

## NEW INFORMATION CONTAINED WITHIN THIS SUBMISSION

- Perinatal and Maternal Mortality Review Committee (PMMRC) recent reports show that nearly 20 percent of baby deaths and more than one-third of maternal deaths each year are potentially avoidable (page 19)  
Mortality rates are not improving (page 18)
- There has been a 27% increase in the number of avoidable baby deaths in just one year (98 babies up to 124 babies) according to the PMMRC
- ACC now estimates that caring for just one brain-injured child will cost \$34 million
- A Wellington pilot project show one-third of maternal admissions to ICU are potentially avoidable (page 14)
- The gap is widening between NZ and everyone else in the OECD for perinatal mortality rates (page 16)
- The recent Referral Guidelines process and outcome document are seriously flawed and dangerous for women and their babies (page 9)
- The recent Maternity Consumer Survey shows a markedly rising rate of women discharged from hospital before they are ready (13 % to 28%) and also that more than one-quarter of new mothers are receiving less than their minimum entitlement of postnatal visits (page 20)
- Ministry data collection gaps remain, especially around primary maternity services outcomes (page 13)
- A new pilot project improving GP/midwife communication in the care of high risk women has not been fully evaluated (page 9)
- The new Clinical Indicators list includes very limited data on outcomes for babies (page 15)
- Free (re)training of GPs in maternity care has not been taken up, as we predicted (page 25)
- Bereaved parents have been surveyed for the first time (page 18) and one-third of these have said that they did not receive enough information on why their baby died.

Submission  
to the Health Select Committee  
by Jennifer Maree Hooper

[22-6-12]

We would welcome the opportunity  
to speak to our submission before the Committee



**This submission is made by  
Jennifer Maree Hooper  
on behalf of the  
AIM: Action to Improve Maternity Charitable Trust.**

**This is a network of hundreds of maternity consumers and supporters  
who share the belief that the New Zealand maternity system  
safety and quality can be improved.**

## Executive Summary

The maternity consumer network AIM: Action to Improve Maternity is working to improve the safety and quality of New Zealand's maternity service. It is a charitable trust involving many hundreds of families and their supporters.

The Health Select Committee October 2010 *Report to the House* maternity recommendations were made in response to our first submission. We have used the framework of these recommendations to examine the following eight areas in the light of recently available information:

- birthing philosophy
- a non-fragmented model of care and communication flow
- issues around data collection
- the investigation of deaths
- postnatal care
- lead maternity carer training
- accountability
- support for families

New information presented to support this submission includes:

- data from the Perinatal and Maternal Mortality Review Committee (PMMRC)
- comparative data from the OECD
- information on recently finalised maternity projects of the Ministry of Health

The Ministry Maternity Quality Initiative is a practical and tightly-focused plan with measurable outcomes. We have welcomed the introduction of this sensible approach, but quality and safety outcomes for women have already been compromised given the flaws evident in the initial programme implementation. Examples of these shortcomings are the problems and deficiencies around the Referral Guidelines process and content along with crucial omissions in the newest Maternity Consumer Survey (see below).

AIM strongly advocates that all of the previous recommendations of the Health Select Committee be noted and implemented in the current maternity system as soon as is practicable, to improve maternity safety and quality for all.

## Summary of Our Key Submissions

### We submit

- that the long-recommended and long-awaited **perinatal database** and epidemiology unit be established with alacrity; that it be set up independent of the Ministry given the continuing evident gaps in Ministry maternity data (see page 13). The estimated cost to the Hon. Pete Hodgson in 2006 was that such a unit would cost \$4million. Knowledge gained from this type of carefully collated information could reduce the current enormous human and monetary cost in lost and damaged lives. For example, ACC has recently estimated that the cost to them of just *one* brain-injured baby as a result of treatment injury is now \$34 million.
- that for the sake of public protection, the provision of a Health Benefits Payments number (enabling independent practice) to any new medical or midwifery graduate be dependent on the supply of documentation from a DHB that the person has spent at least **12 months after graduation in the labour ward of a level 2 or level 3 hospital** (see page 22). This is in keeping with the 2009 Health Select Committee recommendation, “ ... *that it [the Government] require both the Medical Council of New Zealand and the Midwifery Council of New Zealand to ensure that new graduates have significant post-graduate monitoring, supervision, and education updates, before going into independent practice. In our view, with regard to midwives, this should be for at least a year after graduation*”.
- that affected families be offered the **opportunity to be involved** in DHB mortality reviews, DHB Sentinel Event management programmes and the work of the PMMRC and that similar local DHB reviews, again including the involvement of affected families, be developed for serious morbidity situations so that the lessons learned can be more readily circulated and more broadly applied (page 19); that an ‘Adverse Maternity Outcome’ referral and advocacy service be set up to support these families.

**(Please see Appendix, page 29, for a full list of our submissions made in this document)**

## **Contents**

New information bullet point summary	page 1
Executive Summary	page 4
Summary of our key submissions	page 5
Contents	page 6
Preamble	page 7
1/ Birthing philosophy	page 8
2/ A non-fragmented model of care	page 9
3/ Issues around data collection	page 13
4/ The investigation of deaths	page 18
5/ Postnatal care	page 20
6/ Lead maternity carer training	page 22
7/ Accountability	page 26
8/ Support for families	page 28
Conclusion	page 30
Appendix	page 31

## **Preamble**

In September 2009 the earlier inception of this consumer network ('The Good Fight') met with the Health Select Committee. This meeting left the network representatives feeling 'heard' and we subsequently became aware of a huge amount of work over the following months carried out by the Health Select Committee in response to our submission.

Responding to our original submission, both the Health Ministry submission (undated) and the 5-5-10 NZ College of Midwives submission expressed similar themes: that deaths and disabilities are simply an unavoidable part of any maternity service and that some families, including the 'already traumatised' families of our consumer network, may never fully recover from such adverse events. On both counts this view is dismissive of the genuine concerns and efforts of our network families and is therefore offensive to us. In fact, the Ministry and the College would both do well to view the recent reports of the PMMRC showing as they do, that more than one-third of maternal deaths are potentially avoidable and nearly 20 percent of perinatal deaths are also potentially avoidable.

The final Health Select Committee recommendations were made in its *Report to the House* in October 2010. We want to take this opportunity to extend to the members of the Health Select Committee our profound and heartfelt thanks for their extensive work and the careful attention to our concerns which led to these recommendations. We believe that if these recommendations had been fully implemented in the interim, lives would have been saved and many serious injuries avoided.

Despite millions of dollars of new funding being allocated to maternity care by the National Government since it took office in November 2008, we have no evidence that maternity system safety or quality has improved. This is because of continuing and major deficiencies in the baseline maternity data collection systems undertaken by the Ministry of Health.

Additionally, ACC has recently announced that the cost to them of a brain injured baby is now \$34 million per child. On top of this, our many families affected by avoidable birth injuries continue to pay with their quality of life along with their emotional and physical wellbeing. There are now hundreds of these families in our network including many who have become involved since our last submission. We believe that the time is right to revisit the excellent but as yet mostly un-implemented 2009 recommendations of the Health Select Committee, especially given the release of more recent concerning relevant data and information.

## **1/ Birthing Philosophy**

As detailed in our 2009 submission, we remain firm in the belief that there should be a complete change in the philosophy behind New Zealand's maternity system that will move the emphasis away from 'a normal life experience' toward a safe and satisfying birth experience.

The current Health Ministry philosophy is contained within the overarching vision statements known collectively as the 2011 'Maternity Standards'. We note that Standard 2 states that, 'Maternity services ensure a woman-centred approach that acknowledges pregnancy and childbirth as a normal life stage.'

While this may be true sociologically, according to expert opinion, the reality is that 50-60% of New Zealand women will require medical assistance at some stage during their pregnancy, labour, birth or soon afterwards to achieve a healthy outcome for them or their babies. We believe that for many years an over-emphasis on 'normal' birth has created an environment of risk for women and their babies and that people have suffered as a result.

The Pregnancy and Childbirth Collaborative Review Group of the Cochrane Research Group has indicated that the previous blanket endorsement of 'midwifery care for all women' in the light of new information is being reviewed later this year. The final determination on this issue will not be available until after October. This revisiting is happening because of international research raising concerns about midwifery –led care, such as a recent large Dutch study of nearly 38,000 women. This study showed that infants of pregnant women at low risk whose labour started in primary care under the supervision of a midwife had a higher risk of delivery related perinatal death and the same risk of admission to the NICU (neo-natal intensive care unit) compared with infants of pregnant women at high risk whose labour started in secondary care under the supervision of an obstetrician. The researchers called these results 'unexpected'.

We present below as much information on the New Zealand situation as we have been able to gather.



## 2/ A non-fragmented model of care and communication flow

**Inter-professional pilot project:** In 2009 as part of the Maternity Quality Initiative, a demonstration project was initiated by the Canterbury DHB and the Wairarapa DHB. This pilot project, analysed by the Sapere research group, was aimed at improving the continuity of care for pregnant women with high needs. It was also aimed at improving the collaboration between maternity and general practice over the woman's overall primary and maternity care. Unfortunately the earthquake events in Canterbury disrupted the ease of assessment of women's experiences of this pilot project, especially of women in the most affected eastern part of the city. Given the uncertain results, the project concept was not rolled out to all DHBs. But despite this incomplete assessment, the CDHB has continued the pilot project on beyond the finish date of 31-12-11. There is now another 6 months of data now available from the CDHB to assess the effectiveness of this project and its acceptability to both the women and health professionals involved.

We submit that any data from the continuation of the CDHB demonstration project aimed improving inter-professional cooperation in the care of high risk women, be made available and analysed.

**Referral Guidelines:** The *Government Response to the HSC Recommendations* noted that the Ministry was at that time updating its referral guidelines for when LMCs should require consultation with or handover of care to other professionals. The *Response* view was that these "... guidelines will improve quality and national consistency in clinical practice". The result of this work is *Guidelines for Consultation with Obstetric and Related Medical Services (Referral Guidelines)* published by the Ministry on 1<sup>st</sup> February 2012.

The AIM network has serious reservations about both the process of development of these guidelines and also safety and quality of the ultimate document. The 'consumer' representatives on the committee developing these guidelines included during the process both Ms Sharron Cole, currently the CEO of the Midwifery Council (at the time of this committee work she was the Midwifery Council Registrar) and also Ms Lynda Williams of the Auckland based Maternity Services Consumer Council who is also a midwifery tutor. We are also concerned that the professional chosen to facilitate this work and the associated workshops was Dr John Marwick, whose advice in 1986 to the then Minister of Health was instrumental in moving towards the Nurses Amendment Act 1990 upon which the current maternity service rests. We raise

important questions about the involvement of all three of these people given their evident and serious conflicts of interest. Our submission to the referral guidelines work included the following:

*We have been advised by Allen & Clarke Policy and Regulatory Specialists Ltd that the Parents Centre is representing consumer interests on the Expert Working Group. We wish to draw attention to the fact that the CEO, Parents Centre New Zealand is also currently CEO of the Midwifery Council and is their Registrar. She is a former Deputy Chair of the Midwifery Council and is the current Chair of the Midwifery Council Professional Conduct Committee. We have been advised that the Maternity Services Consumer Council is also representing consumer interests. The person representing the Maternity Services Consumer Council on the Expert Working Group is a midwife educator. On that basis, a majority of the members of the Expert Working Group are midwives or are associated with midwifery organisations. The balance of the Expert Working Group membership consists of health professionals. There does not appear to be any adequate or un-conflicted consumer representation.*

*Furthermore, the Expert Working Group's facilitator co-authored the 1986 foundation policy document on which the 1990 maternity reforms were developed. He is facilitating the working group that is reviewing his work. Our full submission may be viewed on our website [www.aim.org.nz](http://www.aim.org.nz)*

In AIM's view, that these people were chosen for these roles raises questions around the Ministry ability to adequately recognise conflicts of interest in the people it selects for various tasks.

We submit that the relevant Ministry staff review the requirements around conflict of interest for chosen consumer representatives on various committees, according to the State Services Commission best practice.

The resultant *Referral Guidelines* document is clearly about funding and status and is not based on clinical best practice. The *Government Response* expressed hope that these "... guidelines will improve quality and national consistency in clinical practice" is most unlikely to be fulfilled. In the interim, even more mothers and babies health and lives will be placed at risk as these deficiencies become more evident. For example, the document does not attempt to act as an authoritative guide to urgency. For instance the only reference to cardiorespiratory depression at birth is:

*"8011 Severe infant depression at birth e.g. Apgar score of 6 or less at 5 minutes with little improvement by 10 minutes Emergency."*

This is clearly not an attempt to improve the early involvement of paediatric and/or obstetric staff at emergencies and any practitioner who struggles with this type of seriously 'flat' baby for 10 minutes before calling for help should surely be culpable, in our view. This poor advice rests in a document which has as its main focus, the funding of paediatric and obstetric consultations and

furthermore the status of different professionals, particularly the protection of the status of LMC midwives. Unfortunately practitioners are likely to rely on the face value of this document as clinical best practice when it has never been developed as such. The inadequacies of this document are brought into even sharper focus by the PMMRC 6<sup>th</sup> report released 13-6-12, in which cord blood gases were recommended for all babies with an apgar of less than 7 at *one* minute and that if a hypoxic (low oxygen) brain injury is suspected, then, "*early consultation with a neonatal paediatrician is recommended in order to avoid a delay in commencing cooling*".

Further comment from our Referral Guidelines submission giving some examples of other clinical emergencies where the life-threatening nature of these is not adequately addressed is as follows (bearing in mind '*category E*' means an emergency response):

*a. 5018 meconium liquor, moderate or thick, we submit that the presence of meconium liquor, be up graded to category E. We also submit that the condition be amended to read "meconium or any abnormal discoloration" and that the words "moderate or thick" be deleted. We understand that there is a divergence of clinical opinion regarding the significance of meconium in amniotic fluid. On this basis, we are of the view that a precautionary approach be taken.*

*b. 8011 severe infant depression at birth, e.g. Apgar score of 6 or less at 5 minutes with little improvement by 10 minutes, we are not of the view that an LMC should wait 10 minutes before referral. We submit that referral should be immediate in those circumstances and that the condition, and, its description be amended accordingly and upgraded to category E.*

*c. 6003 post partum haemorrhage (PPH) > 600 mls with ongoing bleeding, we submit that this constitutes an emergency situation and should be upgraded to category E. The reasons for this are self evident.*

*d. the un-numbered and un-described condition at page 49 of the Discussion Document, Birth Injury, we submit that if an infant has been injured this requires the urgent attention of a paediatrician. On that basis, it should be upgraded to category E.*

*e. 8054 Apnoea, we submit that if an infant is not breathing, or not breathing normally, this constitutes an emergency situation and should be upgraded to category E.*

*f. 8056 Stridor, nasal obstruction, or respiratory symptoms not specified elsewhere, we submit that along with 8054 Apnoea, any significant respiratory distress should be treated as an emergency and upgraded to category E.*

Our final concerns around the *Referral Guidelines* document is these are merely suggestions, though the recent Coroner Mataenga's ruling in the case of Baby Adam Barlow released 7-5-12, indicates that the legal profession may be regarding these guidelines as more prescriptive than does the current midwifery leadership. Our submission included the following:

*AIM is concerned that the Revised Referral Guidelines are merely guidelines. We are of the view that Revised Referral Guidelines should contain minimum standards with legal effect. By way of comparison, New Zealand's Animal Codes of Welfare contain recommendations, guidelines and minimum standards. The minimum standards are deemed to be regulations, meaning that while a breach of a minimum standard in a code is not an offence, failure to adhere to such minimum standards may be used as evidence to support a prosecution, while compliance may be a defence. We submit that the Revised Referral Guidelines should be elevated to the status of a code, and amended to contain minimum standards with legal effect.*

We suggest that a better, safer way, is to start with the clinical safety needs of the woman and her infant as being paramount and then to build a common-sense evidence-based strongly clinical framework around that from the ground up. Some kind of enforceable regulation may be necessary to ensure prompt and appropriate referral, but the regulations here are aimed at different priorities and we believe that this will be reflected in serious adverse outcomes for families in the near future.

We submit that the referral guidelines be completely and urgently re-drawn, using the strongest available evidence base, with the clinical safety of mothers and babies as being paramount rather than the protection of the role of LMC midwives as is the current priority.

**Standardised notes:** We are also concerned that standardised notes for ease of electronic referral seem to be taking an inordinate amount of time and that the time frame of 2014 for implementation of this will place mothers and babies at unacceptable, avoidable risk in the meantime.

We submit that the standardised electronic clinical notes system be given priority to enable nationwide implementation by 2013.

### 3/ Issues around data collection

**Incomplete data:** The *Government Response to the HSC Recommendations* was of the view that the Health Quality and Safety Commission in conjunction with the improved “data warehouse” of Ministry maternity information (functional since July 2011), will be able to combine to provide the function of a national perinatal epidemiology unit such as that recommended for consideration by the HSC, repeatedly by the PMMRC and by a large number of other entities over many years.

It is our conclusion that this view is flawed.

We believe that pregnant women need data on home birth and birthing unit births compared with hospital birth outcomes. In other words, a woman needs to know (all other things being equal), how would her baby get on should she choose to give birth in each of these environments and also what would be the comparative outcomes for herself. Neither the Ministry or the Health Quality and Safety Commission can provide her with this information. There is no easily accessible online site where she can go to find it, either. For example, the following basic information omissions exist within the current Ministry data collection:

- information on the rate of episiotomies and vaginal tears in home births and primary birthing units is not routinely collected
- information on transfer rates of babies into NICU from primary birthing units and home births is not collected and/or any later admissions to hospital in the early months of life
- information on transfer rates of mothers into ICU from home births is not collected
- information on transfer rates of mothers from primary birthing units is not routinely collected
- information on the management of the third stage is not collated from primary birthing unit births and home births
- information on the average maternal blood loss is not collated from primary birthing unit births and home births
- information on the average transfer time from various facilities is not collected for transfers from primary birthing unit births to hospitals
- there is no routinely collected information of obstetric outpatient referrals for women choosing home births or birthing unit births compared those choosing a hospital birth

We submit that the long-recommended and long-awaited perinatal database and epidemiology unit be established with alacrity; that it be set up independent of the Ministry given the continuing evident gaps in Ministry maternity data.

**Morbidity data:** This data has never been adequately collected, however a recently released pilot study of Wellington based maternity related admissions of women to ICUs by Dr Bev Lawton sheds some light on this issue, (<http://onlinelibrary.wiley.com/doi/10.1111/j.1479-28X.2010.01200.x/abstract>).

One-third of maternal admissions to ICU in her small pilot study were avoidable. This represents a huge human and monetary cost to our society. It is in keeping with the findings of the recent PMMRC reports showing that one-third of all maternal deaths were potentially avoidable.

We submit that to understand the nationwide extent of this issue, all admissions to level 2 or level 3 ICUs of women between the ages of 10 and 55 should be flagged to indicate whether or not they are maternity related, in much the same way that all death certificate notification of females requires this extra information.

Specific to the Auckland region are growing concerns about the increasing number of women suffering significant birth canal trauma. An ACC funded 'Perineal Tear Clinic' was set up in late 2010 at National Women's Hospital following concern about the poor follow-up of women having suffered third degree tear/anal sphincter injury.

Regarding brain injuries to babies ACC released the following revised cost of care for these children, of \$34 million per child, in 2011:

*Between 1 July 2005 and 30 June 2011, ACC received 158 claims for infant brain injuries occurring either at birth or during the following six weeks. Of these, 78 (50%) were accepted. Caring for a client with a serious brain injury caused by treatment before the age of two results in an estimated liability to ACC of \$34 million. This is an average figure, as the duration of support and degree of disability will vary from case to case.*

The *Growing up in New Zealand* study will provide useful longitudinal information around birth events and subsequent admissions to hospital in the first year of life, but we believe that the Ministry should have already been collecting this data over many years and for all births.

The Ministry collects data on hospital-based post partum haemorrhages (PPH) but no information on average blood loss elsewhere. We know from the annual reports that some 90% of births at National Women's Hospital involve the active management of the third stage including the use of an ecbolic (medication to contract the womb immediately after the birth). Good quality randomised trials have generally shown that use of an ecbolic reduces the PPH risk by 50%. However, the LMC choice of management of the third stage in

home births or primary birthing unit births and how this choice affects women birthing in the community, is unknown.

**Clinical Indicators:** We welcome the publication of the first of the annual reports around clinical indicators as a useful baseline in morbidity trends around hospital births

<http://www.health.govt.nz/publication/new-zealand-maternity-clinical-indicators-2009>.

However, we note that only one of the 12 indicators relates to outcomes for babies and even then, to a very small subset of babies - premature ones. Ministry data shows that 91.6% of babies are born at term and only 7.1% of babies are premature. That the other 11 indicators relate exclusively to the maternal experience of birth is, we believe, a measure of the usual Ministry philosophical emphasis on the birth process for the woman over the outcome for the baby. We also believe that the indicators must be viewed in the light of other reports. For example, the PMMRC has expressed concerns about the relatively high perinatal related mortality rate in the Counties Manukau but the region also has a relatively low rate of births by Caesarean Section according the Clinical Indicators report. It may be that these two sets of outcomes are related.

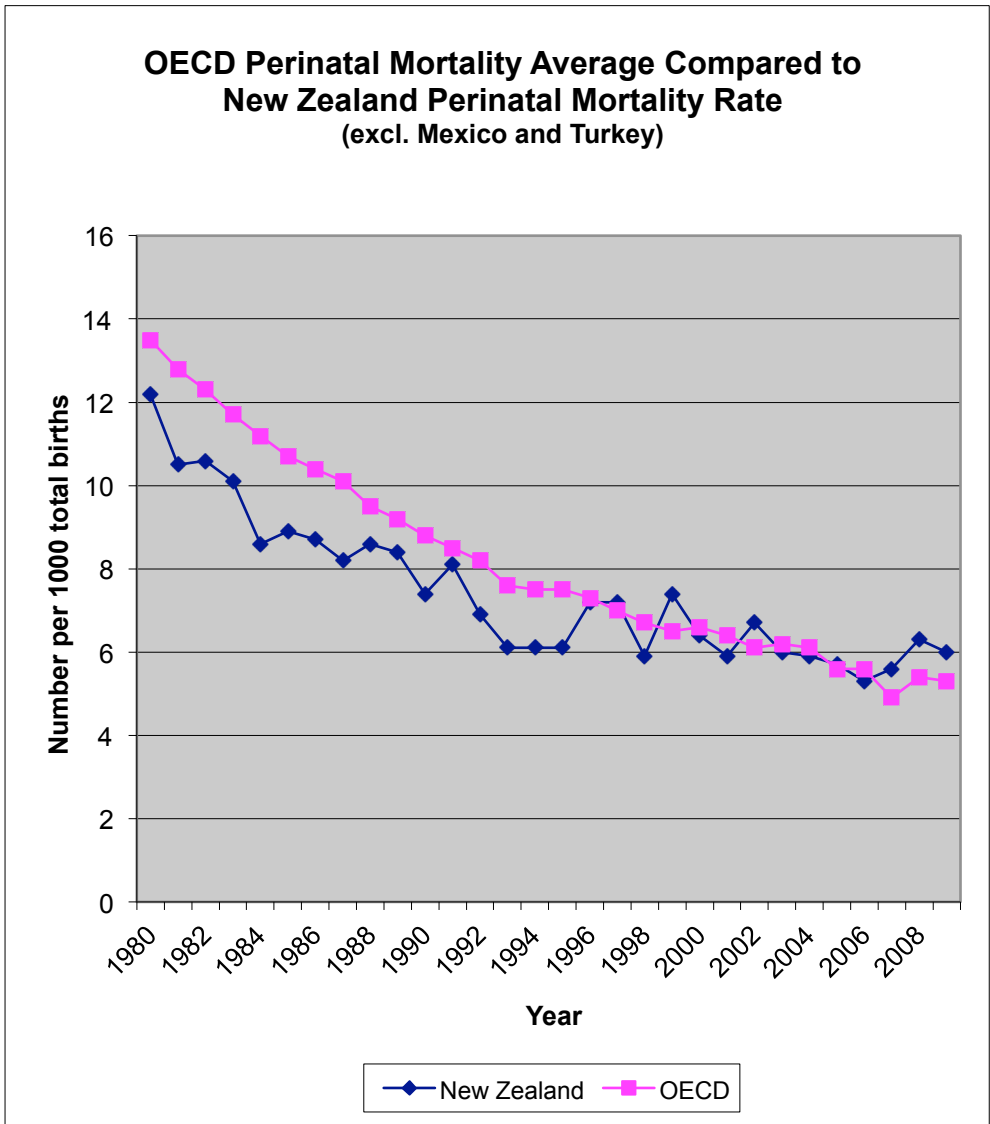
We are puzzled by the following comment in this report:

*There is significant variation between DHBs and between secondary and tertiary facilities in the rates of spontaneous vaginal birth, with facility rates ranging from 51 to 80 percent. This merits further investigation. For some secondary or tertiary facilities, the rates of intervention could be influenced by transfers from primary facilities. Individual DHBs could compare rates of intervention according to where labour was initiated.*

It is the experience of our hundreds of our network women that labour is invariably initiated at home (unless there is a planned Caesarean) regardless of where the birth is intended. What we think would be a better option for comparison in the next report would be not where the labour was initiated where the *birth is intended*.

We submit that the Clinical Indicator list be reviewed at the earliest opportunity to include a wider range of comparable outcome data for babies.

OECD comparative data on perinatal mortality-the gap between us and the rest of the world is widening given our continuing stalled rate of perinatal mortality:



It is also of concern to our network that only in the early part of this year has the Ministry called for project proposals to examine:

*1/ a minimum dataset of demographic, clinical and service use data for all women and babies receiving primary maternity services funded through DHBs.*

*2/ international information on maternity service design, funding and outcomes that enables New Zealand maternity services development to be seen within a wider context. The report produced will assist New Zealand to learn from best practice in other countries.*

We believe that for many years all of this information should have been readily accessible to the public and regularly updated.

In March last year the Ministry recognised deficiencies in its data collection around cancer by setting up the New Zealand Cancer Registry. In similar



fashion we believe that the time is right for the establishment of a comprehensive perinatal data and epidemiology unit, possibly associated with the epidemiology unit initiated in Dunedin by Professor Sir David Skegg and therefore entirely independent of any Ministry functions.

## 4/ The investigation of deaths

**Ministry errors:** Our consumer network is very concerned that the Ministry, in its 2009 submission to the Health Select Committee, contained a number of important errors of fact. We believe that the Select Committee was therefore misled and can only speculate as to the reason for this. An example of error is the comment (paragraph 44) that, “All cases of perinatal death are referred to the Coroner and a number of them result in an enquiry”.

In fact Section 14(2) of the Coroner’s Act 2006 (“the Act”) requires that any person who finds a body to report that finding to the police. The term “body” is defined in section 9 of the Act as a dead person but “... *does not include a dead foetus or a still born child ...*” Essentially the child must show signs of independent life before being regarded as someone for whom a Coronial inquest may be necessary.

**Survey of bereaved parents:** In the most tangible result of our submission and the resultant HSC recommendations, the Ministry has recently for the first time surveyed bereaved parents. It is of note that one-third of these people did not receive adequate information about why their baby died. However we believe that it is vitally important for these people to continue to have a voice in assessing the maternity system.

**Mortality rates:** It is of concern to our network that both the annual perinatal mortality and the annual maternal mortality rates have *not improved* since our last submission. New Zealand’s OECD information, supplied by Chai Chuah, National Director of the National Health Board, is as follows:

Year	Maternal mortality Deaths per 100 000 live births	Perinatal mortality Deaths per 1000 total births
2004	6.8	5.9
2005	8.5	5.7
2006	11.6	5.3
2007	20.0	5.6
2008	9.2	6.3
2009	(not submitted yet)	6.0

In 2009 the Health Select Committee (based on the evidence then available up until 2006) stated that, “... *there has been a relative slowing of the decrease in perinatal mortality over the most recent decades.*” Sadly, it appears that the statement still applies, some three years later.

**PMMRC:** The PMMRC 4<sup>th</sup> report states that around 10% of perinatal deaths were of full term, healthy, full-size babies who died intrapartum (during labour) and whose deaths were largely preventable. The report also details that some 98 perinatal deaths (14% of all perinatal deaths) were potentially avoidable in 2009. 124 of a total of 704 perinatal deaths were potentially avoidable in 2010 (6<sup>th</sup> report).

Further comments from the PMMRC indicate that at least a quarter of mothers of babies who died were not screened for diabetes between 24 and 28 weeks of pregnancy in 2008. This had improved by 2010 (6<sup>th</sup> report).

Recommendations from the PMMRC reports make it clear that care inadequacies have also contributed to other deaths. As noted in the PMMRC submission to the HSC, only 10% of notes are audited by the PMMRC and we believe that the number of avoidable deaths could even be higher if all relevant notes were audited by the Committee.

The PMMRC also noted in its 5<sup>th</sup> report that, *“The New Zealand maternal mortality ratio [19.2/100,000 maternities] is significantly higher than the ratio reported by the United Kingdom for the triennium 2006–2008 of 11.4/100,000 maternities”*. The 6<sup>th</sup> report shows that a similar discrepancy exists for 2010.

**Families not involved:** At no stage in DHB mortality reviews, in the Sentinel Event management programmes of DHBs or in the PMMRC work, are families allowed to be involved. We believe that space should be made for affected consumer involvement in all of these processes. We believe that the setting up of an ‘Adverse Maternity Outcome’ referral and advocacy service for all negative outcomes will greatly improve the support and assistance for these families.

We submit that affected families be offered the opportunity to be involved in DHB mortality reviews, DHB Sentinel Event management programmes and the work of the PMMRC.

We submit that similar local DHB reviews, again including the involvement of affected families, be developed for serious morbidity situations so that the lessons learned can be more readily circulated and more broadly applied.

## 5/ Postnatal Care

**Satisfaction survey:** The most recent Maternity Consumer Survey was released in March 2012. This includes two concerning postnatal care outcomes:

1/ There has been a huge jump in the percentage of women who were discharged from hospital before they felt ready to go home. In the last survey in 2007, 13% of women went home too early but in this one, 28% of women were discharged too early.

2/ One-quarter of women did not receive their minimum of 5 post natal visits. This is a similar level as the previous satisfaction surveys and shows once again that the current modular system of postnatal care payment to LMC midwives along with any effective audit of postnatal LMC visiting is simply not working.

We believe that given this persistent yet crucial gap in care for new mothers, they should be able to choose free care from other providers. This will enhance women's choice. Care from GPs should be accessible at no charge for the quarter of new mothers who are currently failed by the exclusively LMC midwife system. We also recommend that LMC midwives be paid per visit to ensure that women receive their minimum entitlement of visits. One quarter of LMCs are currently allowed to claim for a service which they either have not provided at all or have only partially provided.

The overall quality of the Maternity Consumer Survey does not appear to be of the 'highest standard' as recommended in the HSC recommendations. This comment from the Survey summary comments appears on the Ministry website:

*On average, survey respondents reported notably longer postnatal stays than in 2007. In 2007, 44% of women reported staying more than 48 hours after birth, while in 2011 this had increased to 52%. The number who stayed less than 24 hours is similar, with a small reduction from 27% to 25%.*

In order to determine if the slightly higher percentage of women in this survey being able to stay on in hospital longer is significant compared with the 2007 consumer satisfaction survey, it is essential to know if there was also a higher rate of women who gave birth by Caesarean Section compared with 2007. This is of course because women who have undergone a Caesarean Section birth require a longer inpatient postnatal stay. It should be noted that the overall

Caesarean Section rate is rising in New Zealand steadily each year. In fact we checked with Dr Ashley Bloomfield and were told that the mode of birth was not asked. We believe that it is therefore not possible to comment on the significance of the slightly longer postnatal inpatient stay.

We submit that all future Maternity Consumer Surveys should be of the highest quality as specified by the Health Select Committee recommendation and should address the omissions in questions evident in the one released in March 2012.

## 6/ Lead Maternity Carer (LMC) Training

We note that the HSC recommendation relevant to the training of (Recommendation 9) included the view that “... *with regard to midwives this [postgraduate] training should be for at least a year.*”

The government response to this was that regulatory authorities are the Medical Council of New Zealand and the Midwifery Council of New Zealand and that the Minister of Health cannot require them to make professional requirements compulsory. Recent comment from Sharron Cole, CEO of the Midwifery Council has indicated that the Council is unlikely to require an intern year closely supervised in the hospital system as envisaged by the Health Select Committee. However it is the *Ministry* which approves new Lead Maternity Carers by supplying them with a Health Benefits Payments number in order to access Section 88 payments as independent practitioners. For the sake of public protection, we recommend that provision of a Health Benefits Payments number to any new practitioner be dependent for all new medical and midwifery graduates on the supply of documentation from any DHB that the person has spent at least 12 months in the labour ward of a level 2 or level 3 hospital. This requirement should be implemented with urgency. This should be a requirement for any practitioner wishing to offer their services directly to the public. This simple change will ensure that new graduates are exposed to a much broader range of clinical events and outcomes as well as gaining a greater experience of inter-professional co-operation and teamwork in all sorts of circumstances.

We submit that the provision of a Health Benefits Payments number (enabling independent practice) by the Ministry to any new medical or midwifery graduate be dependent on the supply of documentation from a DHB that the person has spent at least 12 months after graduation in the labour ward of a level 2 or level 3 hospital.

The current postgraduate programme for midwives is called the ‘Midwifery First Year of Practice’ (MFYP). The details are set out by the Midwifery Council on their website. Essentially there are some seminars and group education situations but also approximately one-half a day *per month* of mentorship. Nowhere else in the developed world are midwives with ‘direct entry’ training given so much independent responsibility along with so little direct supervision immediately upon graduation. We believe that the Midwifery First Year of Practice should be renamed the *Midwifery Start of Practice* and be broadened

across the first two years after graduation, and that the first of these two years should be carried out in a level 2 or level 3 hospital environment. This concurs with the 'at least' 12 months of hospital postgraduate internship, as envisaged by the 2009 HSC recommendations.

The effectiveness of the MFYP has never yet been determined. A casual survey of some outcomes was undertaken by the Practice and Research Midwife of the NZ College of Midwives (Lesley Dixon) and published in the midwifery community newsletter (Midwifery News September 2010) but there has never been a formal or independent evaluation of this programme and certainly no specific enquiry of women's views or experiences of having been cared for by new graduates.

Brenda Wraight, the Director of Health Workforce New Zealand, has indicated the cost of the programme. For 2010 it was budgeted at \$1,882,000 across just 125 graduating midwives. This works out at about \$1000 for each monthly half-day meeting per midwife.

We submit that a full and independent analysis be made of the content and effectiveness of the current Midwifery First Year of Practice (involving approximately one-half day per month mentorship), especially from the viewpoint of the mothers who are cared for by these largely unsupervised new graduates.

**Crucial midwifery 'Scope of Practice' gap:** Ms Sharron Cole, CEO of the Midwifery Council, has stated, "*Intubation [placing a breathing tube in the windpipe of someone unable to breathe] of pregnant women is not within a midwife's scope of practice. Intubation of the newborn is an advanced resuscitation task ... Unless they had undertaken advanced training and maintained their skills, midwives would not intubate a newborn*". Our concern is that services are being offered to the public in home birth and primary birthing situations without the public being made aware that such life-saving skills are not easily accessible.

Ms Cole was also unable to specify exactly how many undergraduate hours midwives are required to spend in training in resuscitation skills. It appears that the Midwifery Council does not have a specific minimum requirement for these crucial skills.

In discussing graduate midwives, Ms Cole stated, “... all midwives are required to undertake annual workshops in neonatal resuscitation and maternal resuscitation, the minimum length specified for these being two hours. In every 3 year cycle, midwives undertake a two day technical skills workshop, one day of which is termed a refresher day which is obstetric emergencies and the other a midwifery practice day which covers identified current practice issues. Many midwives attend the PROMPT (1 day course) and ALSO (two day) as well as a number of full day neonatal resuscitation courses in addition to the above requirements.”

We understand from these comments that these resuscitation workshops do not involve intubation of either mothers or babies.

We submit that in the interests of public safety, all LMCs (whether medical or midwifery) should attend the ALSO (Advanced Life Support Obstetric) course annually should they wish to offer their services to the public in home birth or primary birthing unit situations, in order to be competent in skills such as intubation.

In order to determine whether or not HDC and ACC treatment injury complaints are more common in those with less experience, we have approached them for some non-identifiable data but this information is not yet to hand.

**No mandatory disclosure of complaints to new clients:** In discussing the issue of mandatory disclosure of complaints by LMCs to new clients with the Hon. Tony Ryall, we were assured in February that, “... the mandatory disclosure of complaints is a professional requirement of the College [of Midwives]’s *Standards of Practice and concerns about this matter should be discussed with the College*”. However, this assertion was surprising for us, given that no family in our network had ever commented on learning of previous complaints from their LMC herself. So following the Minister’s advice, we raised this matter with Ms Karen Guilliland, the CEO of the NZ College of Midwives. We asked, “*Is it mandatory for midwives to disclose to their clients current and/or historical complaints?*”

Ms Guilliland’s response was, “*The short answer to your question is ‘not as a rule’. There may be cases where a midwife should disclose information voluntarily such as where the Midwifery Council has restricted the midwife’s scope of practice on her practicing certificate, (even though this information is*



*publicly accessible via the website) ... such sharing of information would not be in the same category as a mandatory disclosure of all previous or current complaints.”*

We have therefore concluded that the advice from the Minister’s office is incorrect.

**Section 88 a barrier to GP involvement:** Regarding the (re)training of GPs in maternity, information obtained by our network is that the number of entrants to postgraduate obstetric qualifications training in Auckland has roughly halved between 2006 and 2010 (18 people down to 10) despite the offer of this (re)training being free. As we indicated to the Hon. Tony Ryall in 2008, free training in obstetrics will not attract GPs as the Section 88 funding system does not adequately value the skills they bring to maternity care.

## 7/ Accountability

This is the one point from the 2009 HSC recommendations with which AIM significantly differed. It is the experience of hundreds of families in our network that the complaints process is complicated, not at all transparent and ultimately far from satisfactory.

**Consumer feedback forms:** From the time of our meeting with the Hon. Tony Ryall in 2009, we have advocated that the feedback forms be attached to the Well Child book given to all new parents. It is the experience of the many families with poor outcomes of their maternity experience that they are simply not offered a feedback form. We have no confidence that negative feedback is dealt with effectively at the time of any midwife's bi-annual practice review.

We submit that consumer feedback forms be provided to all new parents detachable from the *Tamariki Ora Well Child* book or else given to all parents at the time of birth registration and that these forms are handled by the relevant DHB.

**Complaints:** it is the experience of our many families that they are often not informed in a timely way that they may be eligible for ACC cover for funeral costs or in other instances, for ongoing care of their treatment-injured children. Most often, once they do approach ACC, the first attempt to make a claim is not accepted. Legal expertise and other advocacy are often necessary to obtain rightful cover entitlements. Complaints to DHBs or to the HDC are, for the families involved, uncertain in outcome and very limited in the redress they can provide. Often getting any kind of result depends on the personal tenacity of the parents. Many bereaved parents or those adjusting to serious disability from adverse unexpected birth events just don't have the capacity to pursue the lengthy complaints processes.

People, who either have a family member unexpectedly die or else have someone become avoidably seriously disabled, surely experience the worst possible results of any interaction with health professionals. Yet only a handful of families within hundreds with these most serious of outcomes are referred to the HPDT (Health Practitioners Disciplinary Tribunal). Families are not routinely told about the role of the HPDT and have no say in whether their case is referred on, often despite serious breaches of the Code of Rights being found.

We submit that an 'Adverse Maternity Outcome' referral and advocacy service be set up to support families through the complex complaints process.

We submit that the Health and Disability Commission consider a possible change to current practice so that all cases of serious morbidity or death resulting from a breach of the Code to the HPDT.

**Case reviews:** Families are not involved in local maternity mortality or morbidity reviews. Sometimes they don't even receive feedback that these events have taken place and what was determined there. They are also not involved in any way in the functions of the PMMRC (see also submissions page 19).

## 8/ Support for families

Despite millions of extra dollars of Government funding flowing into maternity services, support for families has not improved in recent years.

As already detailed, at no stage in DHB mortality reviews, Sentinel Event management programmes of DHBs or in the work of the PMMRC are families allowed to be involved. We believe that space should be made for those directly affected to be involved in all of these processes. As already stated, we believe that the setting up of an 'Adverse Maternity Outcome' referral and advocacy service for all negative outcomes will greatly improve the support and assistance for these families.

There is a great deal of discussion around the issue of supporting families with negative maternity outcomes. For example, the HSC recommendation in 2009 was that, *"We recommend to the Government that the Ministry of Health provide better co-ordinated support through DHBs and community groups for families affected by adverse birth events."* The Ministry submission stated (paragraph 39) that, *"It has been recognised that there is a need to involve affected families more in the process of investigation and reporting back about any improvements in care that result."*

The *Government Response* states that the Ministry is reviewing service requirements for DHBs to provide support services specifically mentioning "bereavement services and support for grief and loss". But ACC data makes clear that treatment injuries leading to avoidable fatalities are only the tip of a rather murky iceberg of injury and disability. The *Government Response* to the above HSC recommendation was so narrowly focussed that families affected by non-fatal birth treatment injuries were essentially overlooked in almost the entire document. The *Response* states, *"The Government supports the need for coordinated support for families affected by adverse birth events, and acknowledges that this support is variable across all DHBs. There is currently a lack of clarity regarding requirements on DHBs to plan and fund these support services for their populations"*. However, nothing has changed at either an official or a practical level from the viewpoint of the hundreds of families in our network.

In his letter to our network dated 10-2-12. The Hon. Tony Ryall noted, *"The Service Specifications for Secondary and Tertiary maternity services require*

*DHBs to provide grief and support services ... If you are concerned that the support is not being provided you should discuss this with the relevant DHB.”*

However, we believe that maternity related mortality and serious morbidity events require nationally consistent high quality and well coordinated responses following more detailed service specifications at Ministry/Minister level. Devolving responsibility for this to individual DHBs as at present currently leaves many affected families unsupported and vulnerable.

Furthermore the third Ministry ‘Maternity Standard’ states, *“All women have access to a nationally consistent, comprehensive range of maternity services that are funded and provided appropriately to ensure there are no financial barriers to access for eligible women”*. It is clear that leadership at a national level is required for this national consistency to meet the specific needs of bereaved women or those coping with birth related disability within the family.

## Conclusions

We have examined eight specific areas of the maternity service using the outline provided by the excellent set of 2009 recommendations made by the Health Select Committee. As with our last submission, we have suggested a large number of practical, low cost initiatives for maternity system improvement.

We have also pointed out our concerns about the factual errors in the submissions to the HSC in 2009 by the Health Ministry. For example, the information around the Coronial investigation of stillbirths which the Ministry incorrectly stated invariably takes place (it never does).

We sincerely hope that our concerns will be noted and that this time in due course effective change will take place in the maternity service, so that we will not find ourselves representing an even larger group of adversely affected families and concerned individuals in yet another three years time.

We wish to express our thanks to the Hon. Tim Macindoe for presenting our petitions to the House and to the Members of Parliament who have heard our concerns in this and the previous Health Select Committee.

The lot of pregnant women, newborn babies and new mothers has *not* improved in the last three years by any measure of the limited outcome data available. We urge the responsible politicians to expect better of their officials and to continue to demand more transparent, practical and effective improvements in the safety and quality of our maternity service for the benefit of those it is set up to serve.

(Please note that we are awaiting further new and relevant data from ACC and the HDC, the Australia and New Zealand Neo-natal Network, a number of DHBs and the four Polytechnics which contain a midwifery school. With permission, we would like to provide the HSC with a supplement to this submission when this further information is to hand).

## Appendix

### **A full list of submissions made during this document:**

We submit that any data from the continuation of the CDHB demonstration project aimed improving inter-professional cooperation in the care of high risk women, be made available and analysed (page 9).

We submit that the relevant Ministry staff review the requirements around conflict of interest for chosen consumer representatives on various committees, according to the State Services Commission best practice (page 10).

We submit that the referral guidelines be completely and urgently re-drawn, using the strongest available evidence base, with the clinical safety of mothers and babies as being paramount rather than the protection of the role of LMC midwives as is the current priority (page 12).

We submit that the standardised electronic clinical notes system be given priority to enable nationwide implementation by 2013 (page12).

We submit that the long-recommended and long-awaited perinatal database and epidemiology unit be established with alacrity; that it be set up independent of the Ministry given the continuing evident gaps in Ministry maternity data (see page 13).

We submit that to understand the nationwide extent of severe maternal morbidity , all admissions to level 2 or level 3 ICUs of women between the ages of 10 and 55 should be flagged to indicate whether or not they are maternity related, in much the same way that all death certificate notification of females requires this extra information (page 14).

We submit that the Clinical Indicator list be reviewed at the earliest opportunity to include a wider range of comparable outcome data for babies (page 15).

We submit that affected families be offered the opportunity to be involved in DHB mortality reviews, DHB Sentinel Event management programmes and the work of the PMMRC (page 19).

We submit that similar local DHB reviews, again including the involvement of affected families, be developed for serious morbidity situations so that the lessons learned can be more readily circulated and more broadly applied (page 19).

We submit that all future Maternity Consumer Surveys should be of the highest quality as specified by the Health Select Committee recommendation and should address the omissions in questions evident in the one released in March 2012. (page 21)

We submit that the provision of a Health Benefits Payments number (enabling independent practice) by the Ministry to any new medical or midwifery graduate be dependent on the supply of documentation from a DHB that the person has spent at least 12 months after graduation in the labour ward of a level 2 or level 3 hospital (page 22).

We submit that a full and independent analysis be made of the content and effectiveness of the current Midwifery First Year of Practice (involving approximately one-half day per month mentorship), especially from the viewpoint of the mothers who are cared for by these largely unsupervised new graduates (page 23).

We submit that in the interests of public safety, all LMCs (whether medical or midwifery) should attend the ALSO (Advanced Life Support Obstetric) course annually should they wish to offer their services to the public in home birth or primary birthing unit situations, in order to be competent in skills such as intubation (page 24).

We submit that consumer feedback forms be provided to all new parents detachable from the *Tamariki Ora Well Child* book or else given to all parents at the time of birth registration and that these forms are handled by the relevant DHB (page 26).

We submit that an 'Adverse Maternity Outcome' referral and advocacy service be set up to support families through the complex complaints process (page 27).

We submit that the Health and Disability Commission consider a possible change to current practice so that all cases of serious morbidity or death resulting from a breach of the Code to the HPDT (page 27).