THE MAKE BIRTH BETTER SURVEY 2019: THE CIRCLE OF TRAUMA FOR PARENTS AND PROFESSIONALS

MAKE BIRTH BETTER CIC

APRIL 2020

#THINKTRAUMANOW

DEAR READER,

The data in this report were collated a year ago during Spring/Summer 2019. At the time, we spoke to parents and healthcare professionals. Our study showed 30% of new mums suffering from mental and/or physical trauma following their birth, are not being given the support they need to cope. These findings were the first step in reflecting what might be happening on a larger scale in the UK – which could potentially affect 200,000 women in Britain each year.

But this is before we were hit by a pandemic.

From our study we were able to draw some other strong conclusions – namely that birth professionals, partners and children are deeply affected by birth trauma too. Many midwifery and obstetric staff are affected by vicarious trauma because of the events they have seen, the conditions they are working in and a lack of emotional support. But again, this is pre-Covid-19. Now, our concern is that trauma will skyrocket for families and staff.

We stand by the conclusions and calls to action we put forward in our original report which follows this cover note. However, in light of the Covid-19 pandemic, we need to talk specifically about how to tackle the traumatic events unfolding right now. There will be a new wave of trauma in the months ahead and we must be ready for it.

Which is why trauma is more important than ever to prevent, recognise and treat.

OUR RECOMMENDATIONS

1. We need to focus on prevention as much as possible now. How?

    a. On our social media channels, we are highlighting birth stories where women felt 'held', supported and empowered, and examples of maternity staff and services providing person-centred, collaborative care despite unusual circumstances.
    b. On our website we list resources encouraging a sense of support, safety and solidarity.

2. Recognition of symptoms must be timely and we must start now. We expect for the peak in trauma-related symptoms to come in the months, and years, ahead. It is imperative that we acknowledge the trauma impact on both parents and professionals through monitoring and support in the short term.

3. There must be access to specialist, evidence-based, trauma-focused care for all which includes both parents and birth professionals in the long-term.

OUR CALLS TO ACTION

National and local NHS leaders must:

1. Address trauma prevention for maternity staff and parents.

2. Think long-term about trauma treatment for maternity staff and parents in the future.

3. Act on the requests from Birthrights and The Royal College of Midwives (RCM) for maternity services to be ring-fenced and for all women to be offered a safe and positive childbirth experience and ensure that new NHS England clinical guidance is followed

WE ARE LAUNCHING #THINKTRAUMANOW

Make Birth Better are calling out to parents(to-be), frontline workers and everyone else who cares passionately about changing the system around birth to join our mission. To take a stand and urge policy makers to think about trauma prevention and treatment. Now, more than ever.

So, we are launching #thinktraumanow: we call for everyone to contact their local MP to ask them how they will ensure that local maternity services are ring-fenced and how will they prioritise trauma prevention now, as well as trauma-focused treatment later. There's an email draft for people to use available on our website: www.makebirthbetter.org.

We also encourage everyone to download and share our #thinktraumanow Instagram tile together with a picture of them hitting the send button on the email to their MP. Again, details are on our website or Instagram feed @birthbetter.

As with the pandemic, together we are strong.

Join us and #thinktraumanow!

Wishing you all well,

The Make Birth Better Team

PRODUCED BY:

Caroline Ingman, Rebecca Moore, Janice Smith, Emma Svanberg & Nikki Wilson

CONTRIBUTORS:

Susan Ayers, Professor of Maternal and Child Health, City, University of London

Sakina Ballard, Make Birth Better parent ambassador & Founder, Real Birth Project

Debra Bick, Professor of Clinical Trials in Maternal Health, Warwick University

Maria Booker, Programmes Director, Birthrights

Julianne Boutaleb, Consultant Perinatal Psychologist

Ruth Butterworth, Consultant Clinical Psychologist

Sheena Byrom OBE, Midwife Consultant and Director All4Maternity.com

Debbie Chippington-Derrick, Chair of Trustees, Association for Improvements in Maternity Services

Rowan Davies, Head of Policy and Campaigns, Mumsnet

Elizabeth Duff, NCT and women's health advocate

Rosie Duffield, MP for Canterbury

Jane Gibbons, Consultant Clinical Psychologist

Kathryn Gutteridge, President of Royal College of Midwives

Milli Hill, Founder & Director, Positive Birth Movement

Sally Hogg, Head of Policy and Campaigning at the Parent-Infant Foundation

Karen Joash, Consultant in Obstetrics and Gynaecology

Michael Keighley, President, MASIC

Punam Krishan, GP

Lucy Marks MBE, Independent Consultant Clinical Psychologist

Sally Pezaro, Academic Midwife and Researcher, Coventry University

Emma Jane Sasuru, Founder of Unfold Your Wings

Trudi Seneviratne, Chair of Perinatal Faculty, RCPsych

Judy Shakespeare, GP (Retired), RCGP Clinical Champion for Perinatal Mental Health 2014-17

Rebecca Steinfeld, maternity researcher and campaigner

Kim Thomas, CEO, Birth Trauma Association

Maureen Treadwell, Co-Founder, Birth Trauma Association

Alexandra Thornton, Clinical Psychologist

Gill Thomson, Reader in Perinatal Health, UCLAN

Alison Wright, Consultant Obstetrician & Gynaecologist

With thanks to Humaaans illustration library

WHAT IT FEELS LIKE TO RECOVER FROM BIRTH TRAUMA

Sakina Ballard, Make Birth Better Parent Ambassador.

In 2011 I gave birth to my first child. The experience was long, exhausting, shocking and physically as well as emotionally destructive as I was left with severe perineal damage.

The birth was the start of what would be years of difficulty as I navigated motherhood without any regular external support apart from my partner, who was also traumatised by our birth.

> *Like many women who have had difficult experiences I was riddled with feelings of guilt and shame, around birth but also breastfeeding, bonding with my baby and my own abilities in motherhood. I was determined to keep going and make it right, even though I did not know what was wrong.*

In 2013 when pregnant with my second child I realised I needed more help and I went to GP and asked for talking therapies. I had three separate courses of Cognitive Behavioural Therapy via my local talking therapies services.

The CBT after birth was useful as it allowed my to start to re-establish the thoughts in my mind and take back some control in my life which had felt lost. I had become so lost in the trauma and put coping mechanisms in place that were denying my own needs.

In the short-medium term CBT was useful, my feelings seemed more manageable and I felt like I was starting to sit back in the driving seat of my life.

However I found that the emotional charge around birth and difficult feelings of guilt and regret were still coming up in uncontrollable ways. I had mastery of my thoughts but not my feelings and memories which were keeping me in my past trauma. I was stuck with challenging feelings that were present each day as I parented my son and subconsciously I was acting them out through overcompensation.

I thought I would never feel well.

It was only after trying a number of different therapies and treatments that I started to feel that my traumatic experience was resolved. These included: Rewind technique with a Human Givens psychotherapist, Reiki, breathing, yoga and hypnobirthing.

Now 9 years later I finally feel like I have the understanding and relationship with my son I had hoped & dreamed of before birth. However it's come through a vast amount of self-motivated hard work & whilst I'm so grateful, there will always be a loss and grief in my heart for the experiences we didn't have - those precious years we will never get back and the suffering this journey has caused him, all of which could have been avoided or reduced.

CONTENTS

EXECUTIVE SUMMARY

Make Birth Better, a Community Interest Company dedicated to reducing the impact of birth trauma for all, conducted two surveys in 2019. These targeted access to support after a traumatic birth and staff training and support needs for maternity, medical and mental health staff.

Birth trauma refers to symptoms of trauma related to birth, as well as the perinatal experience. **1 in 25 women experience PTSD after childbirth, and 24% of women report an element of their birth as traumatic**. [Czarnocka & Slade, 2000]. Recent research has also highlighted the prevalence of vicarious trauma in midwifery and obstetric staff.

We know that the perinatal period is a particularly vulnerable time [MMBRACE, 2019] and women, birthing people and their partners are too often met with a disjointed, reactive service.

We need to talk about trauma for all. The circle of trauma is affecting both parents and professionals.

Key findings of our surveys, outlined in our infographic, include:

- Only 27% of women had ever been asked about their birth experience
- Only 25% of women felt they received the right help after seeking support for their birth trauma
- 30% of women felt they were not offered the support they needed at all
- Only 13% of women who had received psychological help felt it had resolved their birth trauma
- 73% of professionals had never had any specific training on birth trauma

Our report further describes the current context of maternity services, recent policy changes and the impact of third sector organisations in improving access to support for women.

We conclude:

- The lack of awareness and training in birth trauma highlighted in this report, alongside a continued lack of individualised, continuous care may currently be contributing to the high rates of birth trauma.
- NHS services are not currently adequately meeting the needs of women and partners traumatised by birth, in preventative measures, service provision and quality/effectiveness of available support.
- There is a need for all staff to receive ongoing specialised training and support in perinatal mental health care and training including birth trauma alongside bespoke reflective practice and supervision.
- There is a need for all women, birthing people, partners and families to enter a trauma informed maternity system where every member of the team is trauma aware.

We call for:

- ALL maternity and perinatal mental health services to look at the training and wellbeing need of staff teams for the prevention, assessment and treatment of birth trauma (for women, birthing people and partners as well as vicarious trauma themselves).
- Rapid and repeated assessment of birth trauma for all women to ensure we have clear national statistics on birth trauma rates using City Birth Trauma scale administered by health visitors and GPs, and that this data is collated in an accessible format.
- Clearer adherence to current guidelines to ensure all women, birthing people and their partners have rapid access to local, evidence based trauma focused care which is monitored nationally, to ensure best practice treatment.

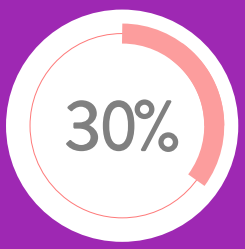
THE MAKE BIRTH BETTER SURVEY 2019: THE CIRCLE OF TRAUMA FOR PARENTS AND PROFESSIONALS

THE CIRCLE OF TRAUMA BETWEEN PARENTS AND PROFESSIONALS IS AFFECTING TOO MANY LIVES

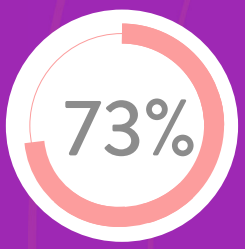
1 in 25 women experience PTSD after childbirth, and at least 20% of women experience some symptoms of trauma.

PARENTS

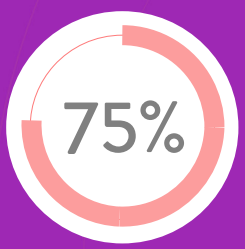
#THINKTRAUMANOW



OF WOMEN WHO EXPERIENCE BIRTH TRAUMA ARE NOT OFFERED THE SUPPORT THEY NEED



OF WOMEN WERE NEVER ASKED ABOUT THEIR BIRTH EXPERIENCE



OF WOMEN FELT THEY DID NOT GET THE SUPPORT THEY NEEDED

We asked **343** women about the support they received after a difficult birth experience

The help was at the same hospital as the birth. I was kicked off for missing too many appointments. ***Attending those appointments always gave me anxiety attacks***

I did over the phone CBT but it ***was too script led, didn't address core issues*** *or allow me to talk about the anxieties PTSD was fuelling*

I felt everyone addressed me as checking boxes not a genuine interest, ***I wish so much that I had been asked about my birth***

I was dropped like a hot potato once my son was 1*. Even though I was midway through treatment and told to self refer back to regular mental health services*

PROFESSIONALS

#THINKTRAUMANOW

H

We asked 332 maternity & mental health professionals on working with birth trauma

73%

HAD NEVER HAD ANY SPECIFIC TRAINING ON BIRTH TRAUMA

62%

SAID SPECIFIC BIRTH TRAUMA SKILLS WERE MOST REQUESTED TRAINING NEED BY STAFF

63%

SAID THE MAIN BARRIER TO BIRTH TRAUMA PREVENTION / TREATMENT WAS LACK OF KNOWLEDGE

Perinatal Mental health training in Trust had no mention of birth trauma

The lack of staff, constant unforgiving workload and demands of people leave us like husks for our families

It's not only women & their partners that are traumatised by birth, it can also have very serious issues for staff. We've all been involved in extremely stressful & emotional situations frequently that expose us to trauma. We all develop coping mechanisms that try & prevent us from the stuff we deal with - but many burn out and leave

WHAT CAN WE DO TO MAKE BIRTH BETTER?

- ALL maternity and perinatal mental health services to look at the training and wellbeing need of staff teams for the prevention, assessment and treatment of birth trauma (for women, birthing people and partners as well as vicarious trauma themselves).

- Rapid and repeated assessment of birth trauma for all women to ensure we have clear national statistics on birth trauma rates using City Birth Trauma scale administered by health visitors and GPs, and that this data is collated in an accessible format.

- Clearer adherence to current guidelines to ensure all women, birthing people and their partners have rapid access to local, evidence based trauma focused care which is monitored nationally, to ensure best practice treatment.

Over the past 18 months, Make Birth Better has spoken to parents and professionals about their experience of support for birth trauma in the UK. We identified a need to explore the current state of birth trauma prevention, treatment and professional training.

We conducted two surveys during Spring/Summer 2019.

Survey 1 explored access to support after a difficult birth in 343 women. We found not only some startling statistics and clear themes around the difficulties in finding therapeutic help after a traumatic birth experience. The findings **also** reflect a lack of awareness of birth trauma both from parents and professionals, difficulties in accessing services.

Nearly half (43%) of women had never been asked about their birth experience at all, and a further 30% had only been asked when they had raised it themselves. Access to support from healthcare services was also difficult for personal reasons - not knowing what was being experienced, fear of stigma, lack of knowledge about services.

Nearly half (47%) of women felt that maternity/mental health services had not been supportive.

Of those who received support, **only 25% felt they received the right help** - with 30% feeling they were not offered the support they needed **at all**.

Of those who received some kind of therapeutic support, a staggering third of women (33%) did not feel it had resolved their trauma at all.

This raises questions not only about access to services but also the quality and effectiveness of the interventions being offered.

Survey 2 explored the experiences of 332 professionals' training and identified some positive findings. However, **nearly three quarters of professionals who are involved in maternity or postnatal care had no training on birth trauma**. Nearly half felt 'somewhat' confident in prevention, identification and management of birth trauma. The survey demonstrated a clear need for increased reflection within services, and many respondents emphasised a need for more specialist skills. The need for a cultural shift within services was also highlighted, as one respondent put it, ***"birth systems focus on physiological risk over psychological risk".***

Our full report outlines recent policy changes and the current state of NHS service provision in the UK, including the experience of working in these services.

WHAT IS THE IMPACT OF BIRTH TRAUMA?

For many healthcare professionals working with women, birthing people, their partners and their families during and after birth, birth trauma is still a bit of a mystery. There is a small group of clinicians, researchers and campaigners who have worked to enhance our knowledge of birth trauma and increase support for those who have been through a difficult birth, however the impact of birth trauma does not yet appear to be widely known.

We know that about 1 in 25 women experience Post Traumatic Stress Disorder perinatally - meaning that they experience a cluster of symptoms including: re-experiencing their traumatic experience, using avoidance behaviours, feeling a heightened sense of threat and a change to their mood and responses. But at least a quarter of women describe some aspect of their birth as traumatic [Dikmen Yildiz et al, 2017, Czarnocka & Slade, 2000]. These are the women who we think are most likely to contact us - those who are below a diagnostic threshold but are living with their symptoms and finding that they affect their day to day functioning. **Almost 50% of women do not disclose symptoms or seek help** [NCT- Hidden Half Campaign].

Even sub-clinical symptoms of trauma can have an impact on how safe someone feels in the world. This is what defines trauma - a traumatic event can leave your view of the world turned on its head, and leave you feeling fundamentally unsafe.

This complexity when it comes to birth trauma has led to a definition which is also complex. Birth trauma describes symptoms of trauma which may be related to the birth itself but also circumstances around the birth. **What makes birth trauma different from other traumatic events is that it is so often dismissed by those around us - as the birth of a healthy baby is usually seen as a joyful event**. And, unlike other traumatic events, we not only have a reminder of it in our baby, but we may even choose to go through it again.

The crucial thing to remember when it comes to birth trauma is that it is entirely subjective [Beck et al, 2013]. It is not so much what happened, but how you felt during the experience, that can cause it to become a traumatic experience.

There are many factors which contribute to a birth being experienced as traumatic - which may include our past history and experiences, our journey to birth, events during the birth, and support afterwards. We know that those who have experienced previous trauma, or who have pregnancy and birth complications are at a greater risk of developing PTSD [Dikmen Yildiz et al, 2017]. Newer research is also pointing to the correlation between PTSD and pregnancy loss [Farren et al, 2019], babies born unwell or needing intensive care [Sanders & Hall, 2018].

But what seems to be key throughout these circumstances is access to support and interpersonal relationships with maternity staff. **When women and birthing people - in the vulnerable state that birth brings about - do not feel treated with care, they are more likely to come out of that experience feeling some symptoms of trauma**.

In short, subjective traumatic experiences during pregnancy, birth or after birth lead to objective clinical symptoms and in some cases diagnoses.

As well as the impact on the mother or birthing person, there is increasing awareness that birth trauma can be experienced by partners too. The symptoms of trauma felt by either or both parents can also have a detrimental effect on the infant, through the parent-infant relationship (Svanberg & Boutaleb, 2020). Vicarious trauma is felt not only by those witnessing birth but those who hear about it.

There is an economic cost too, of course. The impact of birth trauma is felt financially within the healthcare and social care system, as highlighted by the 2014 LSE report (Bauer et al, 2014), and borne by the system in rising litigation cases and costs.

BIRTH TRAUMA IN STAFF

As well as PTSD symptoms, midwives are experiencing high levels of stress, burnout, anxiety and depression (Hunter et al., 2019). The RCM commissioned a recent survey exploring the relationship between the emotional wellbeing of UK midwives and their work environment, completed by 1997 midwives. A total of 83% of midwives scored moderate and above for personal burnout and 67% recorded moderate and above for work-related burnout. **Over one third of participants scored in the moderate/severe/extreme range for stress, anxiety, and depression**.

Comparatively, scores were higher for UK midwives than other countries surveyed to date (WHELM study, 2017). Midwives were more likely to experience higher levels of burnout, depression, anxiety and stress if they were aged 40 and below, had less than 10 years' experience, reported having a disability, and worked in a clinical midwifery setting. **In a previous study, 66% of 2000 midwives surveyed had considered leaving the profession within the last six months**.

The two primary reasons were due to dissatisfaction with staffing levels at work, and dissatisfaction with the quality of care they felt able to provide. These midwives had significantly higher levels of anxiety, depression and stress, compared to midwives who had not considered leaving (Hunter, Henley, Fenwick, 2018). A midwife who is experiencing PTSD or is emotionally exhausted will inevitably struggle to provide compassionate and sensitive care important for childbearing women (Department of Health, 2012).

Similarly, a recent investigation (Slade et al., 2020) reported that obstetricians and gynaecology staff can also experience work-related trauma. Results indicated that 2 in 3 clinicians reported experiencing a traumatic work-related event (728 participants in total; 304 trainee/staff grade; 404 Consultant/Associate specialist). Those with clinical levels of PTSD symptoms had lower job satisfaction, more experiences of work-related traumatic events and reported shorter time since the most difficult traumatic event. **Furthermore, these symptoms were associated with burnout and resulted in higher depersonalisation towards recipients of care**. It is simple to see how such results can increase the likelihood of subjectively traumatic experiences in their patients.

For trainees (out of 215) 30% reduced their working hours, 60% were giving serious consideration to changing specialty, 44% to moving away from clinical practice and 47% to leaving the medical profession. In contrast, for Consultants (out of 310) 15% reduced their working hours and were giving serious consideration to changing specialty (30%), moving away from clinical practice (30%), leaving the medical profession (25%).

Irrespective of whether clinicians had experienced trauma, or their level of responsibility, 91% (out of 764) indicated specific trauma support should be provided, as well as having supportive discussions with either senior colleagues or a dedicated team for this. They proposed training around trauma should be regular and mandatory; shifting from a culture of blame to one of support, in order to help staff.

WHY DID WE FEEL THE NEED TO DO THESE SURVEYS?

With the National Maternity Review (2016) and subsequent 'Better Births' initiative, there has - implicitly at least - been a move towards preventing traumatic births. The inclusion particularly of personalised care with a continuous carer may see a reduction in birth trauma (although quality of carer may be more important than continuity (Patterson et al., 2019). Having a supportive carer throughout the pregnancy, birth and postnatal period has been found to increase the likelihood of a satisfactory birth experience.

For those who have been through a difficult birth and found that they have symptoms of trauma, there have also been moves to offer specialist support. In the last four years, since the 'Improving Access to Perinatal Mental Health Services in England' review and the pledge of £365 million investment in perinatal mental health services by NHS England (as part of the Five Year Forward Plan in 2016), it seems that specialist perinatal services in the UK should be helping to meeting the needs of some parents.

Add to this the emphasis on maternal mental health in: the Maternity Transformation Programme (2016), the Perinatal Mental Health Toolkit from the Royal College of GPs (2015) and the Perinatal Positive Practice Guidance for primary care psychological therapies services (2013), and we are at the point where women, birthing people and their partners with mental health needs should be beginning to have those needs met in primary or secondary care services.

And yet.

When we write posts on social media, we write at the end of our posts 'if you feel the need for further support, please speak to your GP or another healthcare professional'. We talk about the need for in depth birth planning with the support of a trusted midwife. We write about birth choices and the right to choose the type of birth and birthplace, to make informed decisions about maternity care and have those decisions respected.

And almost every time we do that, we get messages from people saying 'I tried that, and they told me what I was feeling was normal', or 'I tried that, and I wasn't eligible for therapeutic services', or 'my obstetrician laughed at my birth plan' or 'my midwife told me I couldn't have the C section I requested'....Women reaching out for support and finding that support lacking. Knowing what was required to have a better birth, or to feel better after birth, but finding their approaches rejected.

The reality is that secondary care perinatal mental health services have been designed to meet the needs of only those struggling with moderate to severe mental ill health, an estimated < 10% of total of perinatal mental health needs (Bauer et al., 2014). Simultaneously, this has occurred with the gradual removal of funding from community based primary care perinatal and children's services, for example a 62% cut in funding for Children's Centres, with the biggest effect in the most deprived areas (Action for Children, 2019). Furthermore, there is disparity between the different regions within the UK and the different UK nations, and services for Northern Ireland and Wales remain limited.

While many policies and guidelines have been created, there is no requirement in place for services or individual practitioners to meet these guidelines. While perinatal services have had increased funding in recent years, they are still designed for a tiny 4.5% of the population [NHSE Perinatal Mental Health Care Pathways] leaving a huge gap when we take into account not just the levels of birth trauma but also the more than 1 in 10 who will experience a depression diagnosis or depressive symptoms within one year postpartum (Petersen et al., 2018).

New aims from NHS England to create Maternity Outreach Clinics may go some way to meeting the needs of those with birth trauma, but may exclude those who have experienced loss, partners or those who have sub-clinical symptoms, and will still cater for a small part of the population. Perinatal Mental Health services are well understood now, but there is a risk that Government may think that the job is done now that more community and MBU teams are in place.

We decided to conduct 2 surveys in order to get an idea of the scope of the problem. What do women experience when they have had a difficult birth? Do they feel supported by services? If not, where do they get their support (if at all)? [survey 1 'Access to Support - Parents']

Following our workshops, communication with a range of professionals and pilot training in April 2019, we also thought it would be useful to hear from professionals about what they feel they need in order to prevent, identify and manage birth trauma. We therefore also invited healthcare and birth professionals to let us know what skills they currently have, their training needs and challenges [survey 2 'Access to Support - Professionals']. Following the surveys, we also spoke to different professionals to hear their experiences of trying to meet the needs of those with birth trauma (Appendix II)

WHAT METHODOLOGY DID WE USE?

We invited women and birthing people to fill out survey 1 on SurveyMonkey, using a mixed methodology (qualitative and quantitative). Participants were invited via our email list, social media accounts and via the Birth Trauma Association peer support group on Facebook.

UK professionals were invited to complete survey 2 on SurveyMonkey, also using a mixed methodology. Participants were invited via our email list and social media accounts.

Questions were created and checked by the Make Birth Better core team. The survey for professionals had further input from psychologists Julianne Boutaleb, Lucy Marks and Jane Gibbons.

As a scoping exercise, no demographic data was collected. This survey provides an overview but is not a representative sample and selection may have led to some bias in the results.

Professionals were invited to share their experience via our Make Birth Better discussion group, and those with particular professional backgrounds were personally invited to reflect on their specific experiences for Appendix II.

Both surveys were open for at least one month.

Results were discussed by Dr Rebecca Moore, Dr Emma Svanberg and Caroline Ingman, and written by Dr Rebecca Moore and Dr Jan Smith. All N/A answers were removed from the final analysis.

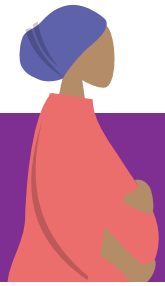
THE SURVEY FINDINGS

In 2019 Make Birth Better ran two online surveys, the results of which are summarised here.

WE LOOKED AT WOMEN'S EXPERIENCES AND ACCESS TO TREATMENT AROUND BIRTH TRAUMA (SURVEY 1)

WE ASKED HEALTHCARE PROFESSIONALS HOW CONFIDENT THEY FELT TO PREVENT, DIAGNOSE AND MANAGE BIRTH TRAUMA AND WHAT SUPPORT THEY FEEL THEY NEED TO REDUCE BIRTH TRAUMA HAPPENING IN THE FUTURE (SURVEY 2).

PARENTS



SURVEY 1 - ACCESS TO SUPPORT (PARENTS)

Our first survey looked at access to support after a difficult birth experience. 343 women answered the survey.

QUESTION	RESPONDENTS	RESPONSE
Have you ever been asked how you feel about your birth experience?	343	Less than a third 27% had been asked about their birth experience. 30% had only been asked when they raised the issue themselves.
Have you sought help from a health care professional due to a traumatic birth? (NB A traumatic birth is one in which you are left with some symptoms of trauma, it is entirely subjective and defined by you)	343	60% had sought help, 18% had not sought help and 17% felt they needed help but had not yet sought help. 5% did not feel they needed help.
If you sought help, did you get the support you needed?	343	25% felt they received the help they needed. 7% were offered support that was not what they wanted, 29% felt they were offered some support, but it was not enough and 9% were on a waiting list. 30% felt they were not offered the support they needed at all.

What has stopped you from seeking help if you need it? (tick all that apply)	343	37% did not know what they were experiencing and 43% did not know who to ask for help. 42% identified that they felt a sense of shame and stigma around their feelings and 47% of women identified a lack of support from services.
If you got support, what kind of support was it?	343	Debriefing, 31%, Health Visitors for listening visits, 9%, PMHT or a Community Mental Health Team, 15%. 10% of women were referred to a different mental health or psychological therapies service, while 9% were given advice on a different option (charity, private or other). We also asked about services related to physical trauma - 10% were referred to a physiotherapist and 6% to a consultant (e.g. colorectal surgeon). 19% were referred or sought help elsewhere, answers included a bereavement midwife, hypnotherapist, parent-infant psychotherapy service, general anxiety management group.
If you did not get the support you needed, did you find your own support?	343	30% of women sourced their care privately. 5% through a charity. 27% used friends and family as their main support. 39% did not find their own support. Narrative comments suggested peer support groups or seeking information online were alternative sources of support (Birth Trauma Association Facebook group; Make Birth Better Instagram; How to Heal a Bad Birth book).

If you were referred for therapeutic help on the NHS, what kind of therapy did you have?	343	47% received CBT with 7% receiving EMDR. 3% received support over the phone, and 2% online support. 41% were offered "other support", including group support, home visits or general counselling
If you had help outside of the NHS what kind was it?	343	23% had general counselling. 9% had CBT, 5% had EMDR. 9% went to sessions of Rewind therapy, 7% psychotherapy, 6% went to a private physiotherapist, and 2% saw a private consultant. 21% mentioned other forms of support including support from friends and family, parent-infant psychotherapy, support in another country and hypnotherapy.
If you had psychological therapeutIc treatment, do you feel it resolved your birth trauma?	343	54% felt it was resolved to 'a certain extent'. 13% felt their trauma was resolved and a third, 33% felt their trauma had not been resolved at all.

> *All the perinatal support was geared around postnatal depression. Since I didn't have this but was traumatised by the birth, the professionals seemed not to think I needed ongoing counselling.*
> *I had an assessment 2/3 days after the birth by the hospital psych team and their report was that I was talkative and articulate and not traumatised enough to need treatment under the psych team.*
> *I was referred by my GP to the perinatal team but was discharged after one session as I did not meet the criteria for postnatal depression. They did not seem to know what to do with the idea of birth trauma (as opposed to postnatal depression). The overwhelming message was that I was not traumatised enough and was not suffering from any psychosis, so I did not require any psychiatric treatment. It was very frustrating.*

COMMENTS FROM PARENTS:

There was a recurrent theme of women having to pay for their own care to access the right support:

- ***"I paid for private psychotherapy"*** and ***"I have had CBT at 18months postnatal and waited two weeks after referral. I then needed to re refer and this time waited 13 months from referral. I ended up paying privately for EMDR as I couldn't wait any longer".***

- One said, ***"I remain frustrated and angry that the bulk of the effective support I have received has been private, I've had to pick what to prioritise in therapy based on cost".***

- ***"I didn't think it would be taken seriously this long afterwards"*** and ***"for the first five years I had no idea that I had PTSD from the trauma of the birth. I didn't realise it was possible. I had had PTSD previously after a car accident but didn't recognise it again as didn't even think it possible". "PTSD I felt was something soldiers suffered from not a mum with a perfectly healthy baby I felt guilty I felt this way".***

Where the support was offered was also key:

- ***"The help was at the same hospital as the birth. I was kicked off for missing too many appointments. Attending those appointments always gave me anxiety attacks".***

Qualitative data suggested that a number of women used a variety of sources

- ***"Psychotherapist. Postnatal doula specialising in mental health. Most of all I needed a reassuring presence.", "I have basically tried all routes", "Self-help - trauma therapy research, yoga and mindfulness".***

Some expressed their frustration at trying many different options but feeling that they were not responded to, or that their sessions did not continue:

- ***"I was referred to perinatal MH counselling but discharged after one session after birth."***

- ***"I was dropped like a hot potato once my son was one. Even though I was midway through Treatment and told to self-refer back to regular mental health services."***

- ***"Referred myself for psychotherapy during 2nd pregnancy. Once I was diagnosed, they then referred me to perinatal mental health midwife who has not been in touch."***

Comments gave insight into what left women feeling that their trauma was not resolved, or could easily be re-triggered:

- ***"It helps you to be at ease and peace with it. However, it is not something you can ever forget. Also if you have triggers then it's like you're back to square one as that wasn't resolved the first time round.", "It hasn't resolved it but has helped me to process and understand it."***

- ***"I know the mechanisms to calm myself down, I understand what's happening inside me better when I have a flashback/suddenly feel upset, so knowledge has been powerful. But it's not resolved feeling like I could have another baby in the future....yet."***

- ***"It helped with the immediate feelings of panic but longer term it is definitely not a cure and I still cannot look back on my experience without anger."***

- ***"Yes, I feel I have largely resolved my trauma. I still feel unable to have another child as a result of my first birth and I wonder whether the feelings of anxiety and depression would come back if I did begin to want/contemplate another pregnancy."***

REFLECTIONS FROM THE MAKE BIRTH BETTER TEAM

- **Services seem to be hard to access, hard to navigate and people are often put off by the feedback they receive from professionals**
- **There are significant barriers to accessing support due to both personal and service related reasons.**
- **That even when it is possible to access services, the support available does not feel fit for purpose and does not often resolve trauma symptoms.**
-
- **Although it is unclear whether 'counselling' may refer to psychological therapies, very few people seem to have received the NICE guided treatments of Trauma Focused CBT and EMDR. In fact, more had been offered the not yet evidence based Rewind therapy than the NICE recommended EMDR.**

PROFESSIONALS

SURVEY 2 - TRAINING OF PROFESSIONALS

Our second survey looked at healthcare professionals. 332 people answered the survey

QUESTION	RESPONDENTS	RESPONSE
What is your profession?	332	Midwives (42.6%), Psychologists (11%), GPs (4%), Obstetricians (4.5%) and Health Visitors (4%). 5% were doulas, 5% antenatal educators, 1.5% psychiatrists and 3.6% psychotherapists. 11% answered as 'other healthcare professionals'
Have you ever had specific training in birth trauma?	332	72.5% had never had any specific training in birth trauma

How confident do you feel in your ability to prevent birth trauma?	332	48% “somewhat confident”, 20.9% felt “not so confident”, 10.9% felt “not confident at all”, 2%, felt “extremely confident”, with 9% feeling “very confident”
How confident do you feel in your ability to identify birth trauma?	332	48.5% felt “somewhat confident” in diagnosing birth trauma, with 32.4% feeling “very confident”, 1.8% were “not at all confident”.
How confident do you feel in your ability to manage birth trauma effectively during the birthing process and postnatally	332	41% felt “somewhat confident”, 26% “not so confident”, 3% felt “extremely confident” and 10% felt “very confident” 6.6% felt “not at all confident”.
What would most enable you to feel more confident in preventing, recognising, managing and treating birth trauma?	332	34% suggested one off birth trauma training, 59% felt bespoke training for their own service, 62% wanted specific skills (e.g. grounding techniques). 59.9% wanted access to birth trauma related resources. 55% identified that access to specialist advice would be helpful, with 35% suggesting specialist supervision was needed

What would enable you to feel more confident in this area?	332	54.8% wanted specialist birth trauma supervision, with 50% wanting regular reflective practice sessions within their profession. 38% asked for whole team reflective practice sessions. 18% wanted more regular general supervision. Changes were also felt to be needed in team culture (37.9%) and 31% identifying the need for management to change
Do you feel that you are treated with kindness at work?	332	60% felt they were treated kindly most of the time. 14.85% felt they were treated kindly all the time. 18.8% felt they were treated kindly only sometimes. 6% felt they were rarely treated kindly at work.
To what extent do you feel you have adequate tools that you are able to use to look after your own wellbeing?	332	38% had tools most of the time, 42% had tools some of the time. 13% felt they were rarely able to use tools to support their own wellbeing and 2% felt almost never able to use tools to support their own wellness.
What do you see as the current barriers for prevention and treatment of birth trauma?	332	Lack of knowledge, 63% lack of funding, 57% and wider social issues such as the narrative around birth, 54%. 37% felt they lacked management support, with 36% feeling the working environment was an issue along with difficult working conditions, such as bullying, for 18%. 13% of professionals felt a fear of reprisal as a barrier to change.

Some thoughts from professionals:

"Some HCPs think birth trauma has not occurred - post birth debrief should be each day to help women to speak out . I once cared for a woman who had an instrumental birth, she burst into tears spontaneously when I hugged her. ***We then discussed the birth and she told me she felt traumatised. I went to speak to the obstetricians about it and they said, "what is she talking about? the birth was fine!"*** *- I felt very emotional for her and put mental health support into place - A professional might not realise the trauma women have gone through. Compassion and kindness play a huge factor in birth trauma prevention and resolution."*

"It's not only women and their partners that become traumatised by birth it can also have very serious issues for staff. We have all been involved with extremely stressful and emotional situations frequently that exposes us to trauma. We all develop coping mechanisms that try and protect us from the stuff we deal with, but many burn out and leave. ***The lack of staff, constant unforgiving workload and demands of people leave us like husks for our families****. If you are involved in a difficult birth you question your decisions and have to live with the fear of 'did I do everything right?' I'm tough and thick skinned after 24yrs but there are times even I sit and cry about not being good enough for our women. Frustration and fear are part of being a midwife, but you always put on your smile and get ready for the next family. I do not think we will ever know the extent of trauma during birth as women often hide it but sometimes you know that they will suffer and there's not enough to help them.* ***You say to your colleagues watch that one but not everyone cares that much.*** *"*

REFLECTIONS

- **Professionals are simply not offered trauma focused training or support**
- **That there is a worrying lack of understanding about what is required, with over half of staff reporting they felt somewhat confident or more in all areas despite the lack of birth trauma training. This may be due to a widespread lack of awareness of the role of avoidance and dissociation in trauma, leaving staff unable to recognise those experiencing trauma without using standardised tools.**

CONCLUSION

Both the surveys, and our conversations with parents and those working within services, paint a picture of services which are currently failing to meet the needs of those who are giving birth in the UK. Not only is access to support for birth trauma impacted by stigma, but also by a lack of awareness, service provision and effective treatment.

We believe that women, birthing people and their partners enter into their maternity journey at a particularly vulnerable time (Barlow, 2015) and are too often met with a reactive, overstretched and emotionally burdened service. The circle of trauma running between professionals and parents is affecting the lives of too many.

24% of women report an element of their birth as traumatic [Czarnocka & Slade, 2000] and some estimate these rates to be even higher. Too many people are currently being traumatised within our NHS system. The effects of birth trauma are life changing and can persist for many years causing a huge burden not only for each woman and her family but for the whole system. Many women go onto develop other difficulties such as depression and there is a huge impact on their day to day lives, their parenting, their relationships with families and friends, their work. This can have a wider impact on the child and the family as a whole.

We believe that many cases of birth trauma are preventable, and that many of the factors which could reduce birth trauma would not be costly.

All of the proposals in the NHS long term plan hold a great deal of promise and offer a route to the type of improvements in care that our research demonstrates is clearly needed. However, change is needed across the system and not just in specialist services.

For those developing and commissioning services to meet these needs, we would suggest that:

- The lack of awareness and training in birth trauma highlighted in this report, alongside a continued lack of individualised, continuous care may currently be contributing to the high rates of birth trauma.
- NHS services are not currently adequately meeting the needs of women and partners traumatised by birth, in preventative measures, service provision and quality/effectiveness of available support.
- There is a need for all staff to receive ongoing specialised training and support in perinatal mental health care and training including birth trauma alongside bespoke reflective practice and supervision.
- There is a need for all women, birthing people, partners and families to enter a trauma informed maternity system where every member of the team is trauma aware.
- Many preventative measures would not be costly, which is of particular pertinence given the high litigation costs in maternity services.

All women, birthing people and their partners all across the United Kingdom need:

- A maternity journey which is trauma informed throughout.
- High quality, evidence based and standardised antenatal education.
- To be asked about their birth experience within the first few months after birth and to have the space and time to be heard, alongside the use of specialist tools such as the City Birth Trauma Scale (Ayers et al., 2018) and for this to be repeated along their postnatal journey at Health Visitor checks.

- To be able to access local, high quality, evidence based trauma informed face to face therapy which meets NICE guidelines and the Perinatal Positive Practice Guidelines, within the NHS including choice and flexibility (DoH, 2013).

- To have the full range of treatment options after birth trauma explained and offered to them such as medication, therapy, peer support, couples therapy, physiotherapy, onward physical health referrals, parent infant therapy.

Make Birth Better calls for the system to change urgently. We hope sharing our data will change the system nationally, locally and at every level, before pregnancy, in pregnancy, at birth and as a parent.

We call for:

- ALL maternity and perinatal mental health services to look at the training and wellbeing need of staff teams for the prevention, assessment and treatment of birth trauma (for women, birthing people and partners as well as vicarious trauma themselves).

- Rapid and repeated assessment of birth trauma for all women to ensure we have clear national statistics on birth trauma rates using City Birth Trauma scale administered by health visitors and GPs, and that this data is collated in an accessible format.

- Clearer adherence to current guidelines to ensure all women, birthing people and their partners have rapid access to local, evidence based trauma focused care which is monitored nationally, to ensure best practice treatment

Everyone who bravely shared their stories here deserves better.

Birth can be and must be so much better for all.

REFERENCES

Action for Children (2019). Closed Doors Report https://www.actionforchildren.org.uk/media/11680/0740-closed-doors-report-final.pdf. Accessed 03/02/20

Ayers, S., Wright, D. B. and Thornton, A. (2018). Development of a Measure of Postpartum PTSD: The City Birth Trauma Scale. Frontiers in Psychiatry, 9.

Barlow, J. (2015). Vulnerable mothers in pregnancy and the postnatal period. Nursing in Practice.

Bauer, A., Parsonage, M., Knapp, M., Lemmi, V., and Adelaja, B. (2014). Costs of perinatal mental health problems. . London School of Economics and Political Science, London, UK

Beck, C.T. Driscoll, J.W. & Watson, S. (2013). Traumatic Childbirth. Abingdon: Routledge

Beck, C.T. (2010). A Metaethnography of Traumatic Childbirth and its Aftermath: Amplifying Causal Looping. Qualitative Health Research 21(3), 301-11

Creedy, D.K., Sidebotham, M., Gamble, J., Pallant, J., Fenwick, J. (2017). Prevalence of burnout, depression, anxiety and stress in Australian midwives: a cross- sectional survey. BMC Pregnancy Childbirth, 17(1):13.

Czarnocka, J., & Slade, P. (2000). Prevalence and predictors of post-traumatic stress symptoms following childbirth. British Journal of Clinical Psychology, 39, 35-51

Department of Health. (2012). Compassion in Practice. Nursing, midwifery and care staff: our vision and strategy. https://www.england.nhs.uk/wp-content/uploads/2012/12/compassion-in-practice.pdf. Accessed 02/02/20

Department of Health .(2013). IAPT Perinatal Positive Practice Guide. London. Available at: https://www.uea.ac.uk/documents/246046/11919343/perinatal-positive-practice-guide-2013.pdf/ aa054d07- 2e0d- 4942- a21f- 38fba2cbcceb

Dikmen Yildiz P, Ayers S, Phillips L (2017) The prevalence of post-traumatic stress disorder in pregnancy and after birth: a systematic review and meta-analysis. J Affec Disord.

Farren J, Jalmbrant M, Falconieri N, et al.(2019) Post-traumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multi-center, prospective, cohort study American Journal of Obstetrics and Gynecology

Glover, V., and Barlow, J. (2014). Psychological adversity in pregnancy: what works to improve outcomes? Journal of Children's Services, 9(2), 96-108.

Hunter B, Henley J, Fenwick J et al. (2018). Work, Health and Emotional Lives of Midwives in the United Kingdom: The UK WHELM study. School of healthcare Sciences, Cardiff University.

Hunter, B., Fenwick, J., Sidebotham, M., and Henley, J. (2019). Midwives in the United Kingdom: Levels of burnout, depression, anxiety and stress and associated predictors. Midwifery 79.

Knight, M., Bunch, K., Tuffnell, D., Shakespeare, J., Kotnis, R., Kenyon, S., Kurinczuk, J.J. (2019) (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2015-17. Oxford: National Perinatal Epidemiology Unit, University of Oxford.

Maternal Mental Health Alliance (2013). Everyone's Business Campaign. https://maternalmentalhealthalliance.org/campaign/ Accessed 02/02/20.

NCT. Hidden Half Campaign (https://www.nct.org.uk/get-involved/campaigns/hidden-half-campaign) Accessed on 02/02/20.

NHS England (2016). National Maternity Review. Better Births. Improving Outcomes of Maternity Services in England: A Five Year Forward View For Maternity Care. London.

Patterson, J., Martin, H., and Karatzias, T. (2019). PTSD post-childbirth: a systematic review of women's and midwives' subjective experiences of care provider interaction. Journal of Reproductive and Infant Psychology, 37(1), 56-83.

Petersen, I., Peltola, T., Kaski, S., et al. (2018). Depression, depressive symptoms and treatments in women who have recently given birth:
UK cohort study. BMJ Open, 8:e022152. Accessed on 02/02/20.

Royal College of General Practitioners. (2016). Perinatal Mental Health Toolkit. https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/perinatal-mental-health-toolkit.aspx. Accessed 02/02/20.

Sanders, M. R., & Hall, S. L. (2018). Trauma-informed care in the newborn intensive care unit: promoting safety, security and connectedness. Journal of perinatology : official journal of the California Perinatal Association, 38(1), 3–10.

Slade, P., Balling, K., Sheen, K.,Goodfellow, L., Rymer, J., Spiby, H., Weeks. A. (2020). Work-related post-traumatic stress symptoms in obstetricians and gynaecologists: findings from INDIGO a mixed methods study with a cross-sectional survey and in-depth interviews. BJOG: An International Journal of Obstetrics & Gynaecology.

Sperlich, M., Seng, J.S., Li, Y., Taylor, J., Bradbury-Jones, C (2017). Integrating trauma informed care into maternity care practice: Conceptual and Practical Issues. Journal of Midwifery & Women's Health, 62, 661–672

Svanberg, E. & Boutaleb, J. (2020). Difficult Beginnings: How birth trauma impacts early parent-infant relationships. International Journal of Birth and Parent Education, 7(2), 17-19

APPENDIX I:

WHO ARE MAKE BIRTH BETTER?

THE CONTEXT

WHO ARE MAKE BIRTH BETTER?

Make Birth Better CIC are a unique collective of parents and professionals dedicated to reducing the life-changing impact of birth trauma. We have a core team of 5 – a clinical psychologist, perinatal psychiatrist, health psychologist, charity CEO and designer, as well as a network of over 150 other parents and professionals who heavily influence the direction of our work, many with lived experience of birth trauma. We work voluntarily and have, as yet, received no external funding.

The Make Birth Better network aims to improve the prevention, diagnosis and treatment of birth trauma through clinically-led education, campaigning and research.

Our vision is to create a world where people no longer suffer from birth trauma.

We offer training, consultation and supervision to individuals and services. This takes place as a multi-professional, skills-based training as well as bespoke training within services, organisations or to individuals. We also raise awareness of birth trauma through campaigns and are involved in academic research (via universities) to improve our understanding of the impact of birth trauma.

MAKE BIRTH BETTER IS A UNIQUE COLLECTIVE OF PARENTS AND PROFESSIONALS DEDICATED TO REDUCING THE LIFE-CHANGING IMPACT OF BIRTH TRAUMA.

THE MAKE BIRTH BETTER NETWORK AIMS TO IMPROVE THE PREVENTION, DIAGNOSIS AND TREATMENT OF BIRTH TRAUMA THROUGH CLINICALLY-LED EDUCATION, CAMPAIGNING AND RESEARCH.

OUR VISION IS TO CREATE A WORLD WHERE PEOPLE NO LONGER SUFFER FROM BIRTH TRAUMA

OUR JOURNEY

In 2018, we held four workshops with parents, healthcare and birth professionals to find out from them what they felt was causing and maintaining birth trauma, at each stage of the pregnancy and postnatal journey.

Alongside these discussions, we collected ideas from emails, messages received on our social media pages and over 75 birth stories received from women who had experienced birth trauma.

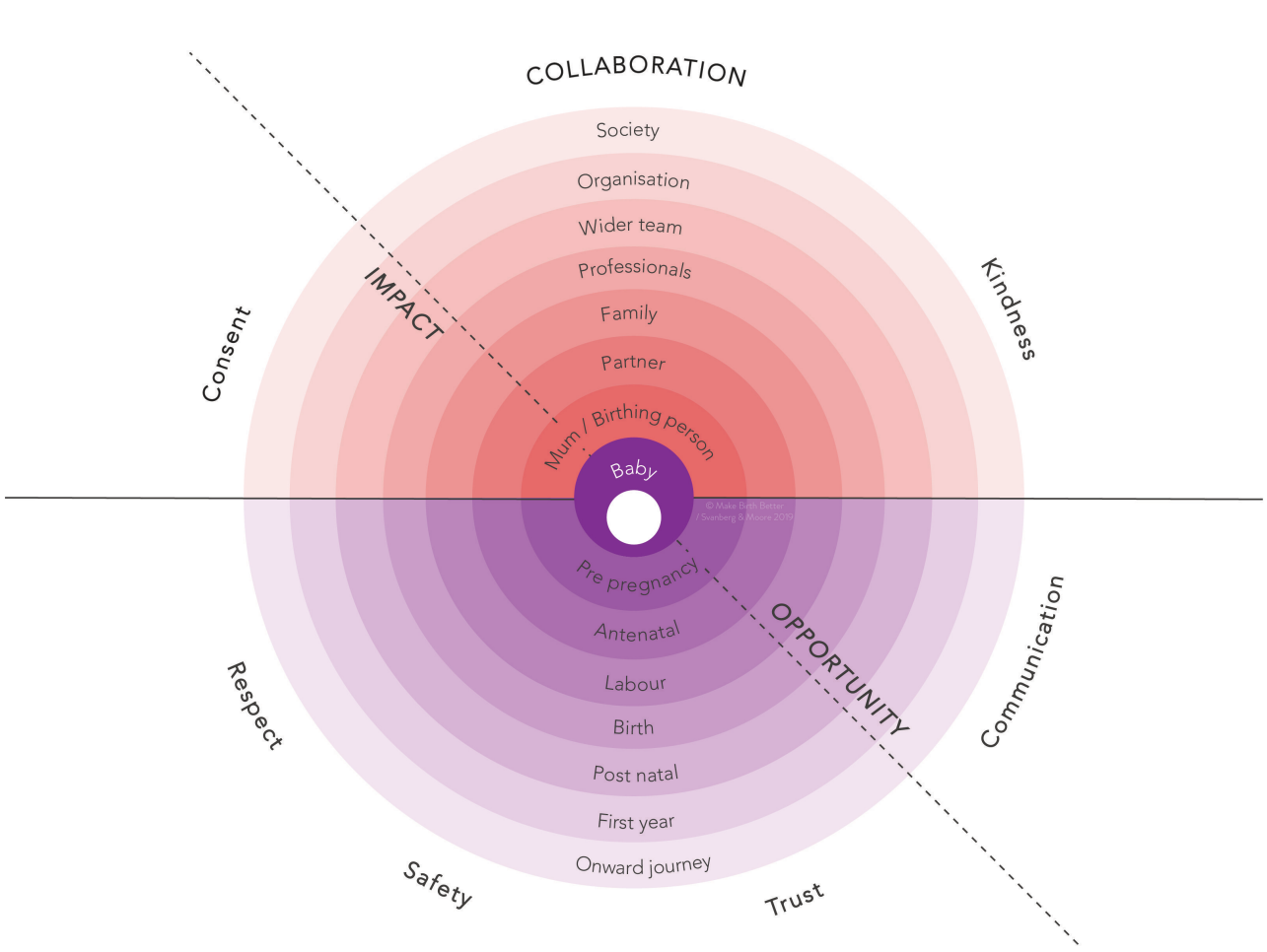
Through this, we created the *Make Birth Better Model*.

THE MAKE BIRTH BETTER MODEL

The Model, a reflective tool for practitioners and parents, highlights the systemic nature of birth trauma. We know from a vast body of research that interpersonal factors during and after birth (the interactions between parents and staff) influence whether or not a person will find that experience traumatic.

The model demonstrates that even these interpersonal relationships are influenced by wider systems too - the team in which maternity staff work, other family members, wider organisations and even society as a whole. Each part of the system has the potential not only to create a traumatic experience but also to prevent it from happening. The model also demonstrates the many different opportunities we have to prevent and treat birth trauma, from primary school education all the way to the later postnatal period.

Finally, the Model outlines the core values we feel can ensure a system remains trauma-informed and trauma-preventing.



We believe that, if we work at each layer of the system to prevent birth trauma and support those who have been through a difficult birth, we could reduce the incidence of birth trauma and prevent it from having a lifelong impact on not just women and birthing people but their families too.

If you would like to read more about the model, please see www.makebirthbetter.org/the-model

We're here, whenever you need us.

APPENDIX II: THE POSSIBLE REASONS

WHY IS THIS HAPPENING?

Reading such startling findings, we felt it was important to consider the possible reasons that services are not currently meeting the needs of women with birth trauma, and may even be contributing to birth trauma causes and maintenance.

We know that the perinatal period is a time of particular vulnerability for women (MMBRACE, 2019), birthing people and their partners and that this can also create vulnerabilities for the developing infant too (Glover & Barlow, 2014). Authors, such as Cheryl Beck (2010) have emphasised the systemic, multi-layered nature of birth trauma – being contributed to and affecting many different people and services involved in birth. We demonstrate this in the Make Birth Better Model. Mickey Sperlich (2017) has suggested a joined-up, multi-layered, trauma-informed approach to the maternity journey.

Of course, with changes to NHS policy and funding being as recent as 2016 - and new policies improving access to specialist perinatal mental health support being pledged as part of the NHS Long Term plan - we must acknowledge that during this transition there may still be women and birthing people who have not accessed support, but that this is a situation that needs to improve.

We asked a number of healthcare professionals working in the field to tell us what they thought the current challenges are in providing support to women, birthing people and their partners after a difficult birth. It is notable that some of these professionals are working in services which have recently received increased funding. Despite this, they told us that their services are still not able to meet the needs of this group. All asked to be anonymised

A BRIEF HISTORY OF NHS SERVICE PROVISION

At the moment, a national birth trauma pathway does not exist, although one is being created by NHS England which should be released in early 2020. This means that at present, if it exists at all, birth trauma treatment is likely to be Trust specific. In London, the Pan London perinatal mental health network have created a Tokophobia toolkit to be used with women with fear of pregnancy, birth or a previous traumatic birth. Many Trusts have their own pathways, some of which are outlined in our Training Manual (see the Make Birth Better website)

There are exciting and hopeful plans within the NHS, with the updated Improving Access to Psychological Therapies Perinatal Positive Practice Guide being released soon, increased funding for specialist perinatal mental health teams and the new NHS Long Term Plan again emphasising perinatal mental health care and the creation of Maternity Outreach Clinics which may target those with birth trauma. As these changes have been so recent, it may be that they have not been represented in these survey results. However, this funding is not equitable in different areas of the UK (Maternal Mental Health Alliance, 2013) and as yet it is not clear whether birth trauma should be assessed and treated within primary or secondary services. At present, the majority of those with birth trauma who have sub-clinical symptoms do not meet the criteria for any mental health service. Further, there are no plans as yet to research or plan for useful preventative measures for birth trauma in both service users and staff.

Our experience at Make Birth Better is that what appears to be available and what patients experience as available are very different.

To gain further insight into this, we asked a number of mental health professionals working within the NHS to tell us how they feel 'on the front line'. All have chosen to remain anonymous.

PRIMARY CARE MENTAL HEALTH SERVICES

In most areas of England, primary care psychological support is provided by Improving Access to Psychological Therapies (IAPT) services, which can often be self-referred into or are accessed via a GP or other healthcare professional. Services differ within Scotland, Wales and Northern Ireland. Despite a major push to improve mild to moderate mental health care with the introduction of IAPT in 2008, the recent Centre for Mental Health Report 'Filling the Chasm' suggested that mental health is still 'on the margins' of primary care policy. Those with complex needs often find that they fall between the gaps of an IAPT service and a secondary mental health service. For staff within IAPT, there have been reports of high levels of emotional exhaustion, (Steel et al, 2015). There have also been questions around the effectiveness of IAPT's approach with a recent study suggesting that only 9.2% of IAPT patients recover. (Scott, 2018)

The Psychological Wellbeing Practitioner

PWPs offer 'low intensity' interventions in IAPT services, often completing triage assessments (first contact with the service), guided self-help interventions and brief problem focused Cognitive Behavioural Therapy interventions.

"I work as a psychological Wellbeing Practitioner (PWP) in a busy inner London Borough run by the NHS. I support those who experience "common mental health problems" in accordance with NICE best practice guidelines using Low- Intensity Cognitive Behavioural Therapy otherwise known as Guided Self Help. This treatment usually consists of 6-8 sessions focussing on symptom reduction, this being measured using standardised quantitative measures such as the GAD-7 and the PHQ-9.

I assess 10 patients a week via the telephone and also deliver treatment via 1:1 face to face sessions, groups and online support. I am expected to both assess and work with perinatal patients (those who have a child under 1 or are pregnant). I joined IAPT in 2017 when we had a specific team in which perinatal assessment and support would be offered to patients who met the criteria (which also included children under 5 at the time). Currently, this team no longer exists.

In terms of training to support perinatal patients- I do not have external training, however, I have been trained in-house. I often question whether a half an hour assessment via the telephone is enough time to hear the stories of these vulnerable people. IAPT does offer perinatal training and our perinatal PWP has gone on this training. However, in a team of 10 this is only one specifically trained person.

I will often bring my perinatal patients to supervision as I have only received one hour inhouse training for assessing perinatal patients which focussed on assessment rather than treatment. Our management team work really hard to support us and meet the needs of perinatal patients. It is not the service at fault here - rather than a reflection on the current state of mental health provision.
The stepped care model means PWPs often do see patients for more general anxiety psychoeducation. I don't feel that there is enough awareness about the anxiety for partners in the slightest, but this may be a system wide issue rather than service specific.

I feel that the NHS in general could provide more training for those working and assessing those with birth trauma. Much of the CPD is expensive and hard to obtain for large groups of staff. The awareness of the impact of birth trauma has slowly improved but it still feels like there is a long way to go in terms of supporting both those who have trauma from difficult births but also their partners. This is especially evident by the erosion of specialist teams within current IAPT frameworks.
Working as a PWP in IAPT is really tough. I currently have 74 patients on my caseload. I admit, at times, I feel that the requirements increase but the support and funding does not. I have felt empathy fatigue, I had a run of 2 weeks of difficult patients/ assessments and no time to process or reflect on what that meant for me as a therapist."

The Primary Care Clinical Psychologist

Primary care psychologists offer high intensity or specialist interventions within IAPT services or other primary care settings.

"As a Clinical Psychologist working in the NHS for over a decade with parents and their babies, I've recently been encouraged by the growing awareness of Birth Trauma.

However, on the ground, the likelihood of accessing meaningful help still feels a postcode lottery. I routinely meet women and their partners whose distress has been misunderstood as postnatal depression or health anxiety. Or whose traumatic birth has been dismissed by Health professionals as 'part of birth' and 'they should be grateful for a healthy baby'.

Although the development of Perinatal Mental Health Teams has been a much needed and greatly valued service development, most women with birth trauma will not meet their threshold for help, as they are commissioned to work only with those with the most severe mental health problems and fathers and partners have not been able to access help from them.

The alternative for parents in need of therapeutic help following a traumatic birth has therefore fallen on local IAPT (Improving Access to Psychological Therapies) services. However, in my experience the majority of IAPT clinicians have had very little training or supervision in Perinatal mental health and may struggle to keep the baby (let alone the birth) in mind.

The NHS Long Term Plan promises more resources to support parents with babies. It can't come soon enough for those struggling with birth trauma."

The Perinatal Mental Health Team Clinical Psychologist

Perinatal Mental Health Teams are secondary care teams, for moderate to severe mental health problems experienced from pregnancy up to the first year after birth (although this is to be extended to 2 years under the NHS Long Term Plan) Increased funding from NHS England under the Five Year Forward Review saw a rapid growth in teams, with 35 new sites being awarded funding.

"We are enormously proud of our new perinatal mental health teams, which are offering thousands of new women a year access to specialist care in a timely way, closer to home and from teams of skilled, passionate and compassionate staff.
By April 2020, 4.5% of women (those with or at risk of the most complex or severe mental health difficulties) who are pregnant or who have a baby under 1 will be eligible to access perinatal teams. However, we know that least 20% of women will experience some form of mental health difficulty in this period and for a huge number of these, a fear of birth or birth trauma will play a significant part. Frequently, those whose needs are seen through a psychological rather than psychiatric lens (responses to trauma being a common factor) are signposted to IAPT because of limited therapy resource within the specialist teams.

We see a large number of families where dad or partner has been traumatised by the experience of birth or the transition to parenthood and while teams can often offer some assessment and signposting, therapeutic support that specifically addresses their perinatal needs simply isn't there. In most areas, dads, partners and those mums who aren't eligible for the specialist teams should be able to access an IAPT service for more mild or moderate needs. Often, however, the IAPT offer isn't family focused - it is difficult for therapists to have the time to liaise closely with midwives and other professionals. Staff frequently don't have the training or support to work with the parent infant relationship and babies may be excluded from the therapy room meaning that some parents can't access support at all
There are still thousands of families who aren't able to access specialist care. We have so much to celebrate… but there is still so much to do"

The Perinatal Psychiatrist

Perinatal psychiatrists work within Perinatal Mental Health Teams and Mother and Baby Units to offer psychiatric support and case management.

'Many women, let alone men, do not get a good service from the NHS after a traumatic birth. Many find their trauma missed, silenced or misdiagnosed in primary care. Often women are asked to self-refer to IAPT which can seem impossible in the midst of trauma. Being interviewed over the phone can seem far too impersonal. Although we have more community perinatal teams than ever, which is welcomed, many women with birth trauma do not fit the remit of perinatal teams and are often than not offered an assessment. Some perinatal consultants are not experts in birth trauma. Trauma may also take time to present, by which time it may be too late for women to be seen in the perinatal period.

As a result, many women end up sourcing their own care. There are pockets of care in the NHS that are very trauma informed and offer excellent care, but they are too few. We must do better'.

The Consultant Psychologist

Highly skilled specialist psychologists offer consultation and supervision to teams, discussing both clinical and organisational challenges.

We spoke to a psychologist offering external consultation to Perinatal Mental Health teams about the challenges of meeting the needs of those experiencing a traumatic birth:

'In my experience of offering consultation to specialist Perinatal Mental Health practitioners and teams, the real difficulty is the lack of a joined up, integrated conceptual framework for thinking about and responding to psychological issues arising from birth trauma. It's as if each practitioner has a part of the elephant as it were! So, the team psychiatrist and CPN might focus on the obsessive compulsive disorder type symptoms that the woman presents with, rather than also thinking about these in the context of the mother- infant relationship as a parent infant psychotherapy practitioner might. Multi-disciplinary team working potentially has real strengths when working with families affected by birth trauma but only if there is shared understanding of how teams can and should work together.

The Mental Health Commissioner

Mental Health Commissioners work to assess local needs, decide priorities and strategies, and then buy services on behalf of the population from providers such as hospitals, clinics, community health bodies, etc. It is an ongoing process and they are responsible for the mental health of their entire population, and measured by how much they improve mental health outcomes.

We spoke to a commissioner of mental health services about the challenges of commissioning services for this population:

"The main issue from a commissioning perspective is designing services that are person centred but meet the varied needs of women and their partners who have experienced birth trauma. Additionally, obtaining funding for these services is particularly challenging given that this group of family's needs often falls between mental health and maternity services."

HOW DO VOLUNTARY SERVICES FILL THE GAPS?

The role of Voluntary Community and Social Enterprises (VCSE) in supporting seldom heard, at-risk groups to access perinatal mental healthcare

maternity action

Ten years of fighting for better maternity rights

MATERNITY ACTION, the UK's leading charity committed to ending inequality and improving the health and wellbeing of pregnant women, partners and young children, has been conducting research to identify the barriers to accessing perinatal mental healthcare confronting women in five at-risk, seldom heard groups across England: Black, Asian and ethnic minority (BAME) mothers, migrants, refugees and asylum seeking mothers, young mothers, LGBT+ mothers and parents, and mothers in Gypsy and Traveller communities.

They have identified numerous, multilevel barriers confronting those in at-risk, seldom heard groups, including individual level barriers (e.g. a lack of awareness of Perinatal Mental Health (PMH) conditions), socioeconomic barriers (e.g. poverty), cultural barriers (e.g. stigma), health service barriers (e.g. long waiting lists) and health system barriers (e.g. gaps in services for those with low to moderate PMI).

They have also identified numerous Voluntary, Community and Social Enterprise (VCSE)-led strategies that are effectively overcoming some – though not all – of these barriers, including:

- Raising awareness about the full range of PMH symptoms and conditions, as well as about local PMH services and treatment pathways
- Advocating for access to PMH services for vulnerable women, either by accompanying them to appointments or by increasing their knowledge and confidence to attend solo
- Reducing the stigma surrounding PMH and/or offering ways to circumvent that stigma, e.g. by providing anonymous, moderated online discussion forums
- Demystifying the role of children's services to reassure women that child removals are rare, and to emphasise the importance of seeking PMH support
- Providing peer support through buddy schemes and group workshops with trained and supervised volunteer peer supporters with lived experience of PMI
- Offering free travel and/or on-site childcare to/at appointments and support groups
- Providing information in plain English and community languages
- Providing a wide range of social support and legal advice

Maternity Action urges commissioners and service providers to work with VCSE organisations to support at-risk, seldom heard groups to overcome these barriers to accessing PMH services.

This research has been supported by the Voluntary, Community and Social Enterprise (VCSE) Health and Wellbeing Alliance, a partnership between voluntary sectors and the health and care system to provide a voice and improve the health and wellbeing for all communities.

If you have any questions or to sign up to receive the full report when it is published, please contact Dr Rebecca Steinfeld, Senior Policy Officer for Health and Wellbeing, Maternity Action: rebeccasteinfeld@maternityaction.org.uk

the birth trauma association

helping people traumatised by childbirth

THE BIRTH TRAUMA ASSOCIATION (BTA) is a small national charity. We were founded in 2004 by two women who realised there was very little support for women who had been traumatised by birth. Since then, awareness of postnatal post-traumatic stress disorder (PTSD) has grown, and we are inundated with requests for help.

We offer peer-to-peer support, through two main channels. The first is through a private Facebook group where women can share their stories and offer help, sympathy and advice. (Partners, both male and female, are also welcome to join, but the vast majority of members are women who gave birth.) The group has more than 8,000 members, with about 70 new requests to join each week.

The second way in which we offer support is through email. Our support inbox is staffed by a small group of volunteers, all of whom have had traumatic births themselves. They are able to signpost women to other services as well as offer sympathy and understanding. Taken together, the support email, our general enquiries line and our public Facebook page receive about 20 contacts a week.
We are now in the process of training a new group of volunteers, which will enable us to start offering live chat support as well.

We're aware from the stories women share that GPs and health visitors aren't always aware of birth trauma or postnatal PTSD and don't always make appropriate referrals. In some cases, women are referred to therapy, but have to wait for several months for the referral to come through. Sometimes the referral is to general counselling, when what is needed is trauma-focused CBT or eye movement desensitisation and reprocessing (EMDR). We hear of cases where PTSD is misdiagnosed as PND, or where women are told by health professionals to forget about their birth and be grateful that they have a "healthy baby." One of the reasons the Facebook group is so valuable is that other members understand that having PTSD makes it impossible simply to put the trauma out of your mind.

Sometimes health professionals refer women to us. This seems extraordinary, as we have no public funding, and rely entirely on donations. We are currently filling a gap that has been created by the lack of appropriate NHS services. We would like to see the NHS increase the availability of support from qualified EMDR and trauma-focused CBT therapists with a specific understanding of postnatal PTSD.

Contact details:
Email: enquiries@birthtraumaassociation.org.uk
Twitter: @BirthTrauma
Website: www.birthtraumaassociation.org.uk

BIRTHRIGHTS is the UK organisation devoted to improving maternity care through a focus on human rights. Rights respecting care is fundamental to reducing birth trauma. It recognises that every pregnant individual is worthy of respect; they are not simply a vessel, and their right to be treated with dignity and to decide what happens to their body is not diminished by pregnancy or birth.

Research shows that women who have a good relationship with their care providers and who feel in control of decisions are much more likely to experience their birth as positive, regardless of how their birth unfolds.

Hundreds of women contact our advice service every year. Many have had a recent traumatic birth and/or are keen to avoid trauma with their current pregnancy. We aim to ensure that individuals are aware of their rights so that they can give themselves the best chance of a positive birth experience. Sadly, we also give advice about how to make an informal or formal complaint where poor care has contributed to birth trauma.
But advice is only one facet of our work – as an organisation we also want to address the root causes of birth trauma.

We train over 1,000 maternity professionals each year in human rights centred maternity care and how it can prevent women, their partners, and indeed healthcare professionals being traumatised by birth. We also conduct research: our recent report "Holding it all Together" co-authored with Birth Companions, looked at the maternity experience of women facing severe and multiple disadvantage, and in 2018 we undertook research with Bournemouth University on the maternity experience of women with physical disabilities.

Finally, we are involved in a wide range of policy, campaigning, and strategic legal work which strives to ensure that women are placed at the centre of their care and treated with dignity during this uniquely vulnerable yet powerful time in their lives.

You can find out more about our work on our website www.birthrights.org.uk or drop us a line at info@birthrights.org.uk (general enquiries) or advice@birthrights.org.uk (advice service)

WHAT NEXT?

The NHS Long Term Plan outlined a number of promising developments in perinatal mental health care, including a proposal to increase funding to:

- Increase capacity to meet the needs of women until their baby is aged 2
- Broaden eligibility criteria to support women who have a diagnosis of personality disorder (who have often experienced trauma that is re-triggered in this period)
- Expand access to psychological therapies to include parent-infant, couples, co-parenting and family interventions
- Offer assessment and signposting to partners
- Introduce 'Maternity Outreach' services to integrate maternity, reproductive health and psychological therapy for women experiencing mental health difficulties directly arising from, or related to, the maternity experience.

Several new Best Practice guidelines have been commissioned to help inform this expansion of services. One of these relates specifically to the psychological / mental health needs of families in the maternity and neonatal setting (including those who have experienced birth trauma). We asked Ruth Butterworth, Consultant Clinical Psychologist, to tell us about this guideline:

"Professor Pauline Slade, Dr Geraldine Scott-Heyes and I have been working with colleagues at the University of Liverpool to develop Best Practice Guidelines for NHS England. We have been asked to explore 'what good looks like' in terms of how the psychological / mental health needs of couples, parents and families are met within maternity and neonatal settings. We have a particular (but not exclusive) focus on the needs of those who have a difficult time during this period - including those with complex pregnancies, fear of childbirth, birth trauma, neonatal care and pregnancy or baby loss - and on ensuring that we consider the experiences of the family as a whole. Our hope is that the guidance will summarise what specialist therapeutic support might be important within these settings, but also (and perhaps more importantly) what aspects of the environment or service delivery themselves might promote psychological wellbeing, and what additional training and support core staff might need.

As a result of the NHSE 'Long Term Plan', from April 2020 services will be able to bid for pilot funding to develop specific 'maternity outreach clinics' from April 2020 to meet these types of need. We hope that publishing our findings in March 2020 will support both services and commissioners as they come to consider what additional investment might be valuable in their area. This report also holds really important suggestions for what is needed. I am really appreciative of the work that Make Birth Better and other similar campaigns have done in recent years, to act as a voice for families and for change. Let's hope that the coming years make that change a reality."

makebirthbetter.org | @birthbetter | hello@makebirthbetter.org