AIMS Ireland Submission to the Joint Oireachtas Health Committee

16th February 2017

Dr. Krysia Lynch, Chair AIMS Ireland

I thank the Chairman and members of the committee for the opportunity to present here today on behalf of The Association for Improvements in the Maternity Services Ireland on the National Maternity Strategy for Ireland 2016 - 2026

When we were invited to participate on the Steering Committee of the National Maternity Strategy by the then Minister of Health Leo Varadkar, we were in a position to inform the Steering Committee on the views and opinions of women and their families based on our recent survey in 2014 of 2,832 users of the maternity services in Ireland. All of the main issues highlighted in our survey were replicated by the Public Consultation carried out as part of the National Maternity Strategy, and we refer the Joint Committee to them. AIMSI were delighted to see the strategy published in January 2016 and we hope to see its full implementation.

As the public consultation showed, the key issues for the users of Ireland’s maternity services are choice in model of care, geographic equity in the provision of care, the importance of informed consent, partnership and trust between caregiver and service user, the lack of midwifery led services (despite the overwhelming international evidence to show it is the safest model of care for women experiencing a straightforward pregnancy), the lack of community midwifery and homebirth services, sub-optimal breastfeeding support, an inadequate provision for perinatal mental health, the lack of service user representation at local regional and national level, and the lack of adequate advocacy and audit services. AIMS Ireland welcome the inclusion of all of these aspects in the recommendations of the National Maternity Strategy. There are several areas which we feel need to be implemented without delay.

Firstly all women irrespective of where they live should have access to the three pathways of care; 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 birth centre. The latter already exist in all of our units but the second is only currently available in a handful of units and there is only one unit offering a homebirth service at present.

Secondly, we would urge the minister to implement the recommendations associated with perinatal mental health. Outcomes and safety of maternity care are generally measured in terms of physical mortality. 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. The area of perinatal mental health remains particularly under resourced, yet admittedly conservative figures show antenatal depression and anxiety at rates of 17-18% and postnatal depression at 18-19%. 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 in this area as vital.

Thirdly, the most frequently commented area in the public consultation related to the suboptimal provision of breastfeeding support. Breastfeeding is the building block for the future health of the nation and we urge the Minister to ensure the implementation of the National Breastfeeding Strategy and also ensure that adequate importance is placed on the breastfeeding recommendations in the strategy. I thank the committee.

Breda Kerans, Vice Chair AIMS Ireland
I thank the chairman and members of the committee. The first recommendation of The National Maternity Strategy was that an implementation plan be set in place within six months of the strategy being published. It is our understanding that there is still no implementation plan in place and if an implementation committee has been formed we have not been invited to participate. Therefore, for the woman and her family on the ground currently using the services the National Maternity Strategy has changed nothing so far.

Speaking as a rural service user, I would like to highlight three things to the committee. Firstly, the options of care and birth choices in Ireland remain a postcode lottery. This is especially true for women living in rural areas where choices are currently extremely limited, and where individual clinicians are able to determine ethos and approach to care, and where the threat of hospital closures and the need to travel even great distances in labour remains a very real concern.

We would urge the Minister to ensure that timely access to maternity services continues to remain an option for all rural women and the threat of small maternity unit closures are removed. We understand that in Northern Ireland smaller rural units became alongside birth centres if they were unable to maintain full tertiary services. Other options also exist and are referred to in our briefing document.

Secondly, the woman’s experience still remains undervalued and is rarely used as a learning tool. The need to fully and independently audit women’s experiences is vital and is alluded to in the recently published National Standards for Safer Better Maternity care and should be acted upon without delay.

Thirdly, the area of informed consent remains a concern for women. Last year a woman was taken to the High Court (Ms B vs HSE) in effort to override her right to informed choice and informed refusal. Ms B won her case. In order to avoid further such cases at great expense to the tax payer and threats to women of “The High Court”, we would like to see the Strategy’s recommendations regarding informed consent and informed refusal implemented in all care settings as soon as possible.

It is our view that many aspects of the maternity strategy could be implemented by restructuring services, and whilst some areas are resource heavy, many are not.

It is our view that the National Maternity Strategy will be unlikely to be implemented in full. The primary reason in our opinion is not due to lack of resources or funding but due to the threat that the strategy places to the status quo.

It is also our view that despite the admirable intention to place the woman and her family at the centre of care, the Strategy’s recommendations appear to currently be undergoing a process of cherry picking in order to selectively increase resources in particular areas of maternity care at the expense of others. I thank the committee.
Briefing Document
Oireachtas Joint Health Committee

By
AIMS Ireland
Dr. Krysia Lynch Chair AIMS Ireland
&
Ms Breda Kerans Vice Chair AIMS Ireland

16th February 2017
Executive Summary

AIMSI receives an average of 40 to 50 direct contacts from women and their families re the maternity services per week. We interact on a daily basis with 5,000 plus women and their families on social media.

We carry out rolling surveys on what matters to women in the maternity service every two to three years and our latest survey ran in 2014 with nearly 3,000 respondents.

The key finding of our What Matters to You Survey 2014 was that of those respondents who answered the survey 55% wanted the choice of Midwifery Led Care.

We offer support and information online via our website (www.aimsireland.ie), via one to one support, via confidential birth healing support and last year we ran a blog for 42 weeks highlighting positive birth stories and evidence based information for Ireland (42weeks.ie)

Six key areas that we feel require attention in the maternity strategy are:

- Equity of geographic access to services across the country, across social class and across ethnic groups.
- Greater provision of choice in service than that which currently exists for most women. This must include more midwifery led and community based services for women undergoing a normal straightforward pregnancy and should include all three pathways of care in all units and all three care settings in all units.
- The development of a perinatal mental health strategy to include sub clinical perinatal mental health.
- The implementation of clear policies on informed consent and informed refusal in the maternity services similar to other areas of the health services.
- Improved breastfeeding support including the publication of the National Breastfeeding Strategy.
- Improved service user involvement in the planning and audit of maternity services including experience surveys, advocacy and audit.

Contact: Chair@aimsireland.com
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 helps 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.

In 2007 AIMS Ireland met with Mary Harney, then Minister for Health. In these discussions we highlighted the areas for concern which we had heard from women. Because of what women had told us in our first “What Matters to You Survey” we knew that women were not being listened to. Their concerns about their safety and that of their babies were not always acted upon. Postnatal care was appalling and the issue of consent was a big issue for many women. Women reported adverse physical and mental health outcomes. To try to capture what we were hearing from women we asked the Minister to act to ensure that all hospitals produced an annual clinical report which would capture a wide range of clinically significant data. We also urged the Minister to ensure that National Clinical Standards were devised and that a robust system of audit was introduced. We felt that this structure of governance required the supervision of an independent body made up of both health care professionals and service users. It has taken ten years and many adverse events to see some of these recommendations start to come to fruition. It is clear however that had women’s voices been listened to and taken seriously ten years ago many of the recent tragedies may have been avoided. Ten years on from our first meeting with a minister for health re maternity care, our birth rate has not reduced significantly, however staffing levels are significantly lower. The issues raised ten years ago have only become more acute.

Service users 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. Yet those who design services rarely seek or indeed listen to their voice in any meaningful way. This has to change.

2. Geographical coverage and reconfiguration of service provision
There were 65,909 births in Ireland in 2015 (CSO, 2015). The vast majority of these took place in Obstetric led units in Munster and Leinster. There were far fewer births in Connacht and much less in the three counties of Ulster. The landscape and infrastructure in much of Connacht and Ulster can present a dilemma to the organisation of service delivery to pregnant women. Arguments around the safety of large centralised units must be weighed against the evidence of increased poor perinatal outcomes when greater distances are travelled or when travel times are disproportionately longer because of poor infrastructure and bad weather conditions. These poor outcomes are especially true for those who are disadvantaged in terms of poverty or access to transport. Use of telecommunications along with centralised governance and staff rotation within hospital groups may negate some of the negative outcomes associated with smaller units while preventing adverse outcomes associated with travelling longer distances, i.e. born before arrival, but lead to increased management of otherwise healthy women (induction). Removal of birth options i.e. closure of units
and increased distance will rule out healthy women from access to homebirth and midwifery led units. Pilkington et al (2014) found that distance to an obstetric unit did not increase neonatal mortality risk except for distances greater than 45 km. Blondel et al (2011) found a doubling of out of hospital births at distances over 30 km.

The Price & Johnson (2006) study of a small maternity hospital labour ward showed that empathy and empowerment could manifest in this setting, suggesting the power of scale effects. Other studies of institutional birth in large units appear to show that women can be stripped of dignity and agency (Baker et al 2005, Keating & Fleming 2009).

3. Models of Maternity Care
There seems to be a consistent and ongoing turf war between differing ideologies within maternity services. This turf war is becoming increasingly obvious within the reconfiguration of services debate. In these turf wars women’s voices are becoming dangerously lost. Women and babies are the raison d’etre for maternity services. Their voice should be uppermost in any discussion on maternity services. The repeated failure of all concerned to hear these voices will cost lives. AIMS asked women what they wanted from their service in a very comprehensive study. Nearly 3000 women responded.

The key findings around options were:
- Of those that did not currently have midwifery led care available, 55.5% said they would choose midwifery led service (on lines of MLU/ DOMINO) if it was available to them
- Of those that did not currently have a homebirth service available to them, 19.7% said they would like to have homebirth service available to them
- 58.5% of respondents said that they would personally choose a free standing birth centre if it were available
- 42.6% of respondents said they would personally choose community based midwifery led care if it were available to them.

Yet despite this clear desire from women to access midwifery led care only 5.5% of respondents stated that midwifery led care was currently available to them (AIMS Ireland, 2014). The Birthplace Cohort Study (Birthplace in England Collaborative Group, 2011) found that for low-risk women who have given birth before, the outcome of giving birth is no worse at home or in a midwife-led unit (alongside or stand-alone) and the rates of intervention were lower. The same study found that for low-risk women who have not given birth before, the outcome of giving birth is no worse in a midwife-led unit (alongside or stand-alone) but is slightly worse for neonates in home births.

These trends in terms of service users’ views with regard to choice of service were repeated in the Public Consultation carried out by the Department of Health and Children as part of the National Maternity Strategy. As the following table from the IPH Public Consultation Document (Keilty et al, 2015) shows over 1 in 2 respondents regarded the choice of services available as very poor or poor, and just under 1 out of 2 respondents regarded information on services as poor or very poor, 1 out of 3 respondents regarded advice on a healthy lifestyle was poor or very poor and 1 out of 4 respondents rating the safety and quality of care given as poor or very poor.
Quantitative examples of choices in care models are given in these two examples from the Public Consultation Document:

- The professionalism and dedication of frontline staff
- Midwifery-led care and community midwives/domino and early discharge scheme.
- Home birth services.
- Access to free care under the Maternity and Infant Care Scheme.
Hospital consultant led services particularly in the context of complex pregnancies and effective management of emergencies.

Combined care (hospital and GP) during pregnancy.

Access to allied specialist support services

However, in addition there were aspects that respondents to the consultation felt required improvement and these included the following:

- Poor breastfeeding support in the hospital and community setting.
- Limited care options and a lack of choice.
- Over-medicalised model of childbirth for low risk women.
- Overcrowding and a lack of resources and staff.
- Inadequate engagement with women and partners in their care.
- Poor staff communication.
- Excessive antenatal clinic waiting times.
- Poor quality and inconsistent antenatal and postnatal care, support and advice.
- Limited mental health supports in the community.
- Unsatisfactory care following a loss or bereavement.

Respondents in the Public Consultation process made the following suggestions for service provision:

- Provide information on care options that is clear, consistent/standardised and unbiased. Make clear the benefits, risks and alternatives for each model of care and publish statistics on hospital intervention rates, safety records, complaints and staff patient ratios.
- Facilitate a choice of care models through the expansion and integration of community and home birth services. Design and deliver services on the basis of international best practice and a strong evidence base.
- Ensure safety by addressing staffing levels and adequately resource and invest in maternity services.
- Make services needs centred by integrating structured feedback mechanisms and service user consultation as part of the planning of all aspects of the service.

Cross cutting themes which could be implemented in high level service planning as suggested by service users in the public consultation:

- Facilitate choice of care (hospital, community, home) and make options available to service users regardless of their geographical location or ability to pay.
- Increase the capacity of midwifery led services for women categorised as a low risk. Expand access to the Domino Scheme, Early Transfer Schemes and Home Birth Services. Establish more Midwifery Led Hospital Units. Integrate home birth services with hospital services.
- Reduce antenatal clinic waiting times by improving the appointment system and increasing the capacity of midwifery clinics and/or outreach clinics.
- Invest in and develop postnatal services in the hospital, community and home setting.
- Implement the HSE Breastfeeding Action Plan and the Baby Friendly Hospital Initiative.

4. Advocacy for women and Perinatal Mental Health

- Up to 30% of women will have some sort of mental health problem during pregnancy
- Clinically 15% will be diagnosed with a mental health problem
- Antenatal anxiety rates are higher in Ireland than in other countries
- Women with traumatic birth experiences will be more prone to mental health problems
- Research states 1/3 to 1/6 women will experience birth trauma
- 6% of women who had a c section will have birth related PTSD
- 3% of women with a vaginal delivery will have birth related PTSD
- Women with pre-existing mental health issues will be more prone to mental health problems
• Perinatal mental illness has been linked to developmental delay in infants.
• Fathers and the wider family are also subject to perinatal mental health problems and this affects perinatal infant mental health
• Psychiatric illness is the leading cause of maternal death in the perinatal period

From its inception, AIMS Ireland has offered support to women who have had difficult experiences in the maternity services. We have provided this support through a dedicated support email and via a confidential birth healing group online and also via birth trauma healing workshops. We support women through the complaints process, we offer them legal advice if required and, most importantly, we provide unbiased, non-judgmental peer support. This is especially important in a system where there is a dearth of any real perinatal mental health support within current structures.

Perinatal mental health is almost completely delivered in general practice with some referral to adult mental health services. This offers little or no access to psychology services. While medical card holders can access six to eight counselling sessions if referred for such, non-medical card holders cannot do so. This is a real barrier for many women and leaves them almost entirely dependent on drug therapies which do little to address the underlying causes. Some of these women are experiencing trauma or PTSD. Without counselling these women can face significant difficulties in subsequent pregnancies which can lead to difficult relationships with care providers. AIMS Ireland has considerable experience in helping these women, and with appropriate funding we could run a dedicated helpline and provide counselling with accredited therapists and facilitated peer support.

Peer support has been a very successful adjunct to mental health services for some time, e.g., Aware and Grow provide facilitated peer support across the country. However new mothers often find current support groups inaccessible, taking place at the wrong times and not baby friendly. Indeed there is a need for a perinatal mental health strategy. The fact that there was no mental health representative on the Maternity Strategy Group was worrying. A recent report, produced by the London School of Economics and the Centre for Mental Health charity showed an economic impact of not only £8 billion to the economy in terms of affected mothers, but also the effect over decades on their children’s prospects, both in terms of development in the womb and during the crucial early years.

The report commissioned by the Maternal Mental Health Alliance (MMHA), showed that the NHS would only need to spend £337m a year, to bring maternal mental health care up to recommended levels around the country. In response George Osborne committed 1.25 billion to be spent on an expansion of mental health services for children and mothers of new babies.

It is important to bear in mind that suicidality is an indication for termination of pregnancy under the Protection of life in Pregnancy Act 2013. With that in mind the legislators have placed a great burden of responsibility on the Department of Health and Children to provide a robust perinatal mental health service. We are well below international best practice in this area. There is little in the way of formally audited screening, aside from antenatal GP visits and the first PHN visit postnatally at home. Furthermore research shows that women are often reluctant to self-refer. Even if audited screening were to take place and women felt safe to self-refer, there is currently a wholly inadequate referral pathway Overall, perinatal mental health is almost completely ignored in our maternity hospitals. Outside of the large Dublin hospitals there is no dedicated perinatal mental health staff, in contrast with France where every maternity unit employs a perinatal psychologist.

5. Informed consent and informed refusal policy

Women have consistently and repeatedly raised this issue with AIMSI over the last 10 years. We included questions related to consent in our recent AIMS Ireland “What Matters to You” survey in order to get a clearer picture of how widespread these issues currently are. AIMS Ireland recognise
that ‘informed consent’ and ‘informed refusal’ are both factors which generally define informed consent. However, for this survey the two were separated because many women report to AIMS Ireland that they are supported in making an informed decision to have a procedure, test, or treatment, but they are not supported in declining tests, procedures or treatments; informed refusal. Guidelines for informed consent and informed refusal in pregnancy are contained within the HSE’s National Consent Policy (2013). 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 revealed that informed consent and informed refusal rates amongst respondents were both disappointingly low, especially when compared with the rates of informed consent and informed refusal in other areas of healthcare. Only just over half of all respondents received the opportunity to make full informed consent and were able to make an informed refusal. Informed refusal rates amongst respondents were notably lower in pregnancy than during other stages of care.

In pregnancy only 56.6% said they were fully informed of the benefits, risks and potential outcomes of tests, procedures and treatments but only 48.9% were given the opportunity for informed refusal of a test, procedure or treatment. During labour and birth only 52.8% of women said they were fully informed of benefits, risks and potential outcomes and 50.2% were given the opportunity for informed refusal. Postnatally, these figures improve slightly with 60.6% feeling fully informed of benefits, risks and potential outcomes and 57% feeling they had the opportunity for informed refusal.

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.
- Induction – medical personnel decide on what date a woman has to 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.
- 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 the recent 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”. [http://www.irishtimes.com/news/crime-and-law/courts/coroner-s-court/inquest-into-death-of-cavan-baby-finds-medical-misadventure-1.2799705](http://www.irishtimes.com/news/crime-and-law/courts/coroner-s-court/inquest-into-death-of-cavan-baby-finds-medical-misadventure-1.2799705)
- 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, yet women report that it’s very difficult to refuse this drug in a hospital setting.
• 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

6. Breastfeeding support
Breastfeeding rates in Ireland are amongst the lowest in the world. These include initiation rates and the rates at 6 weeks postpartum and 3 and 6 months postpartum. Very few babies will reach the DOHC and HSE guideline of six months exclusive breastfeeding and two years (or longer) breastfeeding as part of a mixed diet. Average initiation rates are at around 50% depending on what hospital is surveyed and by three-four months, only 16 per cent of Irish women are exclusively breastfeeding according to a recent TCD study. At six-seven months, just one mother in 40 is exclusively breastfeeding, Gallagher et al (2015).

Women report consistent issues with their breastfeeding experience to AIMSI and did the same in the Public Consultation. In the AIMSI What Matters to You Survey 1 out of 4 women said they found their breastfeeding experience in the immediate postpartum period to be either very poor or poor. Issues such as lactation consultants only being available during week days and failure to diagnose tongue tie early on as well as availability of artificial milk were cited as specific problem areas. Separation of mother and baby after c section and the lack of buy in from some HCPs in hospital settings are also issues as is the variation in terms of advice and support given to women. Postnatal care often has the poorest ratio of midwives to women

Breastfeeding is the fundamental building block on which the health of the nation is built it has been linked to limiting obesity and also to providing protection against a variety of female cancers and autoimmune diseases in the neonate. It also give protection against various digestive tract disorders and type 1 diabetes, getting breastfeeding right is vitally important for mothers and babies alike.

Despite the poor initiation rates in hospital settings, the initiation rates for breastfeeding in community settings and in midwifery models of care is much higher (Quigley et al 2016). NPEC reported rates of breastfeeding initiation of 99.4% for home birth mothers and 97% for homebirth mothers on discharge at two weeks postpartum (Meaney et al. 2016). Figures from midwifery led units and domino models of care show similar higher rates.

Implementation of the many recommendations associated with breastfeeding in the strategy will go a long way to improving experiences and rates and ultimately the health of new-borns and mothers. Implementation of increased midwifery led options and community care are also vital in ensuring improved outcomes in terms of breastfeeding.

7. Aspects of the strategy requiring immediate implementation

1. Maintaining the current numbers of maternity units: This is vital in order to address the issues of the remote location of some rural women and avoid adverse outcomes or unnecessary intervention which would seek to circumvent the issue of distance. If anything the number of centres that women
can go to access maternity care should be increased, with more outreach services and community based services for women with a straightforward pregnancy, e.g., more practice midwives in GPs surgeries and more community antenatal and postnatal services, with greater continuity of care and more homebirth services.

2. The introduction of all pathways of care in all three settings in all regions. The most appropriate provider of care for women experiencing a normal straightforward pregnancy is a midwife. Consultant led care should be utilised in the normal course of events only for women experiencing complications in their pregnancies. Directing women with straightforward pregnancies to a midwife and the supported pathway in an alongside birth centre or at home frees up obstetric resources for women and babies that have known complications and would mean greater continuity of care for all women and less waiting time for all women. It would also ensure that limited human resources would be used to the best of their capacity whilst ensuring patient safety.

3. Dedicated service user liaison/advocacy service. This is especially so in the light of the professional tug of war currently playing out together with fears around litigation. A patient advocacy service can also be used to improve communication between health care providers in transfer of care settings and between maternity units and service users. There is an inherent risk in transfer of care settings i.e. between acute care and primary care, between members of a multi-disciplinary team, and between different hospitals. There is currently a PALS (Patient Advocacy and Liaison Service) in some units. However it is underutilised in maternity units and reports from service users to AIMS Ireland have not been particularly positive, with women feeling that the service is used to explain hospital policy to them rather than to advocate on their behalf.

4. Perinatal Mental Health
There is an urgent need for a perinatal mental health strategy which encompasses ring-fenced funding as in the UK. There is a role for service user organisation involvement in this area.
- **Mother and Baby Psychiatric Beds** There are no dedicated mother and baby psychiatric beds in this country. It is considered best practice to keep mothers and babies (where possible) together when an admission to a psychiatric unit becomes necessary.
- **Increased Perinatal Psychiatrists and Psychologists** There are 3 part-time perinatal psychiatrists in the country all in Dublin and no perinatal psychologist posts.
- **Improved prioritised access to mental health services** Women who require access to mental health services repeatedly tell us they are often left waiting months to be seen. At this particularly vulnerable time for both the mother and her infant it is vital that the impact of perinatal mental ill-health is minimised by timely treatment.

5. The current complaints procedure requires a complete overhaul. The current system often leaves women & families feeling jaded, lied to and frustrated.

6. The collection of robust maternity statistics. AIMS Ireland welcomes the publication of the Monthly Patient Safety Statements, however it is vital that when these statements show rates well above the average for a certain aspect that these are investigated. A recent example was the c section rate for first time mothers in St Luke’s hospital Kilkenny. These showed rates for October 2016 of 50% and for November 2016 of 62%, yet there was no commentary and no action plan from the hospital or the HSE to explain such high rates and this leaves current and future service users nervous and uncertain as to why this should be so in that particular hospital. However, it is also vital that adverse maternal psychological outcomes are included and that the focus is not just on perinatal and maternal mortality. Adverse psychological outcomes carry huge costs for families and for the economy and therefore it is vital that we capture these figures so that a robust strategy to address these issues can be put in place.
7. Service User Experience Capturing service user experience is distinctly different from ad hoc patient satisfaction surveys which are currently carried out in most maternity units. Capturing the service user experience, does not focus solely on whether the service user was satisfied, rather it focuses on what that experience actually was. This can be measured against other service user experience surveys carried out in other countries and against what service providers actually think is being delivered. In a recent New Zealand government commissioned cross-country comparison of maternity systems Ireland was the only country out of the seven analysed that did not capture the service user experience at all. There some good examples of such surveys taking place in Canada & the UK.

8. Improvements in communication at all levels. There are many recommendations within the strategy that call for improved communication. It is well established that transfer of information between health care professionals and between health care providers and service users carries significant risk. Poor communication and poor documentation has been identified as both causal and incidental findings in many recent reports. Investment in IT will go some way to addressing this issue. But this will only be a good as the staff using it. Training and education also plays a part. As outlined above patient advocacy/patient liaison can also play a vital role. They can be used to act as a link for families, who have experienced a traumatic birth for example. Families often feel confused and isolated in the aftermath of a traumatic birth. They find themselves speaking with many different professionals when they need information or referral. They often find themselves making numerous phone calls before they find the correct information. Or find they get hurtful/inappropriate communications.

9. Increased investment in postnatal care including breastfeeding. Postnatal care in maternity units and in the community is extremely poor. Ireland has the lowest levels of breastfeeding initiation in Europe. This is hardly surprising given the lack of support both in postnatal wards and in the community. Visits from PHNs are now very limited. This contributes to low breast feeding rate. It also prevents screening for postnatal depression. In fact in Ireland we have no screening programme for either ante-natal or postnatal depression. Given the number of women who experience both and the impact on outcomes both physical and psychological this is extraordinary. Poor perinatal mental health has been linked to developmental delay in infants, relationship breakdown & suicide. It is therefore vital that all women receive the necessary care & support in a timely fashion. For some women this will involve inpatient care in an acute unit, but for many more it involves primary care only. Often it is women who are do not require emergency admission that are most disadvantaged.

10. Anomaly Scanning in All Units Most Maternity Units are not providing anomaly to all pregnant women. This is largely due to a lack of stenographers. AIMS Ireland echoes the call from the INMO and the IOG to ensure that all women are offered the option of scans of their choice including a dating scan and an anomaly scan.
8. References


HSE v Ms B (2016) In the matter of B and in the matter of Articles 40.3.3, 40.4.2 and 42 A of the Constitution and in the jurisdiction of the High Court. [http://courts.ie/Judgments.nsf/09859e7a3f34669680256ef3004a27de/39c8f665f4e1ca2c802580640052bd76?OpenDocument](http://courts.ie/Judgments.nsf/09859e7a3f34669680256ef3004a27de/39c8f665f4e1ca2c802580640052bd76?OpenDocument)


https://www.npeu.ox.ac.uk/maternity-surveys