Association for Improvements in Maternity Services Ireland (AIMSI)
Email: support@aimsireland.com Website: www.aimsireland.com

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EXECUTIVE SUMMARY

Introduction: Information About AIMS Ireland

AIMSI was founded in 2007 and its mission is to promote normal birth by promoting best international practice guidelines and the use of evidence-based research in maternity care settings. We lobby on behalf of pregnant women as well as provide information and support to women. The majority of women contacting AIMSI are looking for support in relation to traumatic birth experiences, many of whom complain of feeling undermined or not listened to during pregnancy, labour and birth. Recurring issues are: lack of informed consent and informed refusal.

Background and Main Issues

1. **Maternal Death in Ireland –** Ireland is not the "safest place in the world to give birth". The recently published *Confidential Maternal Death Enquiry Report 2009-2011* outlines the inconsistencies in criteria for reporting maternal deaths in Ireland compared to the UK and many other countries. Ireland's maternal mortality rate is much higher than previously thought once data collection has been controlled in an empirically accurate and robust manner. Figures show a jump from 4 /100,000 to 8/100,000 once the proper criteria are used to collect maternal death statistics.
2. **WHO Guidelines for Maternal and Reproductive Health –** Maternity services in Ireland should be in line with what is expected internationally as best practice, such as the WHO guidelines in reproductive and sexual health. These include recently published guidelines called: *Safe Abortion: technical and policy guidance for health systems* (2nd Ed)
3. **Abortion in Historical Context –** The history of abortion can be traced back more than 3500 years with the earliest medical accounts being recorded on the Ebers Papyrus in Egypt in 1550 BC. These papers recount stories of women using potent herbs and abortifacients for unintended pregnancies.
4. **Conflict Between Article 40.3.3, the 8th Amendment and Women's Rights -** When legal restrictions and moral guidelines are put in place to limit a woman's choice to terminate a pregnancy, current legislation makes it very difficult to delineate where a risk to a mother's health ends and a risk to her like begins. From a human rights perspective this can often be misconstrued or misdiagnosed to assert 'foetal supremacy'. This legal grey area was discussed as problematic by notable Attorney Generals in Ireland over 30 years ago. Multiple human rights instruments support a women's right to health and life as paramount, in addition to her right to equality and reproductive self-determination.
5. **Women's Right to Health in a Global Context: European and International –** The *International Covenant on Economic, Social and Cultural Rights (ICESCR), European Convention on Human Rights (ECHR)* and the *European Social Charter (ESC)* all guarantee women the legal right to the highest attainable standard of physical and mental health and equal rights between men and women. The ECHR Court judges unanimously found that Ireland had violated the Convention in regard to article 8 and had failed in providing clear legislation in reference to the X case, where abortion is deemed legal if there is a "real and substantial risk to the life of the mother" (as per Article 40.3.3 of the Irish Constitution). The outcome of the *A,B and C v. Ireland* case has been described as a landmark ruling by the judges in the European Court of Human Rights as it indicated a victory for women in regards to their rights to health,

equality and privacy. But the victory exists only on paper as there continues to be a delay in implementing any clear legislation or guidelines in relation to the European Court ruling.

Principles in the Expert Group Report

The *Report of the Expert Group* sets out four general principles that should apply to the implementation of the European Court of Human Rights judgment and cautions that "the measures that are introduced to give effect to this existing constitutional right should not act as obstacles to any woman who is legitimately entitled to seek a termination on lawful grounds" (DOHC, 2012, p.27). These principles outline the entitlement to lawful medical treatment as well as recommending that "once a clinical decision has been made as to appropriate treatment, it remains a matter for the patient to give informed consent" (DOHC, 2012, p.29). AIMSI has provided support to thousands of women and a recurring difficulty women experience in maternity services is the lack of informed consent. It is often the case that women are not listened to which can make for an extremely traumatic birth or, more tragically, can be a cause of maternal death. Recent cases of maternal death, where the hospital has allegedly or admittedly failed in their duty of care, include that of Savita Halappanavar, Tanya McCabe and Bimbo Onanagu.

Human Rights Issues in Maternity Care and Mental Health

1. **A Comprehensive Mental Health Service –** The DOHC document *A Vision for Change* outlines the need for a perinatal and postnatal mental health service and posits that "women are at peak risk of having mental illness in the perinatal period, contrary to commonly held beliefs that this is a wholly healthy time in a woman's life".
2. **Reducing Stigma -** It is imperative that legislation changes regarding abortion correspond with a change in attitude toward mental health difficulties. In addition to feelings of stigma and shame, there is an overlap in terms of treatment of mental health service users and women in maternity care settings in that both groups are often believed to be lacking in insight and both groups have a history of undergoing treatment without proper information or informed consent.
3. **Informed Consent -** AIMSI research found that over 75% of respondents stated that they felt consent is an issue of concern in the Irish maternity system, and almost 60% said they were not given the option to refuse a procedure, test or treatment. There is compelling evidence that policy changes in relation to women's rights and reproductive health in developed countries are not only necessary but also expected.

Irish Women's Right to Reproductive and Sexual Health – Removal of Barriers

A recent UN Human Rights Council report called the *Right of everyone to the enjoyment of the highest attainable standard of physical and mental health* is seen as a milestone in the area of rights to reproductive and sexual health as it plainly articulates the reasons why legal restrictions in this area constitute a violation of a woman's right to health and an "unjustifiable form of State-sanctioned coercion" (UN, 2011, p. 5). The report is disparaging of the human rights violations that are perpetuated in the few remaining countries, such as Ireland, where abortion is completely criminalised or where it is only allowed to save the life of a woman.

Conclusion

AIMSI believes that these domestic changes in attitudes combined with international human rights laws and policies uphold the need for the Irish government to introduce legislation that regulates access to the highest attainable standard of maternity care, including abortion, without interfering with a woman's right to life, health, privacy, freedom from cruel and inhumane treatment and non-discrimination

AIMS

Introduction: Information About AIMS Ireland

In 2007, the Association for Improvement in Maternity Services Ireland (AIMSI) was started by a group of mothers who were dissatisfied with the maternity care system in Ireland. The mission of AIMSI is to highlight normal birth and to promote mother-and-baby friendly birth practices that are supported by evidence-based research and international best practice. Improving the Irish maternity services includes many factors that rely heavily on a woman's right to make choices about her care in pregnancy and birth. For example, a woman should be allowed to choose where and how she gives birth in line with supportive scientific evidence and international best practice that is documented by the World Health Organisation (WHO). AIMSI would like to see *National Guidelines*, the annual publication of *Obstetrical Clinical Reports* and a clear *Charter of Patient's Rights in Maternity Services* among other changes that fully support a woman during her pregnancy, labour and birth.

While AIMSI lobbies on behalf of women, we also provide support and information to women. We receive hundreds of emails and phone calls annually to our voluntary Support & Information Officers. Many of these contacts tell a compelling story of being badly let down by the maternity care providers in Ireland. Most of these harrowing stories involve women being forced to undergo procedures and interventions, that are often unnecessary, without giving their informed consent or informed refusal. It is far too common for women to experience being operated on, rather than collaborated with, when it comes to their maternity care.

Background and Main Issues

1. Maternal Death in Ireland

In light of the untimely death of Savita Halappannavar and several other maternal deaths - 25 deaths according to the most accurate *Confidential Maternal Death Enquiry (MDE) Report 2009 - 2011* in Ireland - it is no longer suitable to declare Ireland "the safest place... in the whole world [to give birth]" (Conway, PJK in Oireachtas Committee on the Constitution, 2000, p. A143). In fact, our maternal mortality statistics are calculated differently to many other countries, including the UK. Ireland has been using the crudest definition of 'maternal mortality', thereby making our figures appear artificially low compared to our neighbours. The MDE Report uses a much more robust and valid method of collecting this empirical data and the latest report shows a marked increase in the maternal death rate from CSO figures of 4 per 100,000 to the MDE figure of 8 per 100,000. Out of the 25 deaths reported in the 3 years covered in the MDE report, we know that 2 were suicides and 6 were direct maternal deaths and we still await the outcome of the inquiries into Savita Halappanavar's death. In addition to these deaths there are 17 other unexplained, indirect or coincidental maternal deaths in the previous three years.

It may never be known which deaths were inevitable and which were avoidable. For example, the MDE report highlighted the need for "well publicised guidelines for the prevention and management [of] thromboembolic disease" (MDE Report, 2012, p.7) as this features prominently in the causes of maternal death. Additionally, the two suicides reported may have been avoidable if there had been sufficient and timely mental health support for pregnant women, in the same way that we may shortly discover whether a timely termination may have saved Savita Halappanavar's life. These deaths are all tragic and premature and leave a legion of families and close friends behind to mourn the loss of a woman who should be celebrating the birth of a new baby, but instead is no longer alive. Maternity services are obligated to improve and to offer much more to women in terms of securing their bodily integrity, their overall health and well-being and their basic human rights. As one newspaper headline recently stated: "We expect more from maternity services than women not dying" (Jones Dr. J., Irish Times, December 4, 2012).

2. WHO Guidelines for Maternal and Reproductive Health

What we expect from maternity services in Ireland should be in line with what is expected internationally as best practice. This reflects Minister James Reilly's statement released on December 18, 2012: "the Government is committed to ensuring that the safety of pregnant women in Ireland is maintained and strengthened. We must fulfill our duty of care towards them" (MerrionSt.ie). The WHO guidelines for maternal and reproductive health are the most widely used evidence-based research that support women's rights in pregnancy, labour and childbirth. These guidelines recommend the most effective intervention and treatment of the more common complications in maternity settings such as: hypertensive disorders of pregnancy, haemorrhage, placental anomalies and puerperal infection. The other guidelines that the WHO issued in 2012 were on *Safe Abortion: technical and policy guidance for health systems* (2nd Ed). While the guidelines are geared towards making abortion safer in developing countries, Ireland finds itself standing among these countries when it comes to the issue of supporting women's maternal, sexual and reproductive health.

3. Abortion in Historical Context

The history of unintended pregnancies and abortion dates back to ancient China, Egypt, Greece and Rome. Several artifacts, such as the earliest recorded medical accounts on the Ebers Papyrus (ca. 1550 BCE), suggest various methods of inducing abortions including ingesting potent herbs and using abortifacients (Riddle, 1994, p.69). It seems that as long as women have been having children, abortion has been part of this history. It is impossible to know what the reasons were for women of ancient Egypt or Rome for wanting to procure an abortion but it stands to reason that their choices were not entirely unrelated to the same issues women face today. For every woman, there is an individual thought process, involving her health and emotional well being, that is subjective and steeped in socio-cultural values that reflect her situation and her reality.

4. Conflict Between Article 40.3.3, the 8th Amendment and Women's Rights

AIMSI believes that taking a decision to terminate a pregnancy is one that should be made solely between a woman and her doctor. When legal restrictions and moral guidelines are put in place to limit a woman's choice, it makes it very difficult to delineate where a risk to a mother's health ends and a risk to her life begins. Does a woman whose health is deteriorating in a maternity hospital, due to prepartum haemorrage, have the law on her side? How does a medical team make a decision in this kind of urgent situation on what to do with regards to the foetus? The worry is that with article 40.3.3 still as a constitutional guideline in such matters (further complicated by sections 58 and 59 of the 1861 Offenses Against the Person Act), the woman's life is seen as equal to that of her unborn child. The risk to the mother may not only be one that involves her health, and her life, but it appears to also involve a legal grey area that is trying to define what her rights are as a human being versus the rights of the foetus (as described by such notable legal experts as Peter Sutherland SC, AG in 1981 and Patrick Connolly SC, AG in 1982 in the recently released 1981 amendment papers).

From a human rights perspective, the idea that a woman's life is equal to a foetus creates what Elizabeth Prochaska, human rights lawyer, calls 'foetal supremacy'. According to Prochaska, there is no basis in law for foetal supremacy. In fact, Prochaska strongly argues that "the questions being raised over abortion rights have a close relationship to a woman and her pregnancy [as] it is a woman's body and that's what makes human rights in childbirth some of the most fundamental human rights there are, because it involves choices a woman makes over her body" (Carpenter, L., The Guardian, December 16, 2012). The United Nations and other international organisations patently agree with Elizabeth Prochaska: that a woman's right to health is paramount and that multiple human rights instruments support her right to not only health and life, but also her right to equality and reproductive self-determination (Center for Reproductive Rights, 2008).

5. Women's Right to Health in a Global Context – European and International

The *International Covenant on Economic, Social and Cultural Rights* (ICESCR), part of the *International Bill on Human Rights* - ratified in Ireland in December 1989 - guarantees women the legal right to the highest attainable standard of physical and mental health and equal rights between men and women. The *European Convention on Human Rights* (ECHR) (2010) and the *European Social Charter* (ESC) (1961; 1996; 1999) also guarantee the right to health and to equality of women and men. It is article 8 of the ECHR - the right to respect for private and family life - that is at the heart of the *A,B and C v Ireland* case judgment.

The European Court of Human Rights unanimously found that Ireland had violated the Convention in regard to article 8 and had failed in providing clear legislation in reference to the X case, where abortion is deemed legal if there is a "real and substantial risk to the life of the mother" (as per Article 40.3.3 of the Irish Constitution). The outcome of the *A,B and C v. Ireland* case has been described as a landmark ruling by the judges in the European Court of Human Rights as it indicated a victory for women in regards to their rights to health, equality and privacy. But the

victory exists only on paper as there continues to be a delay in implementing any clear legislation or guidelines in relation to the European Court ruling.

Principles in the Expert Group Report

The Expert Group, and subsequent report on the judgment of the *A, B and C v. Ireland* case, set out terms of reference to examine all of the relevant history, medical, ethical and legal background of the European Court ruling and to provide recommendations that are consistent with the Constitution and the laws of the State. AIMSI are most concerned with the way the Expert Group sought to "elucidate [the European Court judgment's] implications for the provision of health care service to pregnant women in Ireland" (DOHC, 2012, p.8).

The *Report of the Expert Group* sets out four general principles that should apply to the implementation of the European Court of Human Rights judgment and cautions that "the measures that are introduced to give effect to this existing constitutional right should not act as obstacles to any woman who is legitimately entitled to seek a termination on lawful grounds" (DOHC, 2012, p.27). These principles outline the entitlement to lawful medical treatment as well as recommending that "once a clinical decision has been made as to appropriate treatment, it remains a matter for the patient to give informed consent" (DOHC, 2012, p.29). In terms of who is qualified to determine if a woman's life is at risk, the Report rightfully suggests that the list of professionals to assess women at risk should not only be limited to medical doctors but should include doctors of other non-medical disciplines, such as midwives and psychologists. The suggestions for a Review Panel are, unfortunately limited to, legal and medical professionals.

The Expert Group sets out that any proposed Review Group must have, *inter alia,* the following attributes:

- *It must be before an independent body*
- *It must be competent to review (i) the reasons for the decision and (ii) the relevant evidence*
- *the procedures should include the possibility for the woman to be heard*
- *it should issue written reasons for its decision*
- *decisions must be timely*

(DOHC, 2012, p. 38)

The above guidelines are of particular relevance to pregnant women, particularly in the context of the prior guidance that once a clinical decision is made, it is up to the patient - the pregnant wowen - to give her informed consent or her informed refusal. It has been the experience of AIMSI that women are not always listened to in terms of their reproductive health and their maternity care, often to the profound detriment of the woman and her child. There are extreme cases, such as the death of Savita Halappanavar, after alleged repeated requests for termination, or the death of Tanya McCabe, who was suffering from septic shock and was wrongfully discharged from hospital or Bimbo Onanuga, who was allegedly crying for help in the hospital but was thought to be "exaggerating" (Reilly, C., Metro Éireann, June 1, 2011). None of these women were listened to and it proved fatal for them all. There are thousands of women over the years, and since AIMSI

was founded, who have not been listened to and who have suffered greatly (physically, emotionally, and psychologically) at the hands of their maternity providers. These providers did not allow them their dignity, their right to bodily integrity and their right to informed consent. Controversies abound in the maternity services, for example the women who were brutally subjected to unnecessary removal of their wombs by Dr. Michael Neary or the women who were unknowingly given crippling symphisiotomies in the maternity hospitals of Ireland (a practice that was outdated and not used in any other jurisdiction), again, without their consent.

Human Rights Issues in Maternity Care & Mental Health

1. **A Comprehensive Mental Health Service**

It must be understood and reiterated that many women in Ireland have been consistently ignored and mistreated by many health professionals in the maternity services according to AIMSI research and support statistics. It stands to reason that if women who are entering a maternity hospital with the intent of giving birth to a healthy baby are often not being reasonably listened to and not being asked for their informed consent, it is difficult to comprehend how a distressed pregnant woman who is assessed as being at risk for suicide will feasibly present herself to a maternity hospital and procure a legal abortion in a safe, supportive and timely manner. Currently there is no extensive liaison service or basic maternity mental health support service in place across Ireland; hence, many women with varying mental health difficulties - ranging from depression and anxiety to bipolar disorder and schizophrenia - can fall through the gaps and remain untreated. Some choose not to share their mental health history due to a fear of it affecting their maternity care or it being used to incriminate them postpartum. The HSE document *A Vision for Change* (2006) outlines a comprehensive mental health service in Ireland that recognises that "women are at peak risk of having mental illness in the perinatal period, contrary to commonly held beliefs that this is a wholly healthy time in a woman's life" (p.156). Budget cuts in the area of physical and mental health over the last 5 years in Ireland have delayed putting more specialised services in place, such as comprehensive liaison mental health teams in all maternity settings and ensuring advocacy and community support for all pregnant women.

2. **Reducing Stigma**

It is imperative that legislation changes regarding abortion correspond with a change in attitude toward mental health difficulties. While not all women who have mental health problems will be at risk of suicide, significantly fewer women will experience any mental health difficulties in relation to having an abortion. In fact, there is no conclusive evidence in any peer-reviewed scientific journals that supports long term psychological consequences of abortion (Cohen, 2006). The stigma attached to both abortion and mental health puts vulnerable pregnant women who are experiencing feelings of hopelessness or entrapment at risk of developing suicidal behaviour (DOHC, 2006). In addition to feelings of stigma and shame, there is an overlap in terms of treatment of mental health service users and women in maternity care settings in that both groups

are often believed to be lacking in insight and both groups have a history of undergoing treatment without proper information or informed consent. The provision of maternity services that treat all pregnant women with equal duty of care is a must when the legislation and regulations are changed in relation to abortion in the coming months. These changes should include patient-centred maternity care that incorporates shared information and decision-making where health care providers "accept the values, culture, choices and preferences of a woman and her family" (ACOG, December 1, 2011). It should also promote the understanding that mental health is essential to overall health - they are not mutually exclusive - and that a woman has a legal right to be supported in her reproductive and sexual health choices.

3. **Informed Consent**

AIMSI conducted a research study on *Availability of Information and Consent in the Irish Maternity Services* (2008) and found that over 75% of respondents in the self-selecting survey stated that they felt consent is an issue of concern in the Irish maternity system, and almost 60% said they were not given the option to refuse a procedure, test or treatment. Many women provided qualitative data in the form of comments on the procedures they were subjected to, with no consent, while under the care of their maternity provider. The most frequently reported procedures that were performed without informed consent were: artificial rupture of membranes (ARM), episiotomy, the use of oxytocin and membrane sweeps. It is difficult to imagine a similar scenario where men would find themselves subjected to interventions or surgical procedures without their consent. This is where maternity care and services are unique - in that women are the sole patients of this service. The AIMSI research highlights the need for consent policies in maternity services as well as the need to tackle the issue of inequality between men and women in relation to their legal right to the highest attainable standard of physical and mental health.

The above inequalities in health care and the issues surrounding informed consent, particularly within the Irish maternity services, are integral to the sexual and reproductive health and human rights of women worldwide. In Europe, 44 out of 47 countries allow for legal abortion if a pregnant woman or girl's health is at risk. While reproductive health policies remain clearly within the jurisdiction of member states, it should be recognised that in 2004, the European Parliament "urged member states to legalise induced abortion under certain conditions, at least in cases of forced pregnancy, rape, or the endangerment of a woman's health or life [with the underlying principle being] that the woman herself should make the final decision" (Baker, 2006, p. 94). Prior to the European Parliament's vote and subsequent report by the Committee on Women's Rights and Equal Opportunities on the state of women's sexual and reproductive health and rights, both the *UN Cairo Conference* (1994) and the *Beijing Conference* (1995) urged reproductive autonomy for women. There is compelling evidence from a variety of reports and research studies that policy changes in relation to women's rights and reproductive health in developed countries are not only necessary but also expected. People believe they have a right "to make their own choices about

sexuality, contraception, marriage and reproduction, without the church or the state telling them how to behave" (Baker, 2006, p.40).

Irish Women's Right to Reproductive and Sexual Health – Removal of Barriers

The main thrust of the argument for supporting the rights of women across the maternity services, whether they are choosing a home birth, a cesarean section, an intervention-free birth or an abortion is summed up succinctly by Anand Grover, UN Special Rapporteur on the Right to Health, who recently spoke at the National Women's Council of Ireland seminar on Women's Right to Health. At a UN General Assembly in August 2011, Mr Grover presented a report, in accordance with the Human Rights Council , entitled: *Right of everyone to the enjoyment of the highest attainable standard of physical and mental health.* This report is seen as a milestone in the area of rights to reproductive and sexual health as it plainly articulates the reasons why legal restrictions in this area constitute a violation of a woman's right to health and an "unjustifiable form of State-sanctioned coercion" (UN, 2011, p. 5). The report is disparaging of the human rights violations that are perpetuated in the few remaining countries, such as Ireland, where abortion is completely criminalised or where it is only allowed to save the life of a woman. Anand Grover said at the UN General Assembly meeting, when presenting this report:

> "Realization of the right to health requires the removal of barriers that interfere with individual decision-making on health-related issues and with access to health services, education and information, in particular on health conditions that only affect women and girls. In cases where a barrier is created by a criminal law or other legal restriction, it is the obligation of the State to remove it. The removal of such laws and legal restrictions is not subject to resource constraints and can thus not be seen as requiring only progressive realization. Barriers arising from criminal laws and other laws and policies affecting sexual and reproductive health must therefore be immediately removed in order to ensure full enjoyment of the right to health." (UN, 2011, p. 2)

The countries that have legalised abortion have generally found that abortion rates do not suddenly increase when legislation changes. In fact, many countries report that over the years abortion rates have stayed the same, or decreased, as increased information and knowledge is disseminated on the proper and effective use of contraception. A comprehensive global study by Sedgh et al., 2012, found that there was a substantial decrease in abortion rates from 1995 to 2003 and that these rates have been relatively stable since 2003. The most salient information that the researchers gleaned from this study was that regardless of the status of abortion laws, unintended pregnancies continue to occur in all societies and woman will continue to access an abortion, whether the law restricts this or not. Evidence from countries with the most restrictive abortion laws suggests that the use of unsafe methods such as abortifacients like misoprostol is increasing widely (Sedgh et al., 2012).

Conclusion

The obvious conclusion is that even if a country has legal restrictions on abortion, women will continue to choose to terminate their unwanted pregnancies. To deny that this is happening in Ireland is to deny the very personal and intimate reproductive choices of thousands of Irish women. It also denies the reality that thousands of women, who can afford it, make the annual journey to the UK or elsewhere in Europe to access an abortion. The loneliness and the stigma attached to this denial should not be underestimated in relation to the impact that having to leave one's family, primary care provider and supportive surroundings to access legal treatment elsewhere has on women. This is particularly poignant for women who are seriously ill or have been medically advised to seek a termination for medical reasons.

In Ireland, we have seen a sea change in attitudes over the last few decades in relation to contentious issues such as contraception, divorce and abortion. Irish citizens have become more global - living and learning in different countries and coming back to Ireland with adapted cultural values and more tolerance and acceptance of others' views. This has been demonstrated by the thousands of people who came out to support legislating for the X case in the wake of the death of Savita Halappanavar or the consistent increase in support over the last decade in the various opinion polls on abortion in Ireland. AIMSI believes that these domestic changes in attitudes combined with international human rights laws and policies <u>uphold</u> the need for the Irish government to introduce legislation that regulates access to the highest attainable standard of maternity care, including abortion, without interfering with a woman's right to life, health, privacy, freedom from cruel and inhumane treatment and non-discrimination.

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