Mayo 42.6%, Mulingar 41.4%, Limerick 42.4%, Portlaoise 44.8%, Waterford 43%, Tipperary 41%). In 1985, The World Health Organisation suggested that a caesarean section rate of over 15% would indicate an overuse of the procedure, and a rate of less than this an under use of the procedure. As rates continue to rise world-wide the WHO has put in place a variety of tools to try and reduce these rates.[8] [9] The overuse of these types of interventions, when combined with lack of informed consent, or worse again coercion can leave women feeling traumatised after their childbirth experiences.

Medicalised childbirth has its place in maternity care, but here in Ireland there are very few other choices. There are very few autonomous midwifery care options, and very few options for low risk women (the majority of people entering our maternity services). There are no birth centres, so common in many other European countries and a very limited home birth service. All women irrespective of where they live should have access to the three pathways of care identified in our National Maternity Strategy; supported assisted and specialised in the three different settings outlined in the strategy; namely at home, at an alongside birth centre and at a specialised unit. Specialised obstetric care exists in all of our units but there are only two alongside midwifery led units in Ireland[10] and only one hospital routinely offering a robust homebirth service. This situation has been ongoing for several years with no resolution in sight. Women in Ireland continue to have minimal choices in their maternity care, which leaves us out of line with other European countries.

[7] https://www.hse.ie/eng/services/list/3/maternity/mpss/

[8] https://www.who.int/reproductivehealth/guidance-to-reduce-unnecessary-caesarean-sections/en/

[9] https://www.who.int/news/item/16-06-2021-caesarean-section-rates-continue-to-rise-amid-growing-inequalities-in-access

[10] The MLU at Cavan and the MLU at OLOL, Drogheda

Midwifery care in community-based settings can truly be women and family centred and are associated with fewer episodes of reported obstetric violence. In the recent Maternity Care Experience Survey, the service that received the highest rating in all categories questioned was the National Homebirth Service.[11] Yet this service only caters for less than 1% of the births in Ireland, and despite promises in the National Maternity Strategy has not been expanded or extended in any significant way. Recommending care options that result in less obstetric violence would come under CA recommendation 37 and be part of a coordinated government approach.

5. Perinatal Mental Health

Outcomes and safety of maternity care are generally measured in terms of physical mortality.[12] The experience of giving birth is both physical and emotional and we feel that women's emotional wellbeing also needs to be evaluated and addressed in terms of safety outcomes and data pertaining to these issues should be regularly gathered and reviewed. The lack of service provision in this area remains particularly under resourced, yet admittedly conservative figures show antenatal depression and anxiety at rates of 17-18% and postnatal depression at 18-19%,[13] with birth trauma estimated at 8,000 survivors a year in Ireland[14] and PTSD rates estimated at between 4 and 6% in general. Whilst there are current plans to invest in specialist mental health services, women with sub-clinical conditions such as depression or anxiety will not be covered under these plans. We would see the need for improved provision for women's health in this area as vital.

Provision should include services for women who have experienced birth trauma, postnatal depression, postnatal anxiety, loss, postnatal traumatic stress disorder and other psychological and psychiatric conditions. These services should be free and part of the referral pathway in the postnatal period. Currently women are mostly paying for services to help them recover from traumatic experiences, the emotions surrounding loss and also generalised anxiety and depression. Some acute services are provided without charge by charities such as Féileacáin[15]. This could be part of CA Recommendation 39d, 38b and 40.

6. Postnatal Support

Freely accessible services for women who experience physical as well as mental and emotional challenges following childbirth. The most important of these would be psychological support, breastfeeding support and physiotherapy support. At present women who are having emotional or mental health difficulties are paying for their postnatal support services and women who are tyring to breastfeed and experiencing challenges are also paying for their services. This could align with CA Recommendation 38b and 40.

7. Breastfeeding for women's lifelong health

As part of improving the delivery of informed consent, more information needs to be given to women of the health benefits to themselves of breastfeeding. Women report to us that firstly the focus on breastmilk, second the focus is on the benefits to the baby. Very little is ever cited about the risks of not breastfeeding for the baby or for the mother. For example, recent research has shown that any breastfeeding reduces fatal cardiovascular disease by 17% in women, stokes by 12% and any cardiovascular episode by 14%.[16] Breastfeeding and its implication for women's health is a gender-based issue that receives very little attention in our maternity services. This could perhaps align with CA Recommendation 37.

8. Education

In our original 2007 manifesto, AIMSI campaigned for the concepts of informed consent and birth and breastfeeding as normal physiological events to be included in the SPHE curriculum. It is important that young people learn and understand that informed consent relates to maternity care. We reiterate that point here

[11] https://yourexperience.ie/wp-content/uploads/2020/09/National-Maternity-Experience-Survey-results.pdf
[12] https://www.britishjournalofmidwifery.com/content/other/birth-trauma-the-mediating-effects-of-perceived-support
[13] https://www.sciencedirect.com/science/article/pii/S0266613820301352
[14] https://nurturehealth.ie/
[15] https://feileacain.ie/
[16] https://www.sciencedaily.com/releases/2022/01/220111091356.htm

and suggest that this aspect is added to other Citizen Assembly recommendations surrounding education. This would align with CA Recommendation 38.

9. The formal recognition of birth rights as human rights

This is especially important for those taking cases involving obstetric violence in Ireland, especially the overriding of informed consent during maternity care. Important public cases include The Ciara Hamilton Case in Kerry, Mother A[17] case in Waterford and the Ms B[18] case in Cavan. In the case of Ciara Hamilton, she claimed she did not receive informed consent for the rupturing of her membranes, although she did consent to having an internal examination. An internal examination is a diagnostic procedure that does not include artificial rupture of membranes. That is an entirely separate procedure requiring full informed consent (one of the potential side effects is cord prolapse which can be life threatening). The internal examination was performed and then without informed consent an AROM was performed, and a cord prolapse ensued. In summing up of the legal case, the judge stated that that Ciara Hamilton positioned herself in such a way as to consent to an AROM. She consented to the vaginal examination and moved down the bed.[19] Is this really so different from the "short skirt" wearing argument? The judge also ruled that Ms Hamilton pay costs.[20] This was viewed by many as a punitive action to discourage other women from taking cases involving lack of consent in the Irish Maternity Services. We would see a survivors' commissioner as having an important role in cases such as these as per the CA Recommendation 39 and in particular 39b and e.

10. Inequity of maternity care provision

Women in Ireland are not offered equal access to maternity care. Some areas are better served than others. It is not acceptable that people receive better services because they have a particular eircode. Other accessibility issues include the capacity to pay. This is particularly true for private homebirth services and private obstetric services. Being in a particular socioeconomic cohort also enables a greater access to services such as fertility services. Ireland is currently the only country in Europe that does not offer women free fertility care. The result is that fertility treatments such as Artificial Insemination and IVF are paid services and marks them as beyond the reach of all women. Other geographic issues include the provision of abortion care; currently there is no abortion provision in Sligo and only 1 in 10 GPs and only just over half of our 19 maternity units are currently providing an abortion service. The access to abortion services is compounded for women from ethnic minority groups and marginalised communities. The access to culturally sensitive care continues to remain a challenge for many women. This would come under the CA Recommendation 37.

11. Data gathering on key maternity issues

We need more transparent and consistent data gathering and a more transparent complaints process. Currently the only timely access that women and researchers have to maternity data comes in the form of the Maternity Safety Statements, but these are not consistently gathered by all units and many units have made very limited entries for 2021. Larger maternity units do not offer the data on the HSE's main site, preferring to embed the data on their own hospital website, other units are simply impossible to find. It is worth noting that when this data reporting mechanism was initiated, there was severe resistance from the maternity hospitals to provide it. We need data performance indicators that will help us to provide a better maternity service for women and pregnant people. We would also like to see a more robust maternity complaints procedure and process which women feel they can access and be truly heard. This aligns with CA Recommendation 43.

12. Terminology

We would like to recommend that the terms "women" and also "pregnant people" be used when referring to users of the maternity services.

[17] https://www.independent.ie/irish-news/courts/hospital-sought-court-order-to-force-mother-to-have-c-section-29120379.html#:~:text=DOCTORS%20safely%20delivered%20a%20baby,co%2Doperate%20with%20medical%20staff.

[18] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5907905/

[19] https://feministire.com/2015/04/

[20] https://ie.vlex.com/vid/ciara-hamilton-v-health-793856465