Response by Birth Trauma Association to the women's health strategy consultation

Introduction

The Birth Trauma Association is a charity founded in 2004 to support parents who have been traumatised by the experience of giving birth or by witnessing a traumatic birth. At the time we were founded, there was little awareness that it was possible to develop PTSD as a result of traumatic birth. That has changed, and a 2017 review of research suggests that one in 25 women develop enough symptoms for a full PTSD diagnosis after birth (Yildiz et al 2017). That translates into roughly 25,000-30,000 women a year in the UK. Many more feel traumatised by birth and may experience some PTSD symptoms but not enough for a PTSD diagnosis. Others develop postnatal depression as a result of the trauma.

We largely support parents (mostly mothers, but some fathers) through a Facebook group that has grown to nearly 11,000 members. Parents share their stories of traumatic birth and offer support to each other. It is a rich source of anecdotal data about women's traumatic experiences in childbirth. We also offer a peer support service over email, which we are extending to phone support.

In the UK, more than four in five women give birth at least once. Giving birth is therefore a significant experience in the lives of most women. Yet our experience as a charity over the past 17 years is of hearing the same stories over and over again: of women's pain being dismissed, of poor communication, of mistakes being made during labour and of deeply inadequate postnatal care. We welcome the government's decision to develop a strategy for women's health and believe that if problems in maternity care were successfully addressed, then many other elements of the strategy would fall into place.

Our submission to the consultation is based partly on our experience of supporting women and listening to their stories over a number of years, partly on a survey of 798 members of our Facebook group that we conducted in 2020 and partly on the growing body of research into women's experiences of childbirth.

Women's voices

Probably the most frequent complaint we hear from women is that they were not listened to during labour or postnatally. One study of traumatic birth (Hollander et al 2017) found that many women believed that their trauma could have been reduced or prevented by better communication, with 39% citing "communicate/explain" in response to a question about what the caregiver could have done to prevent the trauma.

Complaints we hear frequently include:

- Requests for pain relief (particularly epidurals) being denied
- Health professionals refusing to believe a woman when she says she is in labour, or that labour is far advanced

- Women not being informed about events that are happening during labour – some women report only learning about key events in their labour after requesting their notes
- Intimate examinations or procedures (such as cervical sweeps) being carried out without consent being sought
- Women being laughed at or shouted at during labour
- Women being denied support or help (including breastfeeding help) on the postnatal ward
- Women having their postnatal mental health problems dismissed

For example, our 2020 survey showed that 38% of women reported procedures being carried out on them without their consent, and 34% saying that requests for pain relief had been turned down.

These are some of the comments made in the free text section of our survey:

"I was shouted at, laughed at, said it's nothing, as easy as going to the toilet and I'm making it wrong (not pushing properly), the baby was stuck under my bone with her arm – shoulder dystocia."

"Midwives wouldn't listen to me when I told them I was in full labour, left me in a bed covered in my blood & induction paraphernalia after my waters broke & still wouldn't let me call my husband, refused me an epidural because according to them I wasn't in labour, left alone in the dark with back to back contractions feeling like I couldn't breathe, finally after I got the strength to clamber out of bed to get help, a receptionist helped me back to bed & then got a midwife who finally agreed that maybe I should be in a delivery suite only for my daughter's head to be born midway and then they asked me (with baby's head hanging out) to move myself from the ward bed onto the delivery suite bed. My husband missed the birth of our daughter & my life has never been the same since. I barely sleep because of the flashbacks, hurt & anger."

Postnatally, women frequently report a lack of care that borders on the callous. Physically unwell, exhausted or even unable to walk after a traumatic birth they may find that they are expected to fend for themselves (see eg de Graaff *et al* 2018). Traumatic birth (particularly involving loss of blood) can make breastfeeding harder, and women often find themselves struggling and failing to breastfeed, the sense of grief and loss adding to the distress of a difficult birth. At this stage, when support is particularly needed from health professionals, it is often not forthcoming.

Many women report having their mental health problems after birth ignored or minimised. Some mention having their PTSD misdiagnosed as PND, for example, or being told to "move on" or be grateful that their baby is healthy. From our survey:

"It has been extremely difficult to get treatment for PTSD on the NHS, and any treatment I have had has been very short and the damage of being discharged despite no improvement …has been hugely damaging and triggering (asking for help in the hospital and not getting it was a huge part of my trauma). Every time I read in a birth trauma book or article that 'if

you think you have PTSD talk to your GP and you will get help' it makes me deeply sad as I talked to my GP, mental health midwife on the ward (didn't ask any ptsd questions), my midwife, my health visitor, and it was only when I found the perinatal mental health team's number nine months postpartum and phoned them in anger asking why they kept rejecting my GPs referral that they finally took me on."

It's common for the six-week postnatal check to focus on the baby rather than on the woman's physical or mental health. This represents a missed opportunity to identify problems such as continued pain from tearing or psychological symptoms such as flashbacks.

Although four percent of women experience PTSD after childbirth, the figure rises to 15% for high-risk women (Grekin and O'Hara 2014) – typically those who have previously experienced trauma or mental health problems. We would like to see a much greater focus on trauma-informed care during pregnancy and childbirth, so that women who have traumatic histories (e.g. refugee women, women who have experienced sexual abuse, or women who have had a previous traumatic birth) are not retraumatised during childbirth.

Information and education on women's health

One thing women often tell us is that they weren't prepared for the reality of birth. Antenatal education tends to minimise the things that can go wrong, perhaps out of a desire not to frighten women. Emergencies are commonplace in childbirth, however, and the experience of an emergency can be more frightening if the woman doesn't expect it. Events such as postpartum haemorrhage, which affects five percent of women, are a routine matter for a maternity team but terrifying for a woman who feels she may be dying.

We also find that health professionals are not good at informing women about the risks relating to childbirth. If a patient goes into hospital for, say, a gall bladder operation, they will be informed, in precise terms, of the risks attached to the operation. This doesn't happen in childbirth. Indeed, there is a tendency by some hospitals to emphasise the risks of caesarean birth while not informing women of the risks of vaginal birth, in particular instrumental birth. Many women who come to us have severe injuries as a result of forceps birth, for which they felt completely unprepared. We are particularly concerned at the paternalistic attitude of many hospitals in their approach to women's decision-making, such as the refusal of Oxford University Hospitals NHS Foundation Trust, until recently, to allow maternal-request caesarean – in direct contravention of NICE guidelines.

We also believe that pregnant women should be given information that takes into account their individual risk profile. The Montgomery vs Lanarkshire Health Board ruling (UKSC 2015) made it clear that Nadine Montgomery, because she had diabetes, should have been informed that she had a greater risk of shoulder dystocia. She was not informed of the increased risk, and the subsequent shoulder dystocia birth meant that her son was born with serious disabilities. The ruling should have obliged hospital trusts to be open and honest with women about their individual risks, but this has not happened in all cases. Factors such as a woman's size, her ethnicity and her age, among others, all contribute to her individual risk profile. Without information, women can't give informed consent.

Many women tell us that they are also poorly informed about what to expect postnatally. One respondent to our survey wrote:

"Wish I'd had more info on possible experiences post birth & what might be normal/abnormal as felt terrified the whole time. It's only now 2 years after having son that I've been given info on scar tissue care & that's cos I asked at a smear. Just thought I had to put up with penetrative sex being painful."

In recent years it has become clear that a significant minority of women are ignorant of their own anatomy and the related terminology. A 2017 survey found that 44% of women were unable to correctly identify the cervix as the neck of the womb, for example (Jo's Cervical Cancer Trust 2017). Obviously this makes clear communication even more important, particularly among women who are not native English speakers. Yet the language used by caregivers ("trial of scar," "fetal distress", "rupture of membranes" and so on) can often be opaque. We'd like to see more thought given to developing terminology that women find comprehensible.

Women's health across the life course

Physical injuries as a result of childbirth can have a longstanding effect on women's health. For example, some women remain in constant pain, or experience urinary or faecal incontinence, as a consequence of childbirth injuries. More than 30% of women who give birth vaginally suffer trauma associated with future morbidity such as "female pelvic organ prolapse, sexual dysfunction and anal incontinence" (Skinner 2019, p.37). Approximately 6% of first-time mothers giving birth vaginally experience third- or fourth-degree tearing, also known as obstetric anal sphincter injury (OASI) (RCOG 2019). Different research studies have shown an incidence of between 13% and 36% of major levator trauma (avulsion) in first-time mothers giving birth vaginally (Skinner 2019, p.37).

These injuries are often minimised or ignored by health professionals, and the effect on mental wellbeing is under-recognised (Kettle and Tohill 2008). Research in Australia looked at a retrospective cohort of 200 women who had experienced OASI (Evans *et al* 2020). Four years post-OASI there was "considerable ongoing morbidity" (p.560) with more than half experiencing ongoing symptoms. Of those, 38% were experiencing significant ongoing bowel symptoms including either flatal incontinence, fecal urgency or fecal incontinence. Nearly two-thirds reported sexual dysfunction. About a quarter of all the women surveyed reported postpartum depression or anxiety. We have also been approached by women with severe and ongoing pudendal pain that has driven them to despair. One woman in our survey wrote:

"I delivered my twins with a vaginal birth on theatre but was prepped for a c section too so numb from the chest down. I had a whole team of people in theatre watching me give birth. After the delivery I was in the HDU for a night and in higher amounts of pain. At that point I wasn't offered effective pain relief. It was as though they didn't believe me. Years later I was diagnosed with pudendal neuralgia and a labral hip tear and coccyx pain."

These kinds of injuries can affect a woman's ability to work, her self-esteem, her relationship with her partner and her decision whether to have another child. Sometimes

the impact of a physical injury during birth doesn't become apparent until menopause, when women may experience organ prolapse.

We would like to see more training of health professionals – midwives, obstetricians, GPs and health visitors – in childbirth injuries, so that they can be identified and treated promptly. Research into prevention of these injuries would also be welcome.

Similarly, mental health problems as a consequence of traumatic childbirth can affect women for a long time if left untreated. We are sometimes approached by women who still feel the effects of a traumatic birth that happened 20 or more years ago.

We would like to see recognition of the extent of postnatal PTSD in women. The most authoritative recent research suggests that one in 25 mothers experience postnatal PTSD. This means that birth is one of the biggest causes of PTSD in the UK (probably coming second only to sexual abuse and rape). Yet, although women are screened routinely for postnatal depression, they are not screened for PTSD and because many don't know it exists, they may not seek professional help for their symptoms. Anecdotally, we know that some women's PTSD is misdiagnosed as PND.

We welcome the planned launch of new perinatal mental health services in England. However, because diagnosis of postnatal PTSD is often delayed until a year or more after giving birth, some women may not be able to access these services. We feel this could be addressed either by a concerted effort at earlier diagnosis – through routine screening, as suggested above – or by recognising that postnatal mental health problems may continue well over a year after birth and making sure appropriate help is available.

Two treatments are recommended for PTSD: trauma-focused CBT and EMDR (eye movement desensitisation and reprocessing). Both are highly effective, but waiting lists for referral to these therapies on the NHS can be several months. We would like to see more therapists trained in these techniques and available on the NHS to women who need them.

We know that women can also be helped by peer support, and it would be good to see government investment in this type of therapeutic support. As a charity, we support thousands of women, but we do not have an external source of funding and we are run mostly by volunteers.

Women's health in the workplace

Traumatic childbirth can have an impact on women's ability to work, both because of physical injury and mental distress. One woman in our Facebook group still finds sitting down immensely painful years after giving birth. She had to give up her job as a writer and take a job as a supermarket worker because it allowed her to stand up. Another woman, Gill Castle, had to leave her job as a police officer as a result of her physical injuries. (Gill now has a public profile taking on physical sporting challenges to raise money for us.) As well as having an impact on the woman herself there is an economic cost in the loss of talented women to the workplace.

The psychological symptoms of PTSD – flashbacks, anxiety, avoidance – can also make it hard to work, and research has found that it can lead to people losing their job (Jason, Mileviciute, Aase *et al* 2011). This is particularly the case if the work setting is a reminder of the trauma – we have found that women who previously worked in hospitals or clinics sometimes find it impossible to return to work.

Research, evidence and data, e.g. aspects of health or medical research that overlooks or neglects women's perspectives or experiences and the consequences of this

Clearly maternity research is by its nature focused on women rather than men. However, our view is both that there is not enough research into either the causes of maternal morbidity or ways in which maternal morbidity could be prevented. Neither is there adequate research into the experience of morbidity on women themselves. Finally, where research data exists, it is often not applied to the real-world setting. (Our research officer is currently running a project, Maternity Outcomes Matter, that aims to reduce the harm to mothers and babies during birth: http://maternityoutcomesmatter.org.uk/)

In maternity, the biggest causes of injury to mother and baby, and hence the greatest cause of litigation, are related to traumatic vaginal birth. One study (Baskett *et al* 2007) found that babies born by forceps have a fourfold higher rate of trauma than those born by spontaneous vaginal delivery, while the rate for those born by Ventouse is three times higher. While trauma can occur during caesarean birth, the rate is 60% lower compared with vaginal delivery. This is a clear example of where data is available but isn't being applied. We would like to see more effort put into reducing deaths and injuries, in particular by offering planned caesareans to women with clear physical risk factors, such as a large or badly positioned baby.

Maternity cases account for 50% of NHS litigation payments, though only 10% of the claims (Yau *et al* 2020). This is because brain injury at birth requires funding to pay for a lifetime of care. The NHS pays roughly £12.7m a week for the costs of obstetric harm. While improving the safety of maternity care is essential for the wellbeing of mothers and babies, it is also imperative to make sure that money currently spent on litigation is transferred to health care.

Similarly, we believe that women's experiences of childbirth are often underplayed and minimised in research. The incidence of ani levator damage, for example, as a result of vaginal childbirth, continues to be underestimated despite recent research in Australia, mentioned earlier, showing rates to be relatively high.

Between 600,000 and 700,000 women give birth every year in the UK. It would be immensely helpful if relevant data from individual maternity units, particularly on birth injuries, could be routinely collated and analysed to improve outcomes. (The continued use of paper records is a hindrance to this, though we appreciate this is changing.) There is also huge potential for maternity units to improve through learning. This can be done both by implementing a more open, blame-free culture internally where health professionals are encouraged to share their mistakes, and by sharing good practice between maternity units.

We would also like to see performance in maternity units evaluated according to outcomes rather than process. The tendency of some units to focus on process has, we believe, been disastrous. The Shrewsbury and Telford NHS trust boasted for several years of its low caesarean rate. We now know, thanks to the Ockenden Review, that in the period the trust was focusing on reducing caesareans, mortality and morbidity rates among mothers and babies were unnecessarily high. If someone (either at the trust itself or at the regulator) had identified the high mortality rate at Shrewsbury and Telford and investigated why it was happening, many lives might have been saved. Instead, complaints by parents were brushed under the carpet and complainants treated as if they were making a fuss about nothing – something we also saw happen in Morecambe Bay and East Kent.

We know that certain interventions in maternity units can improve outcomes. For example, in North Bristol NHS Trust, training from the Practical Obstetric Multi-Professional Training (PROMPT) charity led to a 50% reduction in incidence of hypoxic brain injury and a 100 per cent reduction in permanent brachial plexus injuries to babies. Litigation claims have been reduced from £25 million before the launch of PROMPT to £3 million in the 10 years that followed. (See www.promptmaternity.org for more details.)

The PROMPT training is partly about ensuring that teams have the technical competence to respond in the right way in a given emergency, but it is also about improving team-working and fostering a learning ethos founded on a collective commitment to continuous improvement and critical reflection. It would be good to see other maternity units take a similar approach – and we see no reason why that shouldn't happen. A constant frustration for us as a charity is to see the same mistakes made over and over again, unnecessarily.

At the end of 2020, the Ockenden Review made seven important recommendations for improving care (enhanced safety; listening to women and their families; staff training and working together; managing complex pregnancies; risk assessment throughout pregnancy; monitoring fetal wellbeing; and informed consent (Ockenden 2020). We were encouraged to see Liverpool Women's Hospital take steps to implement these recommendations and we hope other hospitals will follow suit.

Outcomes for black and minority ethnic women are a particular concern. MBRRACE reports have repeatedly shown much higher maternal mortality rates for Black women in particular, but morbidity and stillbirth rates are also higher amongst Black and other ethnic groups (see eg MBRRACE 2020). Although MBRRACE provides useful information on causes of maternal mortality, the causes are not broken down by ethnicity, and it would be hugely helpful if more granular data could be collected that would enable that analysis to be made. We would welcome more research that focuses specifically on the outcomes for Black, Asian and minority ethnic women and their babies so that the causes can be tackled.

We know that a substantial minority of pregnant women have a history of trauma, including rape and sexual abuse, previous traumatic birth, female genital mutilation (FGM) and refugee status. We would like to see more research into the impact of trauma, and more maternity units trained in trauma-informed care, so that these women can be better supported during labour and birth and avoid being retraumatised.

One particular concern we have is the defensiveness of hospitals when it comes to complaints and a readiness to cover up mistakes. We know from numerous reviews, such as the Ockenden and Kirkup investigations, that there is a culture of cover-up in maternity units. We are alarmed at the frequency with which women tell us that their notes contain false or inaccurate information, or where they have been told by the hospital that their notes are missing. We can only truly improve maternity care if hospitals are willing to own up to mistakes.

Covid-19 impact

Most of the information we have on the impact of Covid-19 is anecdotal, and comes from what women have told us in the past fifteen months since restrictions were put in place. Common complaints include having to experience scans and antenatal appointments alone, and in particular, having to go through much of labour without their partner present. One woman describes waking up alone after her baby was born under general anaesthetic and not knowing where her partner was or whether her baby was dead or alive. She was physically unable to reach for the bell and was not attended to for three hours. Some have described being required to wear masks during labour. Postnatally, access to midwives and health visitors has been limited, and women have felt isolated.

These are quotes from our 2020 survey:

"Due to the current restrictions in hospitals, my husband had to leave shortly after the birth, I didn't see him again until 2 days later when he came to pick us up. This is obviously unavoidable at the moment and I completely understand that it has to be done, but it does make things very difficult."

"Due to Covid-19 my partner was not allowed into theatre for the delivery. I was only notified of this prior going into theatre. Not even my midwife was allowed into theatre as she wasn't fit-tested for the masks…Because of the pain and exhaustion I was not in the right mindset to make the right choices during labour and delivery. I feel like I could have had more support from staff to make the right choices."

"Covid situation definitely made it all worse. I couldn't see my baby girl for over 24 hrs after she was born as she was taken to a unit in a different county and visiting was so restricted. I feel like I am still grieving for those first few hours."

What we saw during the pandemic was an exacerbation of the way mothers are frequently treated in non-Covid times – with their own needs put last rather than first.

Conclusion

The difficulties we see in maternity care – poor communication, a refusal to listen to women, a tendency to minimise women's pain or women's concerns, an unwillingness to gather and analyse data – are emblematic of the problems women experience from the health care system throughout their lives. We believe that there is, quite simply, a reluctance to take women's health seriously. A women's health strategy that addresses the problems in maternity care, such as poor communication and a reluctance to implement

good practice, would go a long way to addressing the problems in women's health care in general.

References

Baskett T.F., Allen V.M., O'Connell C.M., Allen A.C.(2007) 'Fetal trauma in term pregnancy'. *Am J Obstet Gynecol*. Nov;197(5):499.e1-7. doi: 10.1016/j.ajog.2007.03.065. PMID: 17980187

Yau, C.W., Leigh, B., Liberati, E., Punch, D and Dixon-Woods, M. and Draycott, T. (2020) 'Clinical negligence costs: taking action to safeguard NHS sustainability' *BMJ* 368 doi: https://doi.org/10.1136/bmj.m552

Evans, E., Falivene, C., Briffa, K., Thompson, J. and Henry, A. (2020) 'What is the total impact of an obstetric anal sphincter injury? An Australian retrospective study'. *International Urogynecology Journal* 31, 557–566

de Graaff L.F., Honig A., van Pampus M.G., Stramrood C.A.I. (2018) 'Preventing post-traumatic stress disorder following childbirth and traumatic birth experiences: a systematic review.' *Acta Obstetricia et Gynecologica Scandinavica 97*, 648–656
Grekin R., O'Hara M. (2014) 'Prevalence and risk factors of postpartum posttraumatic stress disorder: a meta-analysis.' *Clinical Psychology Review 34*, 389–401.

Hollander, M., van Hastenberg, E., van Dillen, J., van Pampus, M., de Miranda, E. and Stramrood, C. (2017) 'Preventing traumatic childbirth experiences: 2192 women's perceptions and views'. *Archives of women's mental health*, *20*, 4, 515–523.

Jason, L., Mileviciute, I., Aase, D., Stevens, E., Digangi, J., Contreras, R., and Ferrari, J. (2011) 'How Type of Treatment and Presence of PTSD affect Employment, Self-regulation, and Abstinence.' *North American journal of psychology 13*, 2, 175–186.

Jo's Cervical Cancer Trust (2017) 'Half of women don't know what the cervix is' https://www.jostrust.org.uk/node/666780

Kettle C. and Tohill S. (2008) 'Perineal care'. *BMJ Clinical Evid*ence *24*, 1401.
PMID: 19445799

MBRRACE-UK. (2020) *Saving Lives, Improving Mothers' Care Rapid Report: Learning from SARS-CoV-2-related and associated maternal deaths in the UK March – May 2020* Oxford: National Perinatal Epidemiology Unit, University of Oxford

Ockenden, D. (2020) *Emerging Findings and Recommendations from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust*, HMSO.

RCOG (2019) 'New information resource on obstetric anal sphincter injury launched' https://www.rcog.org.uk/en/news/new-oasi-patient-information-launched/

Skinner, E. (2019) *The link between somatic and psychological sequelae of traumatic vaginal birth*. PhD thesis. University of Sydney.

UKSC (2015) 'Montgomery (appellant) v Lanarkshire Health Board (Respondent) (Scotland)'. https://www.supremecourt.uk/cases/docs/uksc-2013-0136-judgment.pdf

Yildiz P., Ayers S., Phillips L. (2017) 'The prevalence of posttraumatic stress disorder in pregnancy and after birth: A systematic review and meta-analysis.' *Journal of Affective Disorders 15,* 208, 634–645.