AIMS Ireland Response to the Citizens' Assembly: Article 40.3.3 in the Delivery Room

AIMS Ireland in December 2016 submitted a factual, evidenced, and referenced submission to the Citizens' Assembly. This submission was based on legislation, primary and secondary research, and the personal experiences of women supported by AIMS Ireland who were directly affected by the 8th Amendment, ranging from coercion to threats of the involvement of the HSE, child protective services, or the initiation of legal proceedings in the High Court.

In that document AIMS Ireland made submissions on the operation of the 8th Amendment to the Constitution (Article 40.3.3°) in continued pregnancy with respect in particular to the following areas:

1. Women Experiencing Miscarriage or a Pregnancy with a Diagnosis of Fatal Foetal Abnormality (citing *X v Attorney General* [1992] IESC 1; *A, B, and C v Ireland* (2011) 53 EHRR 13; and the tragic cases of Savita Halappanavar, Malak Thawley, and the woman known as Miss Y)
2. Respect for Informed Consent and Informed Refusal (citing § 7.7.1 of the Health Service Executive's National Consent Policy QPSD-D-026-1.1 V 1.1, May 2016; the case of *HSE v Mother A* in March 2013; *HSE v B & Anor* [2016] IEHC 605; AIMS Ireland's What Matters To You? Survey in 2014; and *Hamilton v HSE* [2014] IEHC 393)
3. Capacity and advance directives (citing the Assisted Decision Making (Capacity) Act 2015 and *P.P. v Health Service Executive* [2014] IEHC 622)

During proceedings in the Citizens' Assembly on Saturday, March 4th 2017, a member of the Assembly asked if there is scope for abuse of Article 40.3.3º in the delivery room, where procedures take place without women's consent. The response, from the Chair Ms Justice Laffoy, was that the legal opinion is that there is no such scope and that if this were to occur it would be a question of medical negligence.

AIMS Ireland were not asked to present to the Citizens' Assembly. We wish to take this opportunity, as an organisation consisting of and representing women/people accessing

care in the Irish maternity services, to outline the very real and substantial issues arising as a result of and as a consequence of the 8th Amendment functioning in practice as a barrier to consent in continued pregnancy and childbirth. It is our firm belief that the 8th Amendment prevents the successful litigation of these abuses of the rights of women and people accessing maternity care in Ireland; both because of the legal ambiguity it creates in our legal system around rights in maternity care, and also because of the necessary tension it establishes in Irish law between the rights of the mother and of the unborn.

The video of the query from the CA member and the answer from Emily Egan, SC (first) and Ms Justice Laffoy (second – as paraphrased above) can be viewed at this link, at 02:43 mins: https://www.youtube.com/watch?v=hEknurI2FH0

Overview

The 8th Amendment hangs like a spectre over reproductive rights in Ireland. Reproductive rights, maternal health, and the provision of maternity services, are inherently interlinked. As a nation, our reporting and collection of data is patchy. We do not have standardised care. Guidelines created to reflect best clinical practice are not implemented at local level and individual maternity units are under no obligation to do so. We barely have accurate, specific, and detailed data on birth and interventions, and we have no data collected on perinatal mental health. Regional variations in practice significantly affect rates of interventions, near misses, and adverse outcomes. As a result, it is impossible to have an accurate grasp of the scope that the 8th Amendment has in the maternity services.

The Citizens' Assembly requested data and facts on how the 8th Amendment has a direct legal impact on maternity care. For the foregoing reasons, the only way to access this impact is to listen to, to hear, and to trust the testimonies of women who have been personally affected in their pregnancies and births. We must also listen to and hear the medical professionals when they tell us that they do not feel protected in law to support a woman's decisions.

No one records in medical notes when they use the 8th Amendment, as outlined in §7.7.1 of the National Consent Policy, to justify a procedure or intervention. In the handful of legal cases where the 8th Amendment and refusal of consent were pleaded in High Court proceedings, and where the issue is addressed at judgment, the jurisprudence is frequently vague on the 8th and the legal implications it has on maternity services. The 8th Amendment itself is ambiguous and that is exactly the concern which was argued by legal experts in 1983. It is was legally ambiguous then and it is still legally ambiguous today.

The National Consent Policy, the 8th Amendment, and Continued Pregnancy and Childbirth

The right to informed decision making – both the giving of consent and the refusal of it – in in one's health care is recognised and protected in Irish policy, law, and the Constitution. Informed consent is a cornerstone of medical ethical standards, as well as a key principal of bodily integrity. However, the National Consent Policy directly recognises and cites the 8th Amendment to the Constitution as a barrier to informed consent in continued pregnancy and childbirth, recommending the High Court as the appropriate arbiter where a woman's decisions in continued pregnancy go against the recommendations of a health care provider.

Every individual in Ireland has the right to bodily autonomy, to be the main decision maker in their health care, to control their own life, and to decide what happens to their own body. This includes making informed decisions – to consent to or to refuse treatment – which will have an impact on their current health, as well as any short or long-term consequences for the individual to consider. Health care providers are expected to present all the information pertaining to the procedure in layman's terms (the benefits, risks, and any future implications) in order to provide guidance to informed decision making; however, the decision is ultimately that of the individual. Finally, for consent to be valid, it must be also be voluntary, meaning that it is given without the application of duress or coercion (whether that be by way of threats or intimidation) from health care providers or external agents. These central principles are outlined in §1 of the National Consent Policy:

> Consent is the giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication about the proposed intervention. Consent must be obtained before starting treatment or investigation, or providing personal or social care for a service user or involving a service user in teaching and research (all defined as 'interventions' for the purpose of this policy). This requirement is consistent with fundamental ethical principles, with good practice in communication and decision-making and with national health and social care policy. The need for consent is also recognised in Irish and international law.

Furthermore, § 1.4 states that "Other than in exceptional circumstances, it is important to note that treating service users without their consent is a violation of their legal and constitutional rights."

The right to refuse consent to a proposed treatment is dealt with in § 7. The Policy states at § 7.7 that "If an adult with capacity to make an informed decision makes a voluntary and appropriately informed decision to refuse treatment or service, this decision must be respected, even where the service user's decision may result in his or her death." However, the Policy is forced, because of the operation of the 8th Amendment, to dedicate an entire section - § 7.7.1 – to the limitations on the rights of pregnant people around consent to treatment. The constitutional constraints of Article 40.3.3° mean that equal rights must be given to the pregnant person and to the unborn. In other words, informed decision making ability in pregnancy – the right for individuals to make the best decisions for them and their baby in their specific circumstances in pregnancy and childbirth – has been removed.

The operation in practice of § 7.7.1 of the National Consent Policy is as ambiguous as Article 40.3.3 itself. § 7.7.1 cites risk as the yardstick by which the decision to overrule a woman's refusal to consent to treatment is to be measured, but it fails to define risk or what constitutes risk or 'risk to life' of the unborn. This leaves interpretation open to opinion and bias, and leaves pregnant people and health care providers in an unacceptable state of limbo. The definition of risk within the Policy is subjective, and the assessment of risk and whether it is significant enough to justify overruling a refusal of consent requires a health care provider to balance the probability of harm to the unborn against the risk of harm to or the burden placed on the woman by the refused treatment. No guidance is given as to how

the threshold between a risk to health and a risk to life is to assessed, and there is no recognition of the practical reality that there are in fact no absolute guarantees in childbirth.

In practice the use of 'risk' by health care providers is often cited as an indication to over-ride the right to informed decision making (consent/refusal) in pregnancy, labour, and childbirth. The National Consent Policy of Ireland addresses the issue of risk in § 3.3:

> Information about risk should be given in a balanced way. Service users may understand information about risk differently from those providing health and social care. This is particularly true when using descriptive terms such as 'often' or 'uncommon'. Potential biases related to how risks are 'framed' are important; a 1 in a thousand risk to complication also means that 999 out of a thousand service users will not experience that complication.

AIMS Ireland have documented significant accounts of women reporting the use of 'risk' coupled with the National Consent Policy as a barrier to informed decision making. 'Risk' is often based on the perception of individual health care providers and without supportive evidence. Pregnant women are often told of the risks they are exposed to in refusal of medical recommendations, but often they do not receive explanations of the risk factors inherent in having the procedure, test, or treatment. Many routine practices in Irish maternity units which are recommended by health care providers carry risk factors and do not follow evidence based practice recommendations.

There are no absolute risks in childbirth and each care option poses specific, individual risk potential. Truly informed choice occurs where a woman receives the information that enables them to understand the benefits and risks of each care option, so that she can then select the care option that she feels most comfortable with.

Furthermore, the National Consent Policy suggests that the 8th Amendment impacts only on refusals of consent to treatment, and not on the giving of consent to treatment. Such a position is nonsensical. Refusal of a medical procedure is not separate to, but is an equal facet of the principles encompassing consent. One cannot consent while being unable to refuse. If a person's ability to refuse consent is constrained then so is their ability to give consent. Consent given in the absence of an ability to refuse is not truly free and voluntary.

For consent to be valid by legal definition, it must be voluntary, provided freely, without duress (*Fitzpatrick & Anor v K & Anor* [2008] IEHC 104).

The ambiguity of the National Consent Policy is further compounded in its failure to provide scope for clarification on exactly when and how the High Court may be considered the appropriate pathway for assessing the validity of a woman's decision to decline a medical recommendation.

In our ten years' experience supporting women accessing maternity care in Ireland, AIMS Ireland has seen patterns emerge in reports of regions', units', and even individual health care providers' use of coercion to achieve women's compliance with a proposed treatment. Certain maternity units, and even individual health care providers, are named with more frequency than others by women who appeal to AIMS Ireland for help when they feel they are being coerced into accepting a particular proposed treatment or procedure. This coercion takes various forms, from the use of threatening language including the threat of the mother being found responsible for harm coming to the unborn child; to threats of the involvement of child protective services; threats of High Court litigation; and the involvement of legal teams. AIMS Ireland's support services have assisted individuals who have been threatened with legal action and social protective services in an attempt to coerce consent. The majority of these threats are never carried out, as women are fearful of the implications and comply under duress.

Differentiating between (a) Medical Negligence and (b) Consent Violations that Occur as a Consequence of Constitutional Constraints

It is important to differentiate between the law of medical negligence, the law of consent as it operates within the tort of assault, and the question of the validity of a consent that is given under duress that has been leveraged as a consequence of the operation in practice of the 8th Amendment.

The law of medical negligence is comprised of four core principles:

1. A medical practitioner has a duty of care towards a patient;
2. A medical practitioner breaches that duty of care by acting in a manner that falls below the expected standard of their profession;
3. This breach of the duty of care must directly cause damage to the patient, which may be psychological or physical in nature; and
4. The damage suffered by the patient must be the result of the breach of the duty of care (this is known as the 'causal connection').

The idea of consent is comprised of two complimentary facets: (1) the ability to make a decision to have a particular test, treatment or procedure; and (2) the ability to make a decision to decline a particular test, treatment or procedure. Consent actions are often tied in with medical negligence actions but are in fact a cause of action in their own right under the tort of assault. It would not be unusual for a lawsuit that includes a claim for assault that is based on a breach of the rules on informed consent to also seek relief in the tort of negligence. One may succeed in the medical negligence action in the case, and fail in the assault action. In its legal incarnation, the doctrine of consent has three key components:

1. The patient must have capacity to give or to refuse consent – meaning they must have the ability, at the moment the decision is being made, to understand the 'nature, purpose and effects' of the proposed test, treatment or procedure;
2. The patient's decision must be voluntary – meaning it must be given freely, in the absence of coercion or duress; and
3. The patient must have received appropriate information regarding the risks and benefits of the proposed test, treatment or procedure (this is known as 'full disclosure').

Finally, to succeed in an assault action based on the absence of a valid consent to the treatment administered, the plaintiff will also need to establish (a) that she suffered damage and (b) that she would not have gone ahead with the procedure if she had been advised properly of the risk which has caused the damage. The fact that any litigation on consent will necessarily involve drafting medical negligence pleadings does not negate the fact that the culture around the provision of maternity care in this country is soaked from beginning to end in an atmosphere of subtle coercion, and that culture arises from the legal uncertainty health care providers have to work in due to the ambiguity of their responsibilities and obligations to the foetus under the 8th Amendment. These responsibilities are, because of the way the 8th is drafted, in direct opposition to and in conflict with their responsibilities to the pregnant woman.

AIMS Ireland have supported many women who report experiencing assault on their bodies in the Irish maternity services. Often these assaults take place when medical interventions

are administered which do not follow best practice evidence which carry independent risks of morbidity. It is our experience that these women are advised, both when they seek legal advice and in the making of complaints to the relevant professional regulatory bodies, that it is the woman's word against the medical professional, and that success is unlikely. Women seeking to litigate assault cases founded on violations of consent in pregnancy and childbirth are generally counselled against taking proceedings. A woman's body being violated is often not enough to build a successful legal case where there is no loss of life or long-term implications on health. The presumption of a risk to the unborn having operated as a medical indicator to justify the intervention is always present and overrides the woman's refusal.

Medical records rarely self-implicate. Medical professionals do not record consent violations implicating themselves, their colleagues, and their place of work. This means both that an assault action based on a breach of the doctrine of informed consent is notoriously difficult to successfully litigate, but also that there simply does not exist data in medical records illuminating the use of the 8th Amendment in this manner.

The case of *Hamilton v HSE* [2014] IEHC 393 was an assault case founded on the principle of informed consent, which also contained a consequence action of medical negligence. Ciara Hamilton took legal action against the HSE on the basis of an invasive medical intervention which she argued was performed without her consent. This intervention contributed to long-term health issues for her baby. The High Court found against her, stating in the judgment that it did not believe a woman would deny a medical intervention recommended by a health care professional. As the consent argument had failed, the consequence medical negligence action then also failed and a costs order was made against Ms Hamilton.

In Ireland informed choice for women on 'how, where and with whom' they want to give birth is also prohibited by the HSE's structure of maternity services provision. For many women the only care option available to them – for geographic, financial, and HSE policy reasons – is hospital care. Hospital care in Ireland is obstetric led in practice and policy and includes many routine interventions which increase distress to babies in labour and increase the risk of adverse affects for women – in the form of intervention, assisted delivery, or

caesarean section. When a practice is said to be ‘routine’ this means that the practice or procedure is done as a normal practice on every pregnant person, not down to medical necessity or evidence, but hospital policy. Other practices may not be routine for every woman, but are frequent in use despite risks. For example recent research by the American College of Obstetrics & Gynecology has shown the use of oxytocin, for induction of labour or to 'speed up' labour, is an independent risk to babies and increases NICU admission.

Furthermore, best practice clearly states that patients should be assessed on an individual basis on their current health and current medical conditions, as well as their previous history. The HSE in maternity care does not provide women with individual assessment, which is a fundamental principle in evidence-based care. Women in Ireland are given extremely restricted choice around their birth options as the perceived risks to the baby are considered more important than women having control over how they give birth.

What Women Have Told Us

In the 2014 AIMS Ireland survey, "What Matters to You?" we looked specifically at the issue of consent. The WMTY survey had nearly 3,000 respondents who were self selecting. Our findings illustrated that informed consent and refusal remain an issue of grave concern to women accessing the Irish maternity services, with only 50% of individuals being provided with the necessary information to assist them in informed decision making. The qualitative data, comments from individuals, provide us with very worrying information as many commented that consent was either implied as the procedure was being carried out (e.g. a health care practitioner informing a woman “we are just going to break your waters now” as rupture of membranes was being performed); or that they felt coerced by hospital policy or a perceived risk to their baby; or influenced by care providers’ opinion that was not based on evidence; or that they were not provided with the information necessary to make decisions for themselves and their baby. Some respondents felt that while they consented, they did not have any choice in doing so.

This is a selection of the comments received from women who responded to the WMTY survey:

> "At every intervention I was threatened with catastrophic consequences if I refused such as 'if you don't have an episiotomy right now the baby won't make it'…'if you don't take antibiotics the baby might have cerebral palsy'"
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> "I was told I had no choice when it came to my treatment, everything was 'hospital policy'"
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> "Benefits of procedures to hurry Labour up were told, risks of these procedures were not told. Benefits of waiting were never once told."
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> "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 there way is best. When we questioned it we were told we were putting our babies life in danger."
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> "At every intervention I was threatened with catostrophic consequences if I refused such as 'if you don't have an episiotomy right now the baby won't make it'… 'if you don't take the antibiotics the baby might have cerebral palsy"
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> "I was given an episiotomy without being asked. I wasn't even informed that the consultant was going to do one it was just done"
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> "They broke my waters without consent. I was told by the consultant that she did not need my permission to break my waters."
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> "Nothing was done without my 'consent' but is it consent when you are bullied into it… as how do you get round the 'put the baby at risk' card even if you know that what you are asking is in line with best practice?"
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> "The following procedures were performed on me without explanation or my consent being sought: ARM, pushing back a cervical lip, a CTG machine was applied to me and when I asked for it to be removed this was refused. My attempts to remove it myself were prevented. I was physically restrained in a position I was not comfortable in (flat on my back) and verbally abused when I did not engage in purple pushing"

The full results from the WMTY survey are available on the AIMS Ireland website at the following link: http://aimsireland.ie/what-matters-to-you-survey-2015/

Conclusion

AIMS Ireland strongly campaigns for recognition of informed choice in maternity care. The decisions we, as pregnant women, as people, make in pregnancy, labour, and birth have serious consequences; for the pregnant individual, for their baby in both short and long-term health and quality of life, and for future pregnancies and births. It is their body; their pregnancy; their baby; their birth. The pregnant person is the best expert on them; their baby; and their circumstances. Only they know what they are feeling and what is important to them. They must be the ones making decisions which will affect them and their baby. They must live with and be happy in the decisions they make. They should be the one to decide 'how', 'where' and 'with whom' they give birth. They should not be asked to give these important decisions away. Medical experts can guide, assist with informed decision making, but they cannot and should not make decisions on the behalf of a pregnant individual. However the 8th Amendment is often used as a method of coercion by the HSE and individual health care providers to obtain consent through coercion.

AIMS Ireland supports pregnant women and other pregnant people. From pre-conception to parenthood, we support a person's right to informed decision making and freedom to informed consent/refusal as is outlined and protected to all other non-pregnant people in Ireland. The 8th Amendment acts as a legal barrier to informed decision making in pregnancy, labour, and childbirth and is directly cited within HSE policy as a constraint on the ability of individuals to invoke this right. The 8th Amendment must be repealed to ensure human rights are ensured in pregnancy.

About AIMS Ireland

AIMS Ireland (Association for Improvements in the Maternity Services Ireland) is a voluntary organisation with charity status which was formed in 2007 by women who saw a need for a consumer driven organisation to support pregnant people's human right to informed decision making in all aspects of health; from pre-conception to parenthood and to push for the full implementation of maternity care standards reflecting evidence based best practice across Ireland. It is a consumer led, campaign pressure group operating with a self-regulating committee elect and a body of members. AIMS Ireland members in 2013

unanimously passed a motion to support Repeal of the 8th Amendment and in 2016 to adopt the position of supporting access to free, safe, and legal abortion services in order to support pregnant people in their right to informed choice in their unique and specific circumstances.