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Decision-making and Consent

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Katharine Handel

Journal Production Team
Danielle Gilmour
Alison Melvin
Julie Ann Crowley
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Editorial

Are you sitting comfortably?

by Alex Smith

How better to start an issue of the AIMS journal entitled ‘Informed Decision-making and Consent’ than with an Arthurian legend? Are you sitting comfortably? Then I’ll begin.

> King Arthur is out hunting with his friends when he decides to separate himself from the others. While he is alone, he comes face to face with Sir Gromer, who has been wronged by Arthur’s nephew, Sir Gawain. Arthur, who had left his sword Excalibur at home, fends off Sir Gromer’s threat to kill him there and then by pleading his defencelessness and saying that there would be no honour in such an execution. Sir Gromer responds by giving Arthur one year and a day to solve the riddle: What is it that women desire most, above all else? “Easy,” thought Arthur, as he returned to his friends, but as the year went by every woman he met gave him a different answer. Then, with the time nearly up, he rides into the forest again and comes across a loathly lady, the Lady Ragnell, sitting by the path. Despite her repulsive appearance, Arthur greets her courteously and takes this last chance to save his life by asking her the riddle. She replies that she knows the answer and will tell him on the condition that Arthur will arrange for her to be married to Sir Gawain. Arthur hurries back to court looking very troubled. How can he burden any man with marriage to such an ugly woman? Gawain can see that Arthur is troubled and invites him to confide. Arthur explains and Gawain, true and noble as he is, immediately agrees to the wedding. With this promise secured, Arthur rides to meet Sir Gromer, stopping by the lady Ragnell who gives him the answer he needs (and here lies the relevance to this journal). What we desire above all else is to have sovereignty, to rule our lives as we see fit, to not be beholden to another.

This is indeed the right answer and Arthur’s life is spared. On the night of the wedding, alone together with Gawain in their bedchamber, the Lady Ragnell suddenly appears as a beautiful young woman. She explains to Gawain that she is under a spell that means she can have her normal appearance by day or by night, but not both. If she is beautiful at night, it might please her husband, but she will spend every day being taunted and ridiculed. If she is beautiful by day, then he must sleep beside her in her loathly shape. The choice is his. Gawain, true and noble as he is, says that this must be her decision, and in doing so, breaks the spell.

This 15th-century tale, ‘The Wedding of Sir Gawain and the Lady Ragnell’, is preceded by the very similar story told by the Wife of Bath in Chaucer’s ‘Canterbury Tales’, 24 tales that were written between 1387 and 1400. In her tale, the answer to the riddle goes a bit further to say that women want sovereignty not only over their own lives, but over those of their men as well.

> Wommen desiren to have sovereynetee
> As wel over hir housbond as hir love,
> And for to been in maistrie hym above.

This could be seen as a very masculine bid for power on the part of women, but I like to think that it refers only to having a higher power over those actions of a man (or a woman for that matter) inasmuch as they affect her (which, when you think about it, would be in almost everything). Others may disagree. In fact there is a lot of debate about whether or not the Wife of Bath’s Tale expounds feminist principles.

The Wife of Bath herself is a strong and authoritative figure. She values the legitimate wisdom born of her own experience (she has been married several times) and values her own interpretation of the literature of the time. Today, she would most definitely be an AIMS reader. However, the tale she tells is complex and in it, the loathly lady, having been given free will, willingly uses it to please her husband, and in both versions of this tale, the happy ending sees the lady beautiful by day and by night.

The freedom to decide at this turn of the story may be part of a ploy to gain her compliance and docility (lulling her with the illusion of choice), or it may be the means of her sexual emancipation (leaving her radiant and unashamed as her authentic self), but either way, the story seems to reinforce the stereotypical ideal of a woman and to disregard her anger, dissent and flabbiness. The interpretations are yours. However, the tale is complicated further when we know that her new husband had previously been arrested for the sexual assault of a young woman. The opportunity to solve the riddle was offered to him through the compassion of the queen as a commutation of a death sentence. This part of the story adds such deep scope for reflection that you may want to sit down occasionally or you will get dizzy. How can women best use their power when they have been violated?

Many thousands of women in the UK alone enter motherhood with the feeling that they have been robbed of something, seized against their will, traumatised by how they were treated. To me, the queen in the story represents the potential of a woman to claim her sovereignty, to realise her own power and authority. Once secure in this, should she show compassion for misguided male thinking and offer a chance for reform – *you have a year and a day to find out what women really want and to respect this* – or should she call for punishment? Which is the stronger stance? This is where I need to sit down, but suffice to say, the tale of the loathly lady, and her answer to the riddle, is evidence that the importance of women's autonomy has been understood at least since medieval times, and probably since time immemorial.[1] It is explored again in this September issue of the journal through the wonderful range of articles we have for you this month.

Emma Ashworth opens this issue by explaining how the Montgomery ruling has strengthened people's rights when giving consent to medical treatment. She states in no uncertain terms that,

> **"Medical patriarchy no longer has any place in maternity care".**

To illustrate this, three short scenarios follow that show how gaining consent should, and should not, sound in practice. I take the character Muriel from the scenarios, and place her in the centre of an examination of the forces at play when people attempt to exercise autonomy, while perinatal education practitioner, Caroline Smith, explores her role in supporting parents to assess all their options, before making decisions that feel right for them. Both these articles show that making and acting on informed decisions is far more complex than simply being informed. Full time mum of two, Maria Lyons writes about being pregnant and non-compliant. She calls on us to reject fear-based healthcare and to take back the reins, ensuring that when we give our consent, it is always consent in the truest sense of the word. Unfortunately, even when women are strong and confident in the knowledge that they legally hold sovereignty over their own person and that of their baby, the deeply entrenched assumptions within the hospital setting as to where power lies, can mean that an individual's autonomy is wrongly denied. This is what happened to Heather Spain when she and her newborn baby were held in hospital against her will. Heather writes an open letter to the midwives involved. Personally, I would like to see this letter used as a mandatory part of the training of anyone involved in maternity care. Coming up for a wonderful breath of fresh air, hospital team Georgia Smith, Charlotte Harford, and Maggie Arlidge tell us how, in their practice, an elective caesarean is tailored, in numerous ways, in accordance with decisions made by the parents. Their approach honours the sanctity of every birth and makes for inspiring reading, as does Laura Jansson's article in which she reflects on the complex interplay between spirituality and perinatal decision-making, and on how caregivers can support clients' autonomy along their spiritual journey to parenthood. And echoing Laura's piece (quite coincidentally), we finish the themed section of the journal with Danielle Gilmour's wonderful poem, 'I've Just Had a Baby'.

1 Further reading:

Stories to Grow by website, 'King Arthur and the riddle: The wedding of Sir Gawain and Lady Ragnell': https://storiestogrowby.org/story/sir-gawain-the-lady-ragnell/.

Satkunananthan A H (2018), 'Sovereignty, agency and perceptions of the grotesque in two medieval interpretations of the Loathly Lady,' Scheherezade's bequest 1 (1): 9–25. www.researchgate.net/publication/329235456_Sovereignty_Agency_and_Perceptions_of_the_Grotesque_in_Two_Medieval_Interpretations_of_the_Loathly_Lady.

Melville A (2019), 'Female 'soveraynetee' in Chaucer's 'The Wife of Bath's Prologue and Tale,' British Library website: www.bl.uk/medieval-literature/articles/female-soveraynetee-in-chaucers-the-wife-of-baths-prologue-and-tale.

Article contd.

As ever, the AIMS Campaigns team has been very busy this quarter. Jo Dagastun explains why the concept of 'shared decision making' contradicts the concept of 'patient autonomy' and consent. Georgia Clancy comments on the recent guidance of the Better Births recommendation. Nadia Higson introduces Scott Mair who writes about his personal experience of birth-related trauma and about the webpage he has started to promote parental mental health. Megan Disley updates us about the latest MBRRACE[2] report, and the team share their commentary on the OASI care bundle debate. Last but not least, we have a Birth Activist Briefing about the importance of involvement in the Maternity Voices Partnership, and news about the AIMS Campaign team's current activities.

We also have two book reviews in this issue; Verina Henchy and Jo Dagastun review the second edition of Margaret Jowitt's 'Dynamic Positions in Birth', and Georgia Clancy reviews 'Making informed decisions on childbirth', by Sofie Vantiers. And we have an obituary for the late Murray Enkin written for us by Tania Staras.

We are very grateful to all our authors, to our peer reviewers – Anne Glover, Caroline Mayers, Georgia Clancy, Natalie Palmer, Megan Disley, Danielle Gilmour, Ami Groves, Carolyn Warrington, Beth Frances, Rachel Boldero, Julie Milan and Winsa Dai – and proofreaders – Josey Smith and Zoe Walsh – to the ever helpful Danielle Gilmour and Alison Melvin who upload all of the material to the website and to ISSUU – and of course, to all our readers and supporters.

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2 MBRRACE-UK: Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK - www.npeu.ox.ac.uk/mbrrace-uk

Article

The Montgomery ruling and your birth rights

by Emma Ashworth

Editor's note: *The duty of doctors, nurses and midwives to gain the patient's consent for treatment has been enshrined in law for many decades, and bodily integrity, or the inviolability of the body, has been a human right for even longer. Yet, we still hear story after story in which well-educated articulate people emerge from maternity care having agreed to treatment they didn't want because they didn't know they had a choice, or because they were afraid to say no. In this article, Emma Ashworth explains a 2015 development in the law that has strengthened the rights of everyone considered as 'having capacity', to make informed decisions about their care. This is followed by some scenarios that allow the AIMS reader to hear exactly how the offer of treatment should sound in practice.*

One of the single most important legal cases that absolutely every birth worker needs to understand is commonly referred to as "Montgomery" [1]. In this case, Mrs Nadine Montgomery brought legal action against the Lanarkshire Health Board in Scotland, and the outcome of the hearing led to one of the most crushing changes to medical patriarchy in British history.

When Mrs Montgomery was pregnant with her son, she mentioned to her obstetrician that she was concerned about her body's ability to safely birth vaginally. Although most women and people in Mrs Montgomery's position would be able to have a safe vaginal birth, she did have a higher chance of experiencing complications than women and people without her medical condition (type 1 diabetes). She is also small in stature and was expecting a baby that was estimated to be quite large, possibly due to the effect of excess sugar in her body related to her diabetes.

Although Mrs Montgomery raised these concerns multiple times, her obstetrician chose to not discuss the option of a caesarean with her. The doctor was of the opinion that

1 Montgomery v Lanarkshire Health Board (2015, March 11): www.bailii.org/uk/cases/UKSC/2015/11.html.
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caesareans should not be discussed because then "everyone would ask for [one]".

Unfortunately, Mrs Montgomery experienced a shoulder dystocia during her birth, which eventually led to serious injuries to her and her baby boy.

The Montgomery case made it very clear that it was not acceptable for doctors* to make decisions on behalf of those in their care, but instead they had an obligation to offer to discuss:

- any material risks, as well as possible benefits, to the mother/birth parent and/or their baby of any recommended course of action (for instance, induction of labour) and
- the risks and benefits of any reasonable alternatives (for instance, awaiting spontaneous labour/having a caesarean)

* The judgement only refers to doctors, but it is assumed that the courts would apply the same principles to other healthcare providers, such as midwives.

The discussion must be personalised, taking into consideration what the doctor either knows or reasonably believes is important to that person. For example, they would need to offer to discuss the risks of a caesarean to future pregnancies when talking to someone they know to be, or expect would be likely to be, planning more babies.

Unfortunately, many doctors and midwives have misunderstood Montgomery, and think that it means that they have to tell women and people all the risks of not accepting offered interventions. This is understandable, because the case was brought against a doctor who did not discuss the possible risks to Mrs Montgomery of a vaginal birth. However – and the importance of this cannot be overstated – this is an incorrect interpretation of this judgement.

So, for instance, giving pregnant women and people:

- a list of reasons why home birth may be risky without discussing the risks of hospital birth, or
- a list of reasons why waiting for spontaneous labour at 41+ weeks may be risky without discussing the risks of induction and the benefits of waiting, or
- a list of reasons why declining an induction at 39 weeks because of an estimated 'big baby' may be risky without explaining the risk of prematurity or harm from induction…

…is not legal, and does not follow the requirements of the Montgomery ruling.

For these examples, to be acting legally, the doctor must offer to discuss the benefits and risks of all of the options, with special focus on those important to the mother or birth parent, impartially and without bias or coercion.

The pregnant or birthing woman or person does not have to take part in these conversations if they are planning to decline an intervention. For instance, if they are intending to birth at home, and therefore decline the intervention of hospital treatment, they do not have to discuss their plans with the doctor unless they want to.

These misunderstandings have somewhat undermined the positive changes that birth activists hoped would come from Montgomery. Despite this, the legal reality is that there must not be any 'decisions about us, without us', and the patriarchal concept of 'doctor knows best' has been clearly and unambiguously shown to not be legally acceptable.

The Montgomery ruling reaffirmed that the only person who can make a decision about their body is the person who owns their body, and in order to make an informed decision, they need to know "*the seriousness of her condition, and the anticipated benefits and risks of the proposed treatment and any reasonable alternatives, so that she is then in a position to make an informed decision*".

The court has ruled: Medical patriarchy no longer has any place in maternity care.

Author Bio

Emma Ashworth is an AIMS Trustee, birth activist and author of [The AIMS Guide to Your Rights in Pregnancy and Birth](). You can find her personal birth activist social media accounts at facebook.com/emmashworthdoula and on Instagram @emma_ashworth_birth_rights.

Article

Gaining a person's consent for medical treatment has to be 'just right'

by Alex Smith

Vintage illustration by Arthur Rackham

Chapter one – This one was too lacking.

MIDWIFE (busily writing in the notes): Everything looks perfect. Let's fit you in for your induction on Thursday, Okay? If we don't see you before, we'll see you then!

MURIEL (looking overwhelmed): Okay

Chapter two – This one was too coercive.

MIDWIFE (busily writing in the notes): Everything looks perfect. Let's fit you in for your induction on Thursday, Okay? If we don't see you before, we'll see you then!

MURIEL (looking anxious but determined): I would rather avoid induction if possible.

MIDWIFE (looking and sounding sympathetic): I know it's not what you want. Fingers crossed; you may go into labour in the next day or two.

MURIEL (taking a deep breath): I have discussed this with my partner. We understand that we could wait a while longer and have extra checks on the baby instead. Wouldn't that be all right?

MIDWIFE (putting her pen down and taking a deep breath): Yes you could do that but we don't recommend it because of the extra risks to your baby.

MURIEL (starting to sense the tension): Is it really much riskier?

MIDWIFE (adopting a regretful but firm and matter of fact tone): Sadly, yes. Babies are twice as likely to die if pregnancy goes beyond 42 weeks. We just don't want to take that risk, do we.

MURIEL (looking browbeaten, Muriel remains silent)

MIDWIFE (standing to see Muriel to the door): So I'll take that as a yes for Thursday shall I? Try not to worry; it's all very routine. Have a lovely afternoon.

Chapter three – But this one was just right and the rate of complaints fell through the floor!

MIDWIFE (busily writing in the notes): Everything looks perfect.

MURIEL (smiling): That's good. I can't wait to meet the baby.

MIDWIFE (putting her pen down and paying Muriel her full and warm attention): Well, you are 41 weeks now, so that's going to be very soon.

MURIEL (looking serious): I hope so because I really don't want to be induced. Some friends have told me it was horrible.

MIDWIFE (matching Muriel's concern): Yes, I understand. There is a place for induction and we can offer this to you as a routine procedure within this coming week – as soon as Thursday in fact – but you are right, some women do find it very hard-going. In some situations it may be beneficial, but it is an invasive procedure and a process that can stretch over a few days. Would it help if we talked through all your options?

MURIEL (sounding relieved and understood): Yes please.
MIDWIFE (remaining calm and measured, the midwife briefly explains the pros and cons of each pathway – induction, expectant management, and carrying on as before): The decision is entirely yours Muriel. You don't need to decide now. Go home and talk it through with your partner. I will email you with the research evidence you asked about. This information will enable you to consider the balance of concerns between the different pathways, but it is really important that you only consent to things that, on balance, feel right to you. Whatever you decide you have our complete support, and you can change your mind at any point.
MURIEL (looking calm and confident): Thank you, I feel so much better now – sort of lighter and happier. I feel I can trust you and turn to you no matter what. I will let you know what we decide.
MIDWIFE (standing to see Muriel to the door): That's perfect. Have a lovely afternoon.

Oatmeal bowl illustration by Tina Bits

Decision-making theory: Does Muriel have free will?

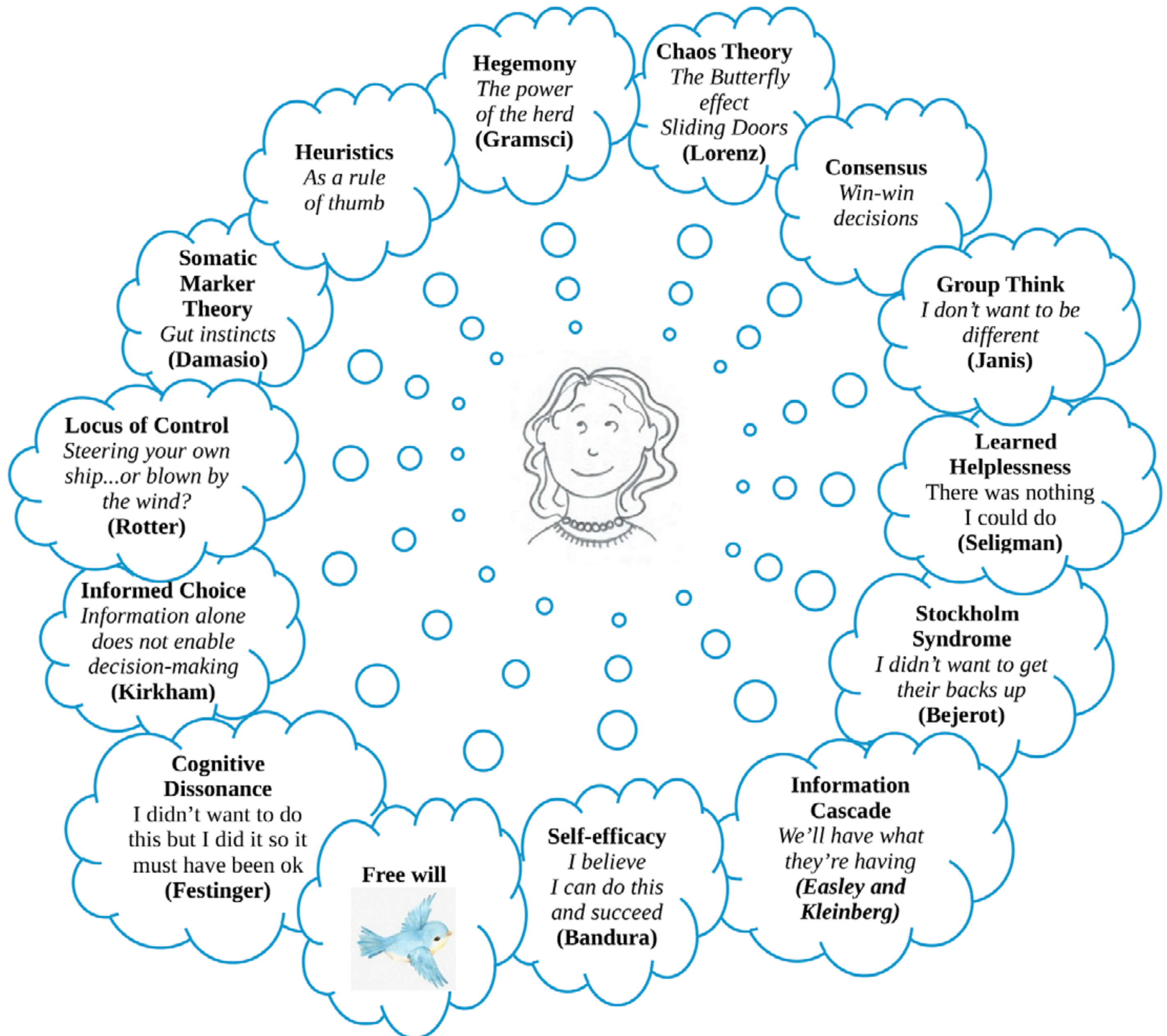
by Alex Smith

Muriel is expecting a baby. She is reassured to know that *if she decides* to engage with the maternity services, because legally she may decide not to, nothing will be done to her without her consent. That is the law.[1] For her consent to be valid, the pros and cons of all possible pathways will be outlined without any pressure on Muriel to accept one in particular. There will be time for Muriel to think things through, and her decisions will be respected and supported even if the midwife or doctor does not agree with them. Any test, examination or procedure that Muriel might allow would be as a result of her own free will; or would it?

The problem of free will – do we have it? – is one of the oldest and most important questions in Western philosophy.[2] While an exploration of the question is beyond the scope of this article, it is safe to say that the jury is still out. Whether or not Muriel, or anyone else for that matter, can truly make free and fully informed decisions about their maternity care, or indeed about their lives, is gloriously and endlessly debatable. This is true even when we feel as if we do make our own decisions, and even when the law protects our right to do so. It may be good at this point to tease apart some of the terminology required in order for Muriel to explore this issue a

1 Nursing Times (2018). Informed consent 1: legal basis and implications for practice. www.nursingtimes.net/roles/nurse-educators/informed-consent-1-legal-basis-and-implications-for-practice-21-05-2018/

2 O'Connor, Timothy and Christopher Franklin, "Free Will", The Stanford Encyclopedia of Philosophy (Spring 2021 Edition), Edward N. Zalta (ed.) Available at: https://plato.stanford.edu/archives/spr2021/entries/freewill/



little deeper.

Free will can broadly be divided into ***freedom of will*** and ***freedom of action***. Freedom of will is very much governed by what we know. For example, it would be difficult for Muriel to have the will to give birth at home if she does not know this is possible, and has therefore never envisioned it. It would literally be unimaginable for her. With knowledge of homebirth as a possibility, Muriel can start to picture the homebirth setting. The image in her head may awaken and resonate with her deepest instincts and suddenly it just feels right. The **somatic marker hypothesis**[3] suggests that feelings and emotions play a critical role in making rational decisions and so Muriel is now free to decide 'I will have my baby at home', but she may not feel free to act on this decision when barriers are put in her way, "I decided to have my baby at home, but I wasn't allowed." It would still be Muriel's human right to stay at home, and it is her legal right to give birth without a midwife in attendance, but even with this knowledge, cultural conditioning as to who holds authority and power in this situation, combined with a cultural fear of birth, may weigh more heavily than knowledge of her rights and leave Muriel feeling as if she had no choice.

3 Somatic Marker Hypothesis – https://psychology.wikia.org/wiki/Somatic_marker_hypothesis

Choice is rather different from **decision-making**. A choice is when a person selects from a menu of options that has been put together by another person or body of people. An informed choice is self-explanatory, and a free choice suggests that no overt or covert pressure or coercion is used to 'force' a choice, as a magician might. There is an element of passivity and limitation in the concept of choice, whereas a decision involves a stronger element of **self-determination**[4] . If I am determined to eat pasta tonight but my local restaurant does not offer me that choice, then I will try another restaurant or make dinner at home. There is a greater sense of a decision coming from within the person; of them being intrinsically motivated and confident to act. The belief that one can have control over the outcome of events in this way is sometimes referred to as having an internal **locus of control**. If Muriel is truly decided about having her baby at home, on hearing that the hospital has suspended their homebirth service, she may contact AIMS for support, write a stiff letter to the Head of Midwifery, make enquiries about independent midwifery and explore the idea of freebirth. On the other hand, if she has succumbed to **learned helplessness** and has an **external locus of control**, she will believe that these things are out of her hands and that there is nothing she can do.

Self-determination theory holds that if a person's need for competence, relatedness and autonomy are met, they will be able to exercise free will or self-determination.

- **Competence** is similar to **self-efficacy**[5]. Competent people are able to interact effectively with their external environment to manage any barriers they encounter. They have equipped themselves with the skills needed to achieve their goals.
- **Relatedness** is the need to have close and affectionate relationships. If Muriel has a supportive family, good friends from the homebirth group, and a midwife with whom she has been able to develop a good relationship (or at least one of these), she will find it easier to exercise free will in deciding where to give birth. It does not matter whether these people agree with Muriel, as long as they respect and accept her autonomy, with unconditional positive regard.
- **Autonomy** is self-government or the ability to 'steer one's own ship', and is about a person's ability to act on his or her own values and interests. It is central to medical ethics and to human rights. It relates to bodily integrity (everyone's right to be free from acts against their body to which they do not consent) and the right to private and family life, a right that was invoked when the European Court of Human Rights established that women can determine the circumstances in which they give birth[6]. A limitation of autonomy is that a person cannot insist that someone does something to them or for them (a medical procedure, for example) against their will. Muriel is at liberty to decline induction of labour but not to demand it; she can exercise personal autonomy but cannot control the actions of others.

> *The only part of the conduct of anyone, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.*
> John Stuart Mill on liberty[7]

Whether or not this limitation of autonomy should be different within the context of maternity care is debatable.

Even if Muriel usually considers herself to be an educated and self-determined woman, even if she knows that her consent is required for any procedure, withholding it may feel very uncomfortable indeed and she may find herself asking if she is 'allowed' to say no. This is because in our culture the subjugation of women within patriarchal institutions is still deeply entrenched; it was only 30 years ago that non-consensual sex inside marriage was made illegal. When women encounter the patriarchal authority of the now normalised medical model of maternity care, they usually and quite unconsciously adopt a

4 Lopez-Garrido (2021) Self-Determination Theory and Motivation. Simply Psychology. Available at: www.simplypsychology.org/self-determination-theory.html

5 Mary Nolan AIMS Journal 2021 Vol 33, No 1 'Self Efficacy: What is it? Why is it important? And what can we do about it?' – www.aims.org.uk/journal/item/self-efficacy-pregnancy-birth

6 Romanis EC, Nelson A. Homebirthing in the United Kingdom during COVID-19. Medical Law International. 2020;20(3):183-200. doi:10.1177/0968533220955224

7 Jacobson, D. (2000). Mill on Liberty, Speech, and the Free Society. Philosophy & Public Affairs, 29(3), 276-309. Retrieved June 12, 2021, from www.jstor.org/stable/2672848

submissive, even fawning position within the power hierarchy, ignoring their own needs, values, and boundaries to conform to what they believe others expect of them. They may submit to unwanted tests, examinations or procedures for fear of not being liked, creating a fuss, getting people's backs up, or being regarded as an irresponsible mother. Rather than being respected, women who express concerns about a procedure may be considered unduly anxious. A midwife may then 'gentle' them into submission[8] : 'It's just routine, we have to do this, try and relax, I will hold your hand until it's over, well done'. Or they may be perceived as being difficult and challenging and will be reined in with direct or thinly veiled threats: 'Yes, it is your decision but we don't want anything to happen to your baby, do we?' Either way we know that they will be talked about behind their back, and the respective midwife or doctor will be commended for gaining patient compliance.

If Muriel stands her ground by declining to follow the hospital protocol, she is very likely to experience efforts to put her back 'in her place'. She may be hounded with repeated talk of risk; pressured, coerced or forced into accepting unwanted treatment; threatened with referral to social services; or even held against her will and not allowed to leave until the doctor says so. Some women say that they were literally 'held captive' by locked doors and security guards. These things constitute **obstetric violence** and can cause long-term physical and psychological injury to the mother and her family. To cope psychologically in this sort of situation, Muriel might experience:

- **Cognitive dissonance**. This is when a person experiences discomfort from conflicting beliefs and seeks to resolve this tension by modifying one of them. Muriel has always believed that hospitals are safe and that midwives are good people. She also believes a midwife is holding her captive and scaring her in a nasty way. Both can't be true so perhaps it is her (Muriel) that is the difficult and dangerous person and perhaps the midwife is only doing her job. This could lead to Muriel feeling gas-lit (psychologically manipulated into questioning her sanity, perception of reality, memories or judgement), or to her experiencing Stockholm Syndrome.
- **Stockholm Syndrome**. This is when, unable to escape the situation, a person starts to empathise with their 'captors' and to justify their actions. They do this in order to stay safe. Even if Muriel is not physically locked in the hospital, **hegemony** (the hidden force within society that imposes and maintains the dominant ideology of that society) can hold her captive in other ways, despite the law that endorses her free will. It may only take a raised eyebrow for Muriel to be pulled into line.

It may seem as if I am demonising the midwife and doctor and perpetrating the 'them and us' relationship, but I absolutely am not. Free will is an 'I and I' situation, with the midwife and doctor subject to the same hegemonic forces as the mother. Just as the law supports Muriel's autonomy, the same law not only compels but (in theory) frees the midwife and doctor to honour and respect her decisions, even when those decisions are leading towards a door unsanctioned by hospital protocol. The law is intended to protect all three. Yet as that portal is approached, those forces bear in and all three start to feel a sense of fear. This isn't so much the fear of death, though this will be part of it, but more the deeply enculturated[9] fear of social or professional opprobrium or condemnation that would be experienced should that death happen outside of the hospital, even when the hospital setting may increase the chance of that outcome. Muriel is likely to seek approval and permission for her decision, which although not legally required, will absolve her from responsibility in the eyes of society. The midwife or doctor, if they cannot bring her back into the fold, are likely to take steps to cover their backs. Of course they will, they are only human. They equally feel that they have no choice. Their behaviours naturally reflect those of the medical model of birth in which they were educated, and strongly reflect the culture of their workplace.

Muriel is likely to seek approval and permission for her decision, which although not legally required, will absolve her from responsibility in the eyes of society. The midwife or doctor ... are likely to take steps to cover their backs. Of course they will, they are only human. They equally feel that they have no choice. Their behaviours naturally reflect those of the medical model of birth...

8 Fahy K. (2002) Reflecting on practice to theorise empowerment for women: Using Foucault's concepts. The Australian Journal of Midwifery February 15(1):5-13

9 Enculturation: the process by which an individual learns the traditional content of a culture and assimilates its practices and values

When midwives and doctors step out of line by challenging the status quo, they too experience censure. This is endemic within the system, and is written about as horizontal bullying or violence[10]. It is explored by Shapiro in her 2018 article '"Violence" in medicine: necessary and unnecessary, intentional and unintentional'[11] and in relation to midwives in particular, by Kirkham in her 2007 article, 'Traumatised Midwives'[12].

It seems, then, that to de-traumatise birth for everyone, we have a complex Gordian knot[14] to unravel, and unfortunately there is no simple linear logic to hand that helps.

Chaos theory says that outcomes from a non-linear dynamic process such as pregnancy and birth would be predictable if all the factors could be taken into account. This would greatly aid decision-making, but the factors are so numerous, complex and changing that it is impossible to identify or map them all. The smallest change in just one factor early in the process can change everything. Sensing this complexity and uncertainty, everyone concerned seeks other ways of making decisions. **Heuristics** are

10 Hastie C. (2006) Horizontal Violence in the Workplace. Birth International. Available at: https://birthinternational.com/horizontal-violence-in-the-workplace/

11 Shapiro, J. (2018) "Violence" in medicine: necessary and unnecessary, intentional and unintentional. Philos Ethics Humanit Med 13, 7 https://doi.org/10.1186/s13010-018-0059-y

12 Kirkham M. (2007) Traumatised Midwives. Available at: www.aims.org.uk/journal/item/traumatised-midwives

13 Determined to conform: Disbelief in free will increases conformity. www.sciencedirect.com/science/article/abs/pii/S0022103112001825?via%3Dihub

14 The Gordian knot is a Greek legend often used as a metaphor for an apparently intractable problem that can be solved easily by finding a solution that renders the perceived constraints of the problem moot.

shortcuts to making quick decisions without all the information. This is the 'as a rule of thumb' method. Muriel, her midwife[15] and the doctor are all likely to employ this method. As a rule of thumb, Muriel takes the midwife's advice, the midwife refers to the doctor, and the doctor sticks to the protocol. Alternatively, the different parties involved may believe in shared **decision-making** and seek a **group consensus**, but Muriel may be very swayed by the views of others and end up making an unnecessary compromise. Worse still, the group decision process can descend into **group think** (remember the Asch experiment[16]) where people agree with things they know to be wrong simply to maintain group harmony; they conform. This is particularly dangerous when dissent is frowned upon. If Muriel isn't seeing the same group or team of people throughout, but a chain of different individuals, their decisions may form an **information cascade** in which the midwife or doctor she sees this week will look in the notes and just go along with what has been written at earlier appointments, sometimes ignoring their own judgement. This apparent concurrence between the midwives and doctors will sway Muriel's decisions, and if she has any remaining doubts she may utilise her own information cascade by finding out *what most other women do* in that situation, and following suit. Following suit is a very common heuristic decision-making strategy when the complexity of the situation makes it hard to decide.

So, when AIMS confirms to Muriel that she is indeed free to make her own decisions in so much as her own body is concerned, and that her midwife and doctor are free to support her – this is both true and not true. On the face of it, this legal fact is the solution that easily unties the Gordian knot and frees everyone from its oppressive bind, but freedom is complicated and this is where it gets philosophical. Muriel might want to look away.

Despite having the freedom not to, the Milgram experiments[17] in the 1960s showed (and still do[18]) that a majority of people will obey someone they see as an authority figure, even when asked to do something they believe will harm someone else and even when this is not aligned with values they hold dear. It appears that the illusion of authority is a force of oppression that could rival the fundamental forces of nature. It is the social equivalent of the electromagnetic force[19] bonding us together and keeping us in shape through conformity and compliance. To overcome this oppressive force, it feels as if you would have to do battle. In fact, the educator and philosopher Paulo Friere warned that, in seeking freedom from oppression, "The oppressed, instead of striving for liberation, tend themselves to become oppressors." We condemn the system and expect all the change to happen there, without exercising the freedoms we do have. Freedom walks hand-in-hand with responsibility. It is a contentious and often unpopular thing to say, but the clue is in the word 'own'. Muriel must own her decisions if they are to be her own decisions. Midwives and doctors must own their behaviours if they are to practice with integrity and in an ethical way, even if this comes at a cost. We cannot say that we did not have a choice, when we did[20]. The price of freedom in this context is the *exercise* of free will – *of being the change you want to see in the world*[21]– and it is the willingness to take responsibility for the consequences, which is not always easy. Friere said, "Liberation is thus a childbirth, and a painful one", but like childbirth, it can also be transformative.

> *We but mirror the world. All the tendencies present in the outer world are to be found in the world of our body. If we could change our-selves, the tendencies in the world would also change. As a man changes his own nature, so does the attitude of the world change towards him. This is the divine mystery supreme. A wonderful thing it is and the source of our happiness. We need not wait to see what others do. (Gandhi 1913)*

So, where does that leave Muriel? She is probably asking herself the same question. The theory can take us round in circles and tie us in knots, but happily the ethics committees and lawyers have stepped in and I refer her to the opening paragraph. Muriel *is free* to do what she feels is best and she should expect our wholehearted support!

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15 Muoni, Tambu. (2012). Decision-making, intuition, and the midwife: Understanding heuristics. British Journal of Midwifery. 20. 52-56. 10.12968/bjom.2012.20.1.52

16 Asch Conformity Replication https://ahp.apps01.yorku.ca/2008/06/asch-conformity-replication/

17 The Milgram Experiment: How Far Will You Go to Obey an Order? www.thoughtco.com/milgram-experiment-4176401

18 Replicating Milgram: Would People Still Obey Today? ww.apa.org/pubs/journals/releases/amp-64-1-1.pdf

19 Electromagnetic force. https://energyeducation.ca/encyclopedia/Electromagnetic_force

20 A proviso: On occasion women are forcibly examined, treated, restrained or threatened and this should be reported to the police as assault. On occasion midwives and doctors are pressured into giving inadequate, negligent care or non-consensual care, and this should be reported to their supervisors, regulatory bodies and to their unions.

21 These words are attributed to Gandhi but are actually a summarised paraphrasing of the quote that follows.

Article

Informed decision-making and the antenatal educator

by Caroline Smith

As a perinatal education practitioner, I work with new parents, both before and after their babies are born. I walk a constant thin line between preparing parents for the reality of birth and not wanting to shatter their dreams. I wholeheartedly support the concept of informed decision-making (IDM), but I am also sufficiently pragmatic to recognise the limitations of the health service. I have also heard hundreds of parents' stories of dashed hopes and substandard care. This leaves me with a sense of tension in my practice; where does my responsibility lie when navigating the divide between expectations and reality?

Parents come to antenatal education with preconceived ideas and hopes for childbirth which are, in part, informed by outside influences, whether that is dramatic depictions on television or 'horror stories' from friends right through to blogs espousing 'orgasmic birth'. The reality of birth will lie somewhere on this spectrum and be different for each individual. Opening parents' eyes to the range of realities also opens up the potential for dashed hopes, and research shows that this can contribute to some parents' feelings of emotional distress in the postnatal period[1].

The difficulty for antenatal educators is how to convey what birth might be like in a way that has meaning for each person. So many parents say, after the birth, "why did nobody tell me?" And most of the time, I am fairly sure they were 'told' but for whatever reason they didn't believe it, or didn't want to hear. We know that a pregnant person's brain chemistry alters to help them 'attune' to their growing baby. Could it also be that there is a biological mechanism which protects pregnant people from difficult information? Maybe there is a need for parents to retain hope in order to psychologically protect themselves, or their unborn baby? This might be especially true for parents who had difficult childhoods themselves and need to believe that things will be different for their baby.

In antenatal education, I aim to support parents as they become aware of their options during birth and to assess the pros and cons of those options. Some people find this process enlightening and respond positively to the concept that birth can be different. Other people find this idea more challenging and perhaps would feel safer not having their beliefs disrupted. If my hope is to protect the emotional wellbeing of expectant parents, then I feel I have an obligation to invite parents to explore their preconceptions without directly challenging them myself.

I also hope to empower parents with the knowledge to make informed decisions about their care, but is this an illusion? Am I implying to parents that they will have more autonomy during birth than they actually have?

Historically, the concept of 'informed consent' was driven by the medical profession, in that doctors would give parents as much information as they felt appropriate. When I worked as a medical secretary twenty years ago, my orthopaedic consultant told me not to mention anaesthetic risks to his elderly patients, in case it scared them. He felt patients lacked the objectivity to make the "right" decision about whether to proceed with their joint replacement operations. In effect,

1 Lazarus, K. & Rossouw, P. J. (2015). Mother's expectations of parenthood: The impact of prenatal expectations on self-esteem, depression, anxiety, and stress post birth. International Journal of Neuropsychotherapy, 3(2), 102–123. doi: 10.12744/ijnpt.2015.0102-0123

he was making decisions for his patients. This approach was most notably challenged in 2015 when the landmark case 'Montgomery v. Lanarkshire Health Board'[2] ruled that risks of medical procedures should be communicated to people based on what a 'reasonable patient' would want to know about. This confirmed that parents have the right to know about any risks associated with interventions and all the alternatives, so they have the opportunity to make an 'informed decision'. Anecdotal evidence suggests that this does not always happen, especially during the Covid pandemic[34] when midwives and doctors have been under greater time pressures than before. It is also known that midwives and doctors are constrained by the policies and procedures of their organisations[5]. This means that not all options may be available, or actively promoted, thereby limiting parents' choices.

There is also a power imbalance between 'patients' and midwives and doctors, who are perceived as the gatekeepers and as more authoritative. Belenky's research on 'women's ways of knowing'[6] suggests that some women are inclined to become subordinate when they feel out of control and vulnerable. I wonder whether, on reflection, some women feel that they have been coerced into a course of action which they later regret. Midwives and doctors need to be aware of this asymmetrical relationship with their 'patients' and not unwittingly prejudice their decision-making.

The psychology of how humans make decisions is an academic discipline in its own right. There are many influences, both conscious and subconscious, that might be at play when people make decisions about birth. Some women are unprepared for the effect of fear and pain on their rational thinking skills[7] . An otherwise highly competent, autonomous woman can find herself in a state of anxiety in which her primal instincts for safety and belonging may take over. When this is combined with the medical professions' risk-averse and litigious culture, it becomes almost impossible to make a considered, judicious decision[8].

There is plenty of anecdotal evidence to support the theory that straightforward birth is perfectly possible for the vast majority of low-risk women, if the environment promotes this. We also know that such an environment can be challenging to achieve in a medical setting. If the majority of women will birth in a hospital or a birth centre, I feel it is important that they are aware of how this environment might affect their decision-making skills, and also the potential limitations on what may be available. Some parents may be encouraged to discover they could have more control by birthing at home, or that they have the right to request adjustments to a hospital setting.

How, then, can antenatal practitioners encourage a sense of control and agency for expectant parents, within the context of the medical hierarchy? Studies suggest that asking questions and having their concerns listened to can help women feel more involved in what happens to them during birth[9,10] and therefore midwives and doctors should engage in a dialogue with parents, rather than just informing them of their options. This may not always happen, so antenatal practitioners can equip parents with skills and techniques for encouraging discussion, such as the use of open questions or decision-making tools like the widely used BRAIN[11]:

B – Benefits?
R – Repercussions?
A – Alternatives?
I – Instinct?
N – Nothing?

2 Hilary Term (2015) Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) www.supremecourt.uk/cases/docs/uksc-2013-0136-judgment.pdf

3 Nelson, A. Vaginal Examinations During Childbirth: Consent, Coercion and COVID-19. Fem Leg Stud 29, 119–131 (2021). https://link.springer.com/article/10.1007/s10691-021-09453-7

4 Jolivet R, Warren C E, Sripad P, Ateva E, Gausman J, Mitchell K, Hacker H P, Sacks E, and Langer A. (2020) Upholding Rights Under COVID-19: The Respectful Maternity Care Charter www.hhrjournal.org/2020/05/upholding-rights-under-covid-19-the-respectful-maternity-care-charter/

5 Darling, F., McCourt, C. and Cartwright, M. (2021) 'Facilitators and barriers to the implementation of a physiological approach during labour and birth: A systematic review and thematic synthesis', Midwifery, 92. doi:10.1016/j.midw.2020.102861.

6 Belenky, M. F. et al. (1986) Women's ways of knowing, the development of self, voice and mind. New York: Basic Books.

7 De Vries, R. G. (2012) 'Midwives, Obstetrics, Fear, and Trust: A Four-Part Invention', Journal of Perinatal Education, 21(1). pp. 9-10.

8 Sundin, J. (2008) Birth Skills. London: Random House.

9 Lewis, C. L., & Pignone, M. P. (2009). Promoting informed decision-making in a primary care practice by implementing decision aids. North Carolina Medical Journal, 70(2), 136–139.

10 Humenick S. S. (2006). The Life-Changing Significance of Normal Birth. The Journal of Perinatal Education, 15(4), 1–3. www.ncbi.nlm.nih.gov/pmc/articles/PMC1804308/

11 Editor's note: BRAIN is an acronym that has been widely used for many years, with no clear knowledge of its origin. It prompts the person to ask: What are the benefits, repercussions and alternatives? What is my intuition telling me? and, What if we do nothing – just wait it out for a while?

Some people may not be used to questioning those in authority and might need to practice these techniques, or maybe empower their birth partner or even a doula to advocate on their behalf. The antenatal practitioner can also model this form of questioning during classes, in a respectful manner, to demonstrate its efficacy. Postnatally, some women tell me that although they didn't get what they wanted during birth, feeling able to ask was empowering.

Lastly, people might also feel empowered if equipped with robust evidence about birth and an understanding of their rights. It can come as a surprise to some people to discover they are able to decline any intervention, and organisations such as AIMS can support parents with tools to help them assert their rights.

In conclusion, I feel my role is to metaphorically open the door and show parents what is beyond. I wouldn't want to force anyone over the threshold, but I hope I can support those who would like to step over.

Author Bio: *Caroline is a full-time single mum to two teenagers and a part-time NCT Practitioner. She holds a BA in Birth & Beyond Education, and works in both antenatal and postnatal education. She lives in north Essex where she indulges her passions for yoga and choral singing.*

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Article

Pregnant and non-compliant: rejecting fear-based healthcare and regaining informed consent

by Maria Lyons

Picture this scenario: a young couple, expecting their first baby, are waiting in the ultrasound clinic for their 12-week scan. A nurse approaches them with a clipboard and states she must give them some information prior to the scan, so that the mother-to-be is able to give her informed consent. The nurse starts by assuring the couple that there is no evidence to suggest the scan may harm the unborn baby. However, she goes on,

> "We must make you aware that there have in fact not been any studies on human populations since the 1990s. Because the technology and equipment have changed significantly since then, we cannot entirely rule out the possibility of harm.[1] Moreover, some more recent studies on animals have indicated that ultrasound can damage biological tissue, and for many years researchers have been calling for a cautious approach and further investigations.[2] Also, the screening is not 100% reliable, so we cannot guarantee that when you have your 20-week scan it will identify any problems that do exist, or that it will not identify problems that do not exist.[3 4] Finally, while the scan today does provide us with some useful information, there is no evidence that it will reduce harms or improve outcomes for you or your baby.[5 6] It is therefore, clinically speaking, not strictly necessary. Please take all the time you need to think this through and let me know if you would like to proceed.

Of course, this does not happen in reality. Ultrasound examination has become so routine that consent is assumed. In the same way, the pregnant woman assumes the procedure is safe, believing that otherwise it would not be recommended and/or that she would be told of any potential risks. The example of ultrasound illustrates two features of the healthcare system which have important implications for the processes of decision-making and informed consent.

Firstly, the word "safe" does not necessarily mean what it means in other contexts. If, for instance, a car is deemed "road safe", we can be sure this is based on the result of rigorous crash testing. In medicine, neither the patient nor necessarily the clinician will know if a product or procedure which has been approved under the banner "no evidence of harm" has undergone extensive and long-term safety trials or no trials at all.[7] Patients are not routinely and explicitly made aware of the distinction between evidence of safety and "to-date" no cause for concern.

Secondly, standard care guidelines and practices are not always informed by the best available medical evidence. Institutional culture and policies, professional norms, peer influence and enthusiasm for the latest technologies all play

1 Haar, Gail ter, (2012), British Institute of Radiology, The Safe Use of Ultrasound in Medical Diagnosis, p.127 www.birpublications.org/pb/assets/raw/Books/SUoU_3rdEd/Safe_Use_of_Ultrasound.pdf

2 'Fetal Thermal Effects of Diagnostic Ultrasound' Journal of Ultrasound Medicine, 2008, www.ncbi.nlm.nih.gov/pubmed/18359908

3 A. Debost-Legrand et al, False Positive Morphologic Diagnosis at the anomaly scan. BMC Pregnancy Childbirth, 2014 (14). (https://obgyn.onlinelibrary.wiley.com/doi/pdf/10.1576/toag.8.4.222.27271),

4 Jolly Joy, Review: Is Ultrasound Safe? Royal College of Obstetricians and Gynaecologists, 2006 (www.ncbi.nlm.nih.gov/pmc/articles/PMC3994389/)

5 Whitworth M, Bricker L, Mullan C. (2015) Ultrasound for fetal assessment in early pregnancy. Cochrane Database of Systematic Reviews, Issue 7. Art. No.: CD007058. www.cochrane.org/CD007058/PREG_routine-compared- selective-ultrasound-early-pregnancy

6 Bricker L, Medley N, Pratt JJ. (2015) Routine ultrasound in late pregnancy (after 24 weeks' gestation). Cochrane Database of Systematic Reviews 2015, Issue 6. Art. No.: CD001451. www.cochrane.org/CD001451/PREG_routine-ultrasound-in-late-pregnancy-after-24-weeks-gestation-to-assess-the-effects-on-the-infant-and-maternal-outcomes

7 Groups that are considered "vulnerable", such as the elderly, children, pregnant women and those with existing health conditions, are routinely excluded from clinical trials by the manufacturers of drugs, antibiotics and vaccines on precautionary grounds, and on the grounds that inclusion would be "unethical". This begs the question of why it is then both "safe" and "ethical" for these pharmaceutical products to then be approved for general use in these untested populations.

a more significant role than they ought to in a scientifically grounded healthcare system.[8] History is not very reassuring in this respect. To give just one of many possible examples, before ultrasound technology was developed, pregnant women were routinely examined using X-ray imaging, again on the principle that there were 'no known harmful effects on the foetus'. Studies in the 1930s were already showing that this exposure was damaging, yet the practice did not rapidly decline until as late as 1975.[9]

Today, the 'precautionary principle'[10] continues to be applied extremely inconsistently. Pregnant women are urged in the strongest of terms not to drink a drop of alcohol, visit a sauna or have a massage in the first trimester while simultaneously being not only offered but encouraged – and frequently ***expected*** – to undergo multiple medical interventions for which there may be no clear evidence of either safety or overall benefit.[11] If public trust and confidence in medical advice is rooted in beliefs which turn out to be unfounded, then the practice of gaining consent cannot be said to be an integral part of the healthcare system in any meaningful sense. This is particularly true in antenatal care where consent is for the most part implied rather than formally expressed.

The central and fundamental principle of consent is the disclosure of relevant information. This information must be clear, accurate, up-to-date and present any existing alternative options including the option of no action. Crucially, according to the latest guidance from the General Medical Council GMC)[12], when communicating potential benefits and risks of harm, the medical professional "should try to find out what matters to patients" as individuals with their own particular histories and priorities. In other words, he or she cannot "rely on assumptions" about what information might be wanted, what factors might be considered significant and the importance that might be attached to different outcomes. The patient has a right to be listened to, a right to make choices and a right to determine independently what risks are and are not worth taking. In ultrasound examination and screening, formal consent is not currently considered necessary, despite these guidelines. The RCOG does, however, acknowledge that the "uncertainties involved…may be great", giving as examples, the risk of false positives or negatives in screening for abnormalities. "It is therefore essential that the woman is made aware of the purpose, uncertainties and implications of screening…".[13]

Personally, over the course of three pregnancies (one ending in miscarriage) and in the care of two different NHS Trusts, I received no fewer than 10 imaging scans in addition to many Doppler examinations. The possibility of harm of any kind was never once communicated to me either in writing or verbally, nor were any uncertainties surrounding the evidence and benefits ever discussed. Moreover, in my third pregnancy when I declined a routine scan, initially my choice was ignored (the scan was scheduled regardless; this also happened with an induction) and thereafter considerable efforts were made, by several different medical professionals, to convince me to change my mind. This experience was repeated every time I chose to forego a routine intervention (such as induction at 41 weeks, continuous EFM or a caesarean after a previous caesarean) in favour of doing nothing. On each occasion a message of disapproval was clearly conveyed to me, the implication being that I was choosing the "wrong" or perhaps a "riskier" option, including in circumstances where there was no evidence to support this view.

8 There is a significant body of literature raising questions about the quality and reliability of medical research, including the manipulation of data and research designs, the misrepresentation of statistics, conflicts of interest and flaws in the system of peer review. In an article provocatively titled 'Why most published research findings are false' (PloS Medicine, August 2005, 2 (8)) John Ioannidis states that "for many current scientific fields, claimed research findings may often be simply accurate measures of the prevailing bias". See also articles by the former editor of the British Medical Journal Dr Richard Smith, 'Classical peer review: an empty gun' (Breast Cancer Research, 2010, (12)), and Drs John Abramson and Barbara Starfield, 'The Effect of Conflict of Interest on Biomedical Research and Clinical Practice Guidelines: Can We Trust the Evidence in Evidence-Based Medicine? (Journal of the American Board of Family Practitioners, 7 September, 2005).

9 Benson and Doubilet (2014) 'The History of Imaging in Obstetrics', Radiology, (273) 2

10 The precautionary principle means that, "...if there is the possibility that a given policy or action might cause harm to the public or the environment and if there is still no scientific consensus on the issue, the policy or action in question should not be pursued." https://eur-lex.europa.eu/summary/glossary/precautionary_principle.html

11 The Covid-19 vaccinations are a case in point. Although pregnant women have not been included in the trials and general safety and efficacy trials are ongoing, the JCVI has advised that pregnant women should be offered the jab:

www.gov.uk/government/publications/safety-of-covid-19-vaccines-when-given-in-pregnancy/the-safety-of-covid-19-vaccines-when-given-in-pregnancy

12 General Medical Council, Decision Making and Consent (2020): www.gmc-uk.org/-/media/documents/updated-decision-making-and-consent-guidance_pdf-84160128.pdf

13 RCOG (2015) Obtaining Valid Consent. www.rcog.org.uk/globalassets/documents/guidelines/clinical-governance-advice/cga6.pdf

My own experiences, and I have no reason to believe they are atypical, raise another vital point about informed decision-making and consent. Again, it is clearly stated in the GMC guidance that both information itself and the manner in which it is presented to patients must be *objective*. Medical professionals must be conscious, in other words, that their own preferences (or more likely, the preferences of their professional organisations) do not unduly influence the language they use or information they provide. Ultimately, they "must not put pressure on a patient to accept [their] advice".[14] The times I received information which failed this test are so numerous I can offer only a small selection by way of illustration. Lack of objectivity took many forms:

- Information is one-sided, e.g. the risks of *not* having an induction are presented while the risks of induction itself are not; the risks of homebirth are emphasised whereas the risks of hospital birth are not mentioned.
- Statistics are presented negatively, e.g. a small increase in the chances of stillbirth are emphasised whereas the overwhelming likelihood of a normal birth is not; figures are presented in relative rather than absolute terms, distorting a patient's perception of risks vs benefits.
- Information is simply false, e.g. I was informed that one glass of wine during pregnancy could cause foetal alcohol syndrome when in fact the study referred to was on the effects of binge drinking.
- Use of anecdotes or "scare stories" either alongside or instead of factual information, e.g. I was offered a distressing account of uterine rupture when I indicated a preference for homebirth.

In each of the situations above I would argue that the information I was given was not designed to inform me but to influence me. This also applies where information was withheld. I had the distinct impression, particularly when I chose a path that deviated from the norm, that I was being managed. The pressure to conform to expectations was immense.[15] In my attempts to shape my own birthing experience, I was continually coming up against barriers posed by someone else's (or some institution's) interpretation of what constitutes acceptable risk and of what constituted my "best interest". Women are told they have choices when it comes to where, when and how to give birth, yet in reality these choices are limited in a myriad of subtle and often arbitrary ways.[16] Moreover, these limitations are being imposed without women necessarily even being conscious that alternative options exist, let alone that they have a right to choose them.

Also notable in the above examples is the way that fear is used to encourage compliance. I observed a recurring pattern in how midwives and doctors presented information to me about my options, doing this in such a way as to heighten the perception of risk associated with not following the approved course of action while downplaying any risk associated with it. This is consistent with broader trends in healthcare and public policy generally. One only needs to look at the growth of government-linked organisations such as the Behavioural Insights Team (informally known as the "Nudge Unit") to see that the use of applied psychology and "emotional messaging" is increasingly seen as a legitimate tool in efforts by policy-makers and managers to incentivise desired behaviours.[17] The crucial difference between these techniques of persuasion and other forms of incentivisation (such as regulation or taxation) is that for it to be effective, the subjects must be unaware that it is happening. This is the antithesis of informed decision-making and it indicates that the erosion of consent in our health service is systemic. That is to say, the problem lies not with individual practitioners, who are for the most part acting in good conscience and in accordance with their training, but with professional and public health bodies and the governments which oversee them.

One could argue that in primary healthcare, as in public health, a certain amount of "nudging" is acceptable when it is "for our own good". To that I would respond, first of

14 GMC (2020) Guidance on professional standards and ethics for doctors – Decision making and consent. (page 12) Available at: www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---decision-making-and-consent-english_pdf-84191055.pdf. Accessed: 15th June 2021

15 This raises further questions which are beyond the scope of this article. Why is this happening? If women were given complete and impartial information, would this change their decisions, and if so, what would be the implications of this?

16 The fact that how long it is considered "safe" to continue a pregnancy or where a woman is "allowed" to labour may differ from hospital to hospital, region to region, is testament to the fact that it is not science but policy which determines these choices.

17 See Institute for Government and the Cabinet Office, Influencing behaviour through public policy: www.instituteforgovernment.org.uk/sites/default/files/publications/MINDSPACE.pdf. During the Covid-19 pandemic, for instance, a government advisory group stated: "The perceived level of personal threat needs to be increased among those who are complacent, using hard-hitting emotional messaging. To be effective this must also empower people by making clear the actions they can take to reduce the threat." https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/882722/25-options-for-increasing-adherence-to-social-distancing-measures-22032020.pdf

all, that the line between guidance and manipulation is very blurry. Secondly, as we have seen, the scientific and evidentiary foundation for these recommendations may be open to debate. Thirdly, the implication behind these techniques is that people cannot be trusted to make rational decisions when provided with objective information. Finally, if we surrender responsibility for determining what is in our best interest to an external authority, we are on a very slippery slope. Unquestioning faith in and obedience to the "experts" today is in principle no different to unquestioning faith in and obedience to any paternalistic authority figure who in the past claimed to know what was best for women, what they could or could not do with their bodies, and how their reproductive capabilities ought to be managed.

Responsibility cannot be given; it must be taken. Likewise, no one can empower anyone else. They can facilitate, listen to, respect and advocate for, but they cannot empower. Power is something only we as individuals can develop for ourselves and it entails the belief that we have a right to control our own lives and the confidence in our own capacity to do so. Information is also inextricably linked to power. We cannot all become experts in every field; but when it concerns our own health and that of our children if we do not do our own research, if we do not continually question, explore and challenge assumptions, then we risk forfeiting personal autonomy in exchange for what may turn out to be only an illusion of safety and improved overall wellbeing. As individuals, we can ensure that when we give our consent, it is always consent in the truest sense of the word.

Also notable in the above examples is the way that fear is used to encourage compliance. I observed a recurring pattern in how midwives and doctors presented information to me about my options, doing this in such a way as to heighten the perception of risk associated with not following the approved course of action while downplaying any risk associated with it.

Author Bio*: Maria is a full-time mum of two.When she can fit it around her family she works as an English language teacher, researcher and charity volunteer.*

An open letter to my midwives

from Heather Spain

Dear Midwives,

My boy is now 22 weeks old, but there's not a day that goes by when I don't wonder what you were thinking when you held me and my then four-day-old newborn captive on the maternity ward, when you initiated the child abduction protocol, resulting in three male security officers physically blocking my path. All I wanted to do – as I explained and begged with you at the time – was to take my broken, bleeding body and shattered soul home to heal; to reunite my baby with his father; and to remove my baby and I from the hospital's increased COVID risk. My son's phototherapy treatment had finished, I wasn't receiving any treatment and there was no need for us to stay in hospital, except to wait for my baby to have a repeat blood test in 12 to 16 hours. I made the wise and fully informed decision to leave the hospital and requested that either the community midwives repeat the test or I'd bring my son back in. You said no. Your Concerns Team have since admitted that it has wrongly become common practice to require babies to wait in hospital for this test, simply for administrative ease. I knew that without a safeguarding court order in place there was no legal way you could compel me to stay. I calmly explained this to you and my reasons for needing to leave. You said no. I went to leave anyway. You punished me for my audacity. You refused to unlock the doors; you pushed in front of me and barred my exit when I tried to slip out; you threatened

me with social services and the police; and finally, you used three big burly men to physically intimidate and block me. I tried to exercise my power to make informed decisions. There I stood: four days postpartum; anaemic and physically wrecked from a post-partum haemorrhage; having not slept for five days; having barely eaten. There I stood: struggling to hold myself upright, struggling to carry my sleeping baby in his carseat, deprived of my partner's support by ludicrous COVID rules. There I stood: just a new mother, trying to do the best for her new, precious, tiny love.

There I stood at my weakest and most vulnerable, trying to exercise my power.

You demolished me.
You committed a crime.
What were you thinking?

The strangest thing was that except for one awful midwife who sneered and belittled me, the rest of you subjected me to this cruelty whilst treating me politely and kindly. You offered me tissues and words of reassurance whilst simultaneously imprisoning me and my baby. What was that about? I think I know. You operate in a broken system, and in this system your behaviour was exactly right. Knowingly or not, you are a layer of enforcement for a system that demands women's unquestioning cooperation and powerlessness. You help to ensure, as the system requires, that women ultimately conform to hospital protocol, whether that is right for her unique circumstances or not. That is how you were able to behave so unthinkingly cruelly with such kindness and conviction. I've since realised that I wasn't shocked or surprised by your behaviour: your antenatal care and treatment of me during the birth had prepared me for this moment. Your attempts to plunder my power and your barely concealed coercion were the sad, ragged threads that ran throughout my pregnancy.

You (midwives) operate in a broken system, and in this system your behaviour was exactly right. Knowingly or not, you are a layer of enforcement for a system that demands women's unquestioning cooperation and powerlessness.

My antenatal care was presented as a given; there was no discussion of choices or decisions. I did not see it that way. I'm someone who compulsively overprepares and overthinks: the minute those two lines appeared on the pregnancy test, I began reading everything I could get my hands on. I knew I had human rights and choices, and that I should be the central and ultimate decision-maker. You disagreed. The first time I made an informed decision – to refuse fundal height measurements – you immediately became flustered and panicked: telling me that I was increasing the chances of my baby dying and literally running for help as if my baby might be in immediate danger. I faced a similar response when I made it clear that I would be declining vaginal exams and, if it came to it, that I would opt for a caesarean before an instrumental birth. You drafted in the consultant midwife and then the consultant obstetrician, who even in the face of my clearly well-researched decision continued to pressure and coerce me into agreeing to have fingers and instruments inserted into my vagina. Why wouldn't you listen to me? You held my homebirth hostage, forcing me into a scan I didn't want to prove to you that my baby was head down, even though I (and you!) could feel his feet in my ribs, the flutter of his fingers deep in my pelvis. I could put my hand on his bottom and wiggle it around. Why wouldn't you believe me?

I didn't necessarily set out on this journey intent on a homebirth, but as my pregnancy progressed, I increasingly lost trust in your ability to do the right thing for me as an autonomous being with her own unique circumstances and not some medicalised birthing object. Yes, I knew you would help keep me and my baby alive, for which I'm immensely grateful, but that is a low bar to set. I should also have had faith that you wouldn't cause me harm, that you would support me to soar – this I couldn't do. I intuitively knew you would cause me harm, that you would be detrimental to my birth. I was right. It is for these reasons that I kept you at arm's length throughout my labour and birth. Luckily, I had a wonderful doula to gate-keep for me. I found out afterwards that after only a few hours of labour you already wanted to transfer me to hospital for augmentation[18]. I was quietly and peacefully labouring and the baby was happy: Why would you disrupt this to send me

18 Editor's note: "Augmentation of labour is the process of stimulating the uterus to increase the frequency, duration and intensity of contractions after the onset of spontaneous labour. It has commonly been used to treat delayed labour when poor uterine contractions are assessed to be the underlying cause." WHO Recommendations for Augmentation of Labour. www.ncbi.nlm.nih.gov/books/NBK258881/

into a vicious spiral of interventions? What were you scared of? When my strength and confidence began to falter, as is normal, all you could offer was a vaginal exam or a transfer to hospital. It was my doula who saved me – offering genuine reassurance and suggesting movement and counterpressure. This was exactly what I needed. When it became clear my baby was near, in you barged, wanting the lights on and your hands between my legs. I fought back, knowing all was well. I told you all was well. My baby and I were a team, working carefully together to give us both the gentlest of transitions. We did exactly that, a sturdy 9lb baby born happy and, having refused to push and allow my body to do its thing, without a tear to me. Giving birth was awe-inspiring; yes astonishingly hard, but being largely uninterrupted, I have never felt more capable, more powerful – like Mother Nature herself, plunging into the depths of physical possibility in order to guide a new soul and new mother into the world. Why don't you trust birthing women? Why didn't you trust us?

Once my baby had entered the world, I relaxed and let my guard down. This was a huge mistake that I doubt I'll ever stop regretting. It was your way from now on. The result? You tugging on my placenta as I attempted a physiological third stage. Me unlatching my baby from his first feed so that you could complete your baby checks. I will never forgive myself for allowing this savage interruption. Light. Cold. Banal chat. Our magic bubble popped. A post-partum haemorrhage that I will forever wonder if you caused with your pre-syntocinon tugging, prodding and palpitating. A transfer to hospital – ripping my heart out as I was separated from my baby; incapable of looking after him and with immoral COVID rules forbidding my partner from accompanying us, even though he posed no more of a COVID risk than I did. Then I ceased to exist. I was nothing but a body, no longer entitled to dignity or respect – left unnecessarily uncovered, legs in stirrups. Your colleagues gained my consent for a procedure under general anaesthetic but then decided to use a spinal block. I did not consent to this. My active withdrawal of consent was ignored. I screamed, cried and shouted, until I had no fight left and lay there, humming to myself – trying to block out the violation; empty and anguished with longing for my baby.

The next day my partner brought my baby to the hospital so we could be reunited. Even then you won't allow my partner entry, even though I was on my own in a side-room. My partner was forced to hand our baby over at reception and I had to listen to you wandering around the corridor trying to work out who the baby belonged to. Yet another unnecessary cruelty.

Do you know what haunts me the most about my experience? The fear of how you must be treating many other women. If you could treat me like this with all my white, middle-class, educated privilege and power, then how are other women faring? It's well researched that if I were a black woman then I would have been four times more likely to die in pregnancy or childbirth. Had I been a young, single woman or from a different socio-economic background then your threats of social services would not only have cut deeper, but would potentially have had serious consequences, especially in Wales, which has the highest proportions of children looked after by the state in the UK[19] . My hospital bay was right next to your midwife station – I heard how you talked about some of the women on the ward with ridicule and disrespect. This will inevitably seep into your treatment of them and their babies. I also had a "low-risk" pregnancy: my decisions were quite straightforward and I was fortunate to be able to afford the support of a doula, but still I had to fight hard. I know from talking with other women and my doula that women branded as "high-risk" or who, God forbid, go over their arbitrary due date face even greater coercion and disempowerment. This behaviour is unacceptable. It is illegal. Every day I feel the weight of all the women on the unkind conveyer belt of birth and ache for the missed opportunities for women to experience empowering, wondrous, heroic births. I don't mean home births for all. I'm not suggesting that any style of birth is better than any other, but I am saying that when a woman is empowered, when she is proactively enabled to access her authentic power, her instinctual wisdom, and to be the central decision-maker then her birth can be glorious. Yes, perhaps bloody and hard and painful but also glorious. Birthing women are warriors: Why do you strip them of their power? I suspect because powerful women in a patriarchal world have always been a monstrous threat. They are not allowed to exist.

So, what do you think?

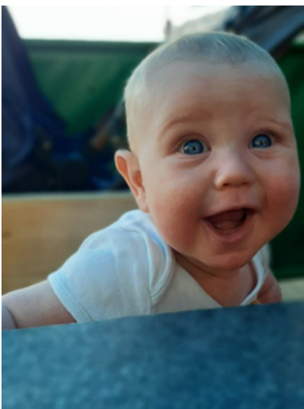
I hope with all my heart that this letter acts as a new lens through which you can see the ways in which your behaviour harms women. How, intentionally or not, you are responsible for trauma, sadness, shame, guilt, powerlessness, violation, and

19 Wales Centre for Public Policy (2021) 'Children Looked After in Wales'. www.wcpp.org.uk/wp-content/uploads/2021/03/WCPP-Evidence-Briefing-Children-looked-after-in-Wales.pdf

regret. That you awaken to the fact your behaviour impacts women's physical, mental and emotional well-being in ways that reach far into the future and affect their relationships with themselves, their partners and their children. I hope this sparks within you an urgent need to look anew at the ways in which you can empower women to have the best births possible: individualised care; providing them with the information and space to make decisions free from coercion; knowing that women can be trusted to make the best decisions for themselves and their babies; treating them with dignity and respect at all times; honouring the woman's unique journey and this momentous moment in her life.

Every day I feel the weight of all the women on the unkind conveyer belt of birth and ache for the missed opportunities for women to experience empowering, wondrous, heroic births.

Your Concerns Team have responded to my formal complaint with apologies and promises of new guidelines and training. I am, of course, grateful for this, but honestly there can be no resolution for me. There is nothing anyone can do that will give me back my first days of motherhood and the lost moments of joy and wonder. My grief is an unwelcome companion that you conjured into being but left me to make peace with and learn to live alongside. All I can do now is to hope that I'm able, in my own small way, to shake the foundations of a birthing system that not only doesn't work for or support women, but often actively works against them. I hope you'll join me on this journey. It doesn't have to be this way.



Yours, in hoping for a better birth for all
Heather & Ted

Author Bio: *Heather Spain is a diplomat, recently returned from working in Afghanistan. She currently lives in South Wales, where she enjoys spending lots of time outdoors and by the sea with her partner and son.*

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#mycaesarean

An innovative service improvement programme to enhance the birth experience for women undergoing elective caesarean

Georgia Smith, Charlotte Harford, and Maggie Arlidge
Gloucestershire NHS Foundation Trust

Introduction

Maternity services have been evolving over the last 20 years, leading to the provision of more patient-focused care. The Department of Health's publication 'Changing Childbirth' was one of the first publications to recognise the need for maternity services to be woman-centred.[1] This was followed by 'First Class Delivery,' which highlighted that women wanted more and better-quality information about services and options for their care.[2]

In 2016, the National Maternity Review report confirmed there were increasing numbers of births in addition to increasing complexity of obstetric cases. There were, however, opportunities to make maternity care more personalised and family friendly. This led to the concept of "Better Births," which is part of the NHS Five Year Forward View and highlights key priorities in improving maternity care. Personalisation of care is one of these priorities, with the underpinning principle that 'every woman should develop a personalised care plan'.[3] Community midwives caring for pregnant women in the UK, routinely discuss a birth plan for women who aim for vaginal births. However, personalising a birth for women undergoing a caesarean is something which is not routinely offered in the UK, contrary to NICE Guidance.[4]

1 Department of Health, London (1993), 'Changing Childbirth. Part 1: Report of the Expert Maternity Group.'

2 Drife J (1997), 'Maternity services: The Audit Commission reports. Listen to women, especially after delivery,' BMJ 314 (7084): 844

3 NHS England (2016), 'National Maternity Review: Better Births: Improving outcomes of maternity services in England. A Five Year Forward View for maternity care': www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf.

4 NICE (National Institute for Health and Care Excellence) (2017), 'Intrapartum care for healthy women and babies. NICE clinical guideline 190.' London: NICE; 2014 (update 2017). Available at: www.nice.org.uk/guidance/cg190.

Usually, when a woman undergoes an elective caesarean, the theatre environment, operative technique and processes once the baby has been born remain the same for each woman, with no personalisation of the experience by the woman. This generic "conveyor-belt" approach can lead to many consequences, including an increased length of time before the first breastfeed in comparison to vaginal birth, with a reduced incidence of exclusive breastfeeding. In addition, birth by caesarean has shown to be an overall less satisfactory experience, culminating in lack of bonding and consequential higher rates of postnatal depression.[5]

We propose an initiative designed to improve the birth experience for all women and their families undergoing a caesarean, without compromising the safety of the surgical procedure itself.

Method

We initially carried out a preliminary survey of women's wishes to provide further credibility to the vision of improving women's birth experience at elective caesarean. We surveyed 20 women who were booked for an elective caesarean at Gloucester Royal Hospital, asking them whether, if such a service existed, they would like to be offered choice regarding certain aspects of their birth. Every woman responded that they wished that this service already existed, which inspired us to continue our endeavour.

We subsequently performed an evaluation of the current system in place for elective caesareans. We used a standard proforma to ask 20 women about their birth experience after electively undergoing a caesarean. Women were asked (1) "When you were booked for your elective caesarean, how much choice for the birth did you feel that you received?" and (2) "Were you made aware of any options available to you for your birth?" They were also invited to write any further comments about their experience. We found that no women were offered choice regarding their birth and no options were discussed with women for their birth. Comments included a desire for a more personalised approach to their care.

We implemented #mycaesarean in December 2020 at Gloucester Royal Hospital.

#mycaesarean is a bespoke service designed to provide women who are already booked for an elective caesarean the option to shape their birth experience. Upon booking their caesarean in antenatal clinic, they are provided with a leaflet regarding the service and a checklist. The checklist is designed to allow women to choose certain aspects to be included in their birth. They are offered low lighting around the theatre, LED candles throughout, their own music playlist via Bluetooth speaker, aromatherapy, lowering of the surgical drapes (either for the whole procedure or just the delivery), time allowed for the baby to be born, delayed clamping of the cord and immediate skin-to-skin. There is also space for the woman to document any other requests they may have with the option of discussing them on the day of their surgery with the operating team.

Regarding the technical aspects of birth, in 2008, Smith et al. proposed the art of natural caesarean, which includes the woman and birth partner being invited to watch the birth, engaging them in the delivery itself and mimicking the scenario of a vaginal birth. The surgical procedure is a "hands-off" approach, allowing time for the baby to spontaneously emerge where possible. As soon as the baby's head has been born, the process of 'fetal autoresuscitation' occurs, whereby the uterine contraction stimulates the baby's lungs.[6] We fully endorse this approach and feel that this process is improved even further when the woman's upper body is assisted upwards slightly, which subsequently increases the intra-abdominal pressure and often helps the spontaneous birth of the baby. We find that in this more upright position, the mother is able to witness the birth more easily and to be ready to receive her newborn baby with open arms. At the time of birth, our midwife is usually scrubbed in order to facilitate the transfer of the baby to the mother's arms or chest, so as not to de-sterilise the surgeon.

Another way in which we preserve the surgical field is by using an additional 70 x 70cm surgical drape which is placed over the standard surgical drapes on the mum's chest. After delayed cord clamping, the birth partner or mother herself are invited to cut the cord, and following this we peel back the original drapes, leaving behind the additional drape so that the sterility of the surgical field is maintained. The midwife present at the birth is then able to assist the baby to have immediate skin-to-skin, which is facilitated further by having the woman's gown untied at the back, with lines and monitoring away from the maternal chest.

Subsequently, the caesarean continues in a standard

5 Stevens J et al. (2014), 'Immediate or early skin-to-skin contact after a caesarean section: A review of the literature,' Maternal & child nutrition, 10(4): 456–73.

6 Smith J et al. (2008), 'The natural caesarean: A woman-centred technique,' BJOG: An International Journal of Obstetrics & Gynaecology 115(8): 1037–42.

surgical fashion, whilst the midwife can support skin-to-skin and help to initiate the first feed. If the couple wish, the baby can be weighed in theatre in full view of the mother and birth partner, with the weighing scales brought next to the operating table.

It was essential to provide thorough training for all staff involved with booking and performing caesareans due to there being many changes to normal procedures. This training was performed prior to the formal launch date and included run-through demonstrations with mannequins and a training video with live examples. In addition, we had some women who directly asked for a 'natural caesarean' and so during these patient-led cases, we were able to demonstrate the #mycaesarean approach to the team prior to the implementation date, leading to a gentle introduction for which we were all well prepared. #mycaesarean requires excellent team-work in order to succeed in making the woman's birth experience as special as possible.

Importantly, all women and their families are counselled prior to the operation to explain that if a surgical complication occurs, it may be necessary to curtail the options put in place to ensure that the safety of both mother and baby is prioritised.

Feedback

After implementing #mycaesarean, we surveyed 20 women about their experiences. Every woman felt that they had been given options for their birth experience and choice to personalise their birth. We were overwhelmed with the free-text comments received from our mothers and their families, thanking us for providing 'an incredible experience which they will never forget.'

A woman who was undergoing her second caesarean explained the importance of immediate skin-to-skin contact with her newborn. Immediate skin-to-skin is in-keeping with the WHO/UNICEF Baby Friendly Health Initiative, with this early mother-newborn contact being critical in promoting successful bonding and the best chance of successful breastfeeding.[7] This comment was particularly poignant as the woman compared her birth to her previous one, where her baby was taken to the resuscitaire, weighed out of sight, and then wrapped up immediately without direct contact even being offered, all as standard practice. She described her birth experience this time as 'an absolute dream', all because she had been directly involved in shaping her care. We were humbled to receive feedback from the theatre staff themselves describing how special each individual birth was and how they now are able to feel part of the woman's experience and make a difference to their care.

Conclusion

We are very proud that our novel #mycaesarean approach has now become the "new normal" at Gloucester Royal Hospital and we want to thank all of the obstetricians, midwives, anaesthetists and theatre staff for their ongoing support in this endeavour. We believe that #mycaesarean is an initiative which can be adopted by all maternity units the UK, as we propose, within the realms of safe practice, that the woman's choice should be integral for all types of births.

Author Bio: Dr Georgia Smith

Georgia is a Senior Registrar in Obstetrics & Gynaecology, working at Gloucestershire NHS Foundation Trust. Georgia is a huge advocate for patient choice and improving the birth experience at caesarean section without compromising patient safety. Georgia leads on the development and teaching of the #mycaesarean pathway and was the main author of the article. Please direct any correspondence to georgiasmith@nhs.net

Author Bio: Charlotte Harford

Charlotte is a Senior Midwife who works as a Delivery Suite Co-ordinator at Gloucester Royal Hospital. She is primarily the patient and birth partner's advocate and will do her utmost for the patient to receive the best possible care from herself and her team. Charlotte has registered the #mycaesarean pathway as a Quality Improvement Project within our trust and has received incredible feedback for the project.

Author Bio: Dr Maggie Arlidge

Maggie is a Consultant Obstetrician with interests in Fetal Medicine and Perinatal Mental Health, working at Gloucestershire NHS Foundation Trust. She is passionate about empowering patients with choice and even incorporates this in her care of high-risk pregnant women. Maggie is the Consultant Supervisor of the #mycaesarean endeavour.

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7 WHO/UNICEF (1989),' Protecting, promoting and supporting breast-feeding: The special role of maternity services': https://apps.who.int/iris/handle/10665/39679.

Article

Seen and unseen: Spirituality as an underestimated dimension of decsion-making around birth

A reflection by Laura S. Jansson

Editor's note: *This issue of the AIMS journal is about decision-making and consent in the perinatal period. Interestingly, while we often imagine that decisions are made by weighing the facts, there is growing evidence that they are strongly influenced by non-cognitive factors; that final decisions come, perhaps even for the most part, from the heart. We also know that the events of this time in a person's life can touch them at their very core in ways that are hard to explain. And so, I was delighted when Laura Jansson accepted my invitation to offer her personal reflection on spirituality as a dimension of decision-making around birth.*

As a doula and author who specialises in facilitating spiritual transformation through pregnancy and birth, I am biased; the clients who seek me out know that they can be open with me about their spiritual needs. However, I am continually amazed by just how close to the surface spiritual considerations are amid the deliberations and dilemmas of the perinatal period, even for people who don't expect it.

Just a few minutes into our first conversation, one expectant parent told me, "I've never belonged to any particular religion. I've never seen myself as a particularly spiritual person. But since getting pregnant, I've started thinking of things differently. It's like another side of me is emerging. I don't even know how to say this – it sounds a bit silly – but I've never felt so…so *holy*." As this woman moved through her pregnancy, validating and voicing this part of her experience, I was privileged to witness her integrate a growing spiritual awareness into her sense of self, manifesting it in decisions which were congruous with her new understanding of the world.

This woman's journey illustrates my belief that there is no such thing as an "unspiritual person". All people, whether pregnant or not, have spiritual needs, including, for example: to seek meaning; to discover wholeness in oneself, oneness with nature and union with others; to experience ultimate belonging and purpose; to redeem pain and loss; to discern one's true identity, and know and be known as such; to find ways to channel awe, admiration, gratitude and joy; or to encounter transcendence. This means that for all of us, decision-making takes place within a spiritual context. Because all people are spiritual, all decisions surrounding pregnancy and birth are made by, and implicate, spiritual persons, and all perinatal decisions have a spiritual dimension.

However, the spirituality of decision-making is expressed variously by different people under different circumstances. Here, I propose four planes on which spirituality intersects with perinatal decision-making, influencing it in multiple

directions on each plane. Spirituality may impact decision-making: 1) implicitly and explicitly, 2) via sources from within and without the decision-maker, 3) by subverting and integrating medical advice, and 4) before and after the decision.

Implicit/Explicit

Even if spirituality is inherent to our identity as persons, for many people, it remains latent, and may never be spelled out or realised as a core component of existence, let alone decisions around pregnancy and birth. Our society views decision-making as a mostly rational process, and childbearing as an action of the body and not the spirit. Therefore, the impact of spirituality upon perinatal decision-making usually remains a dormant force, unrecognised and underexploited by pregnant women and healthcare providers alike.

However, some people have a spiritual life that is (what I will call) "activated", vibrant and explicit, and it becomes a central guiding principle as they move with autonomy through life, pregnancy, birth and parenthood. When we think of someone making spiritually engaged decisions in the perinatal period, perhaps what first springs to mind is a person who adheres to a religion with moralistic prohibitions surrounding specific circumstances, such as abortion, blood transfusions, or IVF. Or we might think of someone facing a medical dilemma who, after considering all the available scientific evidence around an issue, is still left undecided and turns to their intuition, or to their sense of a higher power to cast the deciding vote.

But this is an impoverished view of the impact of spirituality. For a person who centres their spiritual life, spirituality is not just another tool in the decision-making kit, to be employed as needed upon occasion. Rather, for such a person, spirituality is a prism through which life is lived, a lens overlaying and transforming the whole way reality is received, an alternative matrix within which things are interpreted.

A spiritually engaged expectant parent may regard her body as a spiritual field, her baby as a spiritual being, and her pregnancy as a spiritual journey. She may see the events of pregnancy as unfolding not just in the realm of the senses, but simultaneously in an incorporeal,[1] eternal dimension. She may see no separation between the spiritual and the material worlds, so even the statistics and probabilities which she uses to weigh her decisions tell the same story of which her soul sings.

While there may be a crossover between religious engagement and spiritual engagement, it is important to note that the two are not synonymous. A person who centres their spiritual life in this way may not practice a religion, and someone who practices a religion may not centre their spiritual life.

In my experience, pregnancy is a time when many expectant parents spontaneously transition from an implicit to an explicit spirituality for the first time. When birth workers recognise this, it opens up fruitful lines of communication and compassion with their clients. It helps them to understand the deeper grounds on which those clients are making decisions, decisions they themselves might not have made. It enables them to support a vital process that naturally unfolds alongside physical changes for many people in pregnancy.

Within/Without

Secondly, spirituality can give people access to additional resources which help them make decisions – resources which may be perceived as external or internal to the person, or both.

When facing decisions, a spiritually engaged person may seek input from a wider variety of "authorities" than standard maternity provision accounts for. The authorities usually thought to command consideration might include doctors, midwives, antenatal teachers, medical studies, and books. However, this overlooks a whole category of authorities whose advice and guidance might carry equal or greater weight for a spiritually engaged person. This could include authorities perceived as external to the decision-making person, like God/gods, angels, spiritual mentors, sacred Scripture, religious leaders, saints, visions and dreams, ancestors, community traditions, and the natural world. At the same time, spirituality also gives access to a whole realm of inner resources on which expectant parents may draw as they make and carry out their decisions. When facing difficult choices, they may seek to connect with an internal wisdom that they believe to be located in the soul. This internal source may provide a well of strength, confidence and the conviction that ultimately things will come right.

1 not composed of matter; having no material existence

It is easy to understand inner resources as contributing to the autonomy of decision-making in the perinatal period, but perhaps harder to see how external sources can do so, given that they transfer the locus of control outside the persons directly affected by the decision. However, when they offer their perspectives without coercion, external authorities can contribute just as much to autonomy as internal sources. They should not be regarded as an imposition; people's freedom extends to choosing authorities to which to look.

When making perinatal decisions, just as some people need time to go away and research their options, others will need time to consult with sources of spiritual authority, both interior and exterior. It may take longer to connect with these sources, which cannot be summoned upon command like an internet search. Note that care providers do not need to share their clients' belief in the sources' validity in order for them to aid the decision-making process. Simply by respecting the fact that spiritual authorities may be equally or more influential for some people than medical authorities, and allowing time and space for engagement with them, birth workers can support the integrity of their clients' decision-making.

Integrative/Subversive

Thirdly, spirituality seems to have a paradoxical effect on perinatal decision-making as it relates to standard protocols for caregiving. An activated spirituality tends to promote both conformity with, and subversion of, "doctor's orders."

On one hand, surrendering our own will may be understood as one goal of the spiritual life. Loosening our tight controlling grip on the circumstances of our lives can be seen as opening the way to a higher path. And if an expectant parent interprets every event as spiritually meaningful, then anything a healthcare provider advises may appear divinely ordained. It is as if the medical practitioner is temporarily vested with trust befitting a representative of the sacred – or, to personify it one way, the obstetrician becomes the priest. This tends to lead the person making the decision to defer to medical practitioners' suggestions for their care, which in turn tends to promote the birth outcome that is normative for that practitioner and their workplace. Spirituality acts as a vehicle for seamlessly integrating the expectant parent into the system of care.

On the other hand, spirituality can prove highly subversive to medical systems. People who believe in a supernatural force under which all things fall may not regard medical expertise as the highest form of wisdom. Instead, spirituality may give them the deep courage of their convictions to make their own decisions, even when those decisions contravene conventional wisdom. Because spirituality is so individual and so deeply held, a spiritually engaged person may find herself at odds with a one-size-fits-all medical system, and she may make decisions which take her far outside of standard care pathways.

It is fascinating to see how a conviction that greater powers are at work in pregnancy and birth can both dampen and amplify a person's determination to carry out their own will. However, we should resist any temptation to regard the dampening effects as negating autonomous decision-making. Choosing to surrender one's will may look like a passive stance, but it can in fact be part of an active process when it is done in congruence with one's beliefs. After all, the decision to delegate a decision is still a decision.

Before/After

Finally: so far, we have considered how spirituality might intersect with decision-making in the time leading up to a decision. We have seen how spiritual considerations can be an unrecognised but decisive component as expectant parents are weighing their options before any action. But the spirituality of a decision-maker can also impact how she relates to a decision she has already made.

When recalling "what happened", spiritual engagement may have an emotionally insulating effect, with the decision-maker invoking concepts of grace, gratitude or blessing. Where a decision was made and carried out, events may be interpreted as divinely sanctioned. Where circumstances limited the scope of human choice, this may be considered divine intervention. Where things did not proceed according to plan, a conviction that even difficult experiences have a purpose may result in greater resilience, acceptance or resignation. Conversely, if the events resulting from the decision were traumatic, there may be dissonance between the way the decision-maker wants to remember the event and the way she actually does remember it, leading to feelings of guilt, shame or demoralisation.

The effect that spirituality seems to have on the retrospective meaning of decisions underlines the importance not only of the freedom to make decisions

that one can be at peace with in the long term, but also of protecting the ability to find one's own interpretive framework for events after the fact. When speaking with a client about what has happened, care providers can allow them to find their own language for events rather than imposing their own understanding, which may omit or negate the spiritual dimension.

Conclusion

As we have seen, spirituality and perinatal decision-making share many points of intersection, but the picture is complex and multi-dimensional. Since all humans are spiritual by nature, it is vital that we remain free to make decisions which sit well with us as whole people and that not only make rational sense to us, but also align with our deep sense of identity and our place in the world. It is much easier to make such spiritually congruent decisions when one feels at peace, so caregivers would do well to renew their commitment to supporting their clients' spiritual wellbeing throughout pregnancy. By recognising and facilitating the spiritual dimension of decision-making, they can help their clients to make choices which support their experience of the perinatal period as a time of spiritual growth and transformation.

Author Bio: *Laura S. Jansson is an Oxford-based doula, birth educator and mother living and writing at the intersection of birth and faith. She earned her Masters degree in Theology and Philosophy from Oxford University, and has also lived in the USA, Serbia, Germany, and Fiji. Her book,* Fertile Ground: A Pilgrimage Through Pregnancy *(Ancient Faith Publications, 2019), is a guide to the spiritual terrain of pregnancy, with a reflection for each week of the hero's journey.*

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I’ve Just Had a Baby

After Annie Ridout

By Danielle Gilmour

I’ve just had a baby.
Will you not remove your shoes?
Wash your feet?
This is holy ground.
Watch you doff your cap as you approach my throne,
Bow your head,
Lay palms where I tread.
Please speak in more reverent tones.

I am Lucy – honour the mother of mankind.
Here, I’ll show you what to do –
Kiss your fingers and touch your navel,
Light a thousand candles, cast me a circle,
Bring me offerings, keep my vigil.

Do you think I willed this baby into being?
The least you could do is pour a libation
For the blood I’ve spilt and that flows from me still.
Trace my sacred scars and name them a constellation.
I am Elastigirl – my heart and parts have stretched

Beyond recognition,
Even to myself.

I am Eos – where is my golden chariot as I bring you this pink new dawn?
And just moments before, I was Athena, roaring as I rode to war.
Where is my chapel among those raised
For each temple built in a body – cradled in pelvis or hidden by ribcage,
To hold our babies however long they stayed?

I am the Earth,
I am the Sun,
I am Wonder Woman.
I am my mother and yours who allowed us to breathe.
I’ve just had a baby.
Walk backwards as you leave.

Author Bio: *Danielle, from South Gloucestershire, is a mother of three children, one dog and four chickens. She is a Peer Supporter for The Breastfeeding Network, a Volunteer for AIMS, and a poet and member of the Mum Poem Press. You can find more of her work on Instagram @mummy_juice_writes.*

Article

Shared Decision-Making?

by Jo Dagustun, on behalf of the AIMS Campaign team

Decisions about our care are for us – the service user – to make. Yes, but ...

Regular readers of this Journal need no reminder that we – maternity service users – have the right to make decisions about our own maternity care. These decisions are not to be 'shared' with healthcare professionals although we do expect their support as we come to make them, not least by helping us navigate the information we might require. In this article, we reflect on some AIMS work this year to improve maternity service performance in this key area. We also explore the constraints that service users continue to face in getting the care they decide is appropriate for them, and how we can, together, overcome these.

Why has this issue been on our agenda this year? Well, one reason is that we had the opportunity of influencing the new NICE guidance on this topic, during the stakeholder consultation that took place from December 2020 to February 2021. Back in 2017, NHS England had formally asked NICE (National Institute for Health and Care Excellence) to produce practical guidance for health and social care professionals on shared decision-making. Following consultation, this guidance was due to be finalised, four years after it had been requested, in June 2021. You can fnd our detailed response here[1] and the final guidance here[2].

As a starting point, the preference of the AIMS campaigns team was very much that the terminology of 'shared decision making' should be relegated to 'the back office' of the NHS. We understand that the term is meant to reflect the process by which clinicians and patients work together to ensure effective care, rather than being a comment on who takes the final decision, but we are concerned that its use in a patient-facing context is misleading. You can read more in our blog here[3].

Whilst this conversation was proceeding, we had been very pleased to see the new maternity-specific guidance issued in England[4], which made absolutely clear that the role of the maternity services is to support informed decision making on the part of maternity service users. We are grateful to the two service user advocates who worked tirelessly on the relevant Maternity Transformation Programme group to achieve this outcome, Michelle Quashie and Natasha Smith. Thanks to the work of Michelle and Natasha, it is likely that more and more maternity professionals will get the message, over time, that the decisions of service users are legitimate and must be respected. However, there seems to be no rigorous system in place for measuring the extent to which this translates to increased autonomy for service users. AIMS Volunteers will be looking to see that the guidance is reflected in the calls to our helpline, where we hear repeatedly from service users whose decisions haven't been respected - but will the new guidance be sufficient?

What we've learnt over the decades is that the broader culture of the NHS is always an important influencer of what happens in the maternity services. Because of this, AIMS has sought to work alongside others in the health services improvement community this year to highlight the dangers of a simplistic understanding of the idea of 'shared decision making'. We'd like it to be made crystal clear across the NHS, that service users have the legal right to make their own decisions about their care, and that they do not have to share these with anyone. We believe that this will be helpful in

1 AIMS (2021) AIMS response to the NICE 'shared decision making' consultation process – www.aims.org.uk/assets/media/605/submissionnicesharedcareguideline2021feb.pdf

2 NICE (2021) Shared Decision Making - www.nice.org.uk/guidance/ng197

3 National Voices (2021) Improving healthcare: is it time to ditch the terminology of 'shared decision making'? www.gov.uk/government/organisations/nhs-commissioning-board

4 NHS (2021) Personalised care and support planning guidance: Guidance for local maternity systems. www.england.nhs.uk/publication/personalised-care-and-support-planning-guidance-guidance-for-local-maternity-systems/

driving system-wide change.

That is why AIMS, along with others, tried hard to get NICE to recognise the difficulties with the term 'shared decision making', especially in a service user facing context. We made some inroads, but NICE made it very clear that the title of the guidance wasn't up for debate. This is particularly frustrating given that NICE guidance is intended to be service user facing, and that much time has passed since the original NHS England request for the guidance. We're not sure that NHS England would make exactly the same request today (especially given the progress made in maternity on this issue), but we live to fight another day, secure in the knowledge that national maternity services leaders at least understand that we - maternity service users - do not need to share our decisions with anyone. In discussions that went right to the wire, AIMS made sure that this maternity perspective was also adequately referenced in the final NICE guidance.

So that's an overview of recent AIMS campaigning work in this area; but where does this leave individual maternity service users and their ability to make decisions that are right for them and to have these respected? Despite this clear national maternity-care policy (indeed, law) that decisions are ours, and ours alone, to make, maternity service users will not always find that easy. Why is this?

It may sometimes feel that our right to decide is limited to what offers of care we can decline, and that those offers may be - for some of us - frustratingly narrow. AIMS has, of course, been working for 60 years to broaden the range of maternity care options available to all service users, and that work continues (including via NICE - see below), but realistically, our choices will always be constrained by the options available to us locally. AIMS is clear that postcode lotteries have no place in maternity services, for this simply does not meet the important principle - Leave No One Behind[5].

One key local constraint might be resources: perhaps your local service isn't properly resourced to be able to meet the legitimate requests of all local service users. This then can act as a constraint on any particular choice of an individual service user. It is really important that such experiences get fed back to local services, ideally via the Maternity Voices Partnership (MVP)[6]: these Partnerships are well placed to identify local barriers to high-quality care and to seek to resolve these for the benefit of their local service users. In some cases, this might require reminding local services of the national expectations for high-quality services - including, importantly, those set out in NICE guidelines - as it can be the case that local policy has simply developed out-of-step with that and needs to be brought back into line. If the MVP can't help, the next tier up - your Local Maternity System (LMS)[7] - may be a useful place to raise concerns.

Another key constraint might be NICE guidelines. These represent the national level framework, to guide us all - service providers as well as service users - on what healthcare options should be available on the NHS. From this, it follows that not all options will necessarily be offered to all maternity service users. NICE is committed to base their guidance on a careful review of the available research evidence about 'what works'. In preparing this guidance, NICE involves lay representatives and also puts its work out to extensive stakeholder consultation. It is important to remember, however, that NICE guidance is only as good as the evidence on which it is based. So there is also a role for us all - service user advocates included - to flag up where such evidence might be missing, which can then lead to a future research recommendation.

From this, we can see that there is much work to be done, some at the local level and some at the national level, in order to understand, agree and improve the range of care options that should be available to maternity service users. For without those options in place, our decision-making ability will always be constrained. With your support, the AIMS Campaigns team looks forward to continuing to work on this issue in the years ahead.

5 UN Sustainable Development Group - Leave No One Behind - https://unsdg.un.org/2030-agenda/universal-values/leave-no-one-behind

6 National Maternity Voices - Find and MVP - http://nationalmaternityvoices.org.uk/find-an-mvp/

7 NHS England, Local Maternity System. www.england.nhs.uk/north-west/gmec-clinical-networks/our-networks/maternity/local-maternity-system/

Article

Putting Better Births' Personalised Care into Practice: Comments on Progress and Recent Guidance of the Better Births Recommendation

by Georgia Clancy

It's been five years since Better Births (2016) was published and over the last few years 'early adopter' sites across England have been trialling different aspects of the policy ahead of national rollout. In March 2021, NHS England published guidance on the implementation of Better Births' first recommendation, personalised care, in the form of their Personalised Care and Support Planning Guidance document[1]. Drawing on my PhD research exploring women's childbirth preferences, decisions and outcomes in England today[2], in this article I will comment on the recent guidance on personalised care and consider whether it was worth the wait.

In recent years, the goal of delivering personalised care has not been exclusive to the maternity services, but is representative of wider shifts across the NHS put forward in the Five Year Forward View (2014)[3] and Long Term Plan (2019)[4]. The latter of these two documents sets out the NHS's ambition to roll out a 'Comprehensive Model of Personalised Care' across England by 2023/24, including personal health budgets. However, Better Births' concept of Personal Maternity Care Budgets was absent from the recent Better Births Four Years On review (2020)[5], and appears to have been quietly dropped from the Maternity Transformation Programme.

The widespread change towards more personalised care in NHS policy and practice should help to normalise this approach in maternity care for all women, and not just those considered 'high-risk' or with complex needs. Indeed, it is fundamental that management as well as obstetricians and midwives get on board with personalised approaches to care since workplace cultures and differing ideologies of birth and best practice can pose a significant barrier to effecting change.

> In Better Births[6,] personalised care was defined as being centred on the woman, her baby and her family, based around their needs and their decisions, where they have genuine choice, informed by unbiased information.

1 Personalised Care and Support Planning in Maternity Services - NHS video: https://www.youtube.com/watch?v=jlbJyMIqitA

2 Clancy, G. (2021) *Better Births? An Exploration of Women's Childbirth Preferences, Decisions, and Outcomes in England.* Unpublished PhD thesis. Coventry: University of Warwick

3 NHS. (2014) Five Year Forward View, available online at www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

4 NHS. (2019) The Long Term Plan, available online at www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

5 NHS England and NHS Improvement. (2020) *Better Births Four Years On: A review of progress*, available online at www.england.nhs.uk/wp-content/uploads/2020/03/better-births-four-years-on-progress-report.pdf

6 NHS England. (2016) *National Maternity Review: Better Births Improving outcomes of maternity services in England A Five Year Forward View for maternity care (page 8)*, available online at www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf?PDFPATHWAY=PDF

Central to this is the development of personalised care plans for women, which the Personalised Care and Support Planning Guidance document[7] seeks to provide in the form of personalised care and support plans (PCSPs) whereby

> people [have] proactive, personalised conversations which focus on what matters to them...and [pay] attention to their clinical needs as well as their wider health and wellbeing

However, it is unclear how PCSPs fit alongside the types of birth plans which women might make of their own initiative, or whether PCSPs are a formalisation of the birth plan process. Indeed, it is important that any plan for birth is considered a living plan that can evolve during pregnancy and includes preferences for different situations that might arise during labour and birth. Furthermore, women must be adequately informed about their choices and birth options so that they can take on a proactive role in their care and make informed decisions.

PCSPs must meet five criteria as set out in the NHS's Universal Personalised Care Model:

1. People are central in developing and agreeing their PCSP, including deciding who is involved in the process.
2. People have proactive personalised conversations that focus on what matters to them, paying attention to their needs and wider health and wellbeing.
3. People agree the health and wellbeing outcomes they want to achieve in partnerships with the relevant professionals.
4. Each person has a sharable PCSP that records what matters to them, their outcomes and how they will be achieved.
5. People are able to formally and informally review their PCSP.

Applied to maternity care, PCSPs are reminiscent of the approach set out in Better Births, with greater discussion around women's choices during pregnancy and birth and plans continually reviewed and risks assessed at each contact. In addition, and in light of the Montgomery ruling[8] [9], providers are encouraged to respect and seek a better understanding of women's reasoning, values, expectations, previous experiences/trauma and fears. Personalised care is highlighted as being particularly beneficial to people from lower socio-economic groups and presented as a positive step towards reducing health inequalities by tracking the implementation of PCSPs according to age, ethnicity and "complex social factors"[10]. Of course, this is highly topical in light of public pressure for the NHS to tackle inequalities in maternal mortality and AIMS has long called for the improvement of services and experiences for historically under-served communities at risk of poorer-outcomes[11].

Continuity of carer is identified as key to facilitating personalised care through the development of effective and trusting woman-midwife/doctor relationships. Women will also be given responsibility over their personalised care and support plans, with unbiased information to inform these decisions. However, it is important to bear in mind that not all women may want to assume or feel capable of assuming this additional responsibility for their care and appropriate support will need to be provided. Furthermore, the provision of unbiased information often sounds more straightforward than it is in reality and masks the socio-economic, cultural and political factors which influence the information produced, how providers deliver it and in turn how women receive and process information, choosing to act with or against the recommendations of their providers. Indeed, the issue of providing personalised care to women who engage in informed dissent against the recommendations of their clinician is not tackled in Personalised Care and Support Planning Guidance, but rather is delegated to Trusts to develop their own strategies. This is a serious shortcoming in a document which has taken five years to produce.

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7 NHS. (2021) Personalised care and support planning guidance - Guidance for local maternity systems, (page 2) available online at www.england.nhs.uk/wp-content/uploads/2021/03/B0423-personalised-care-and-support-planning-guidance-for-lms.pdf

8 Montgomery v Lanarkshire Health Board (2015, March 11): www.bailii.org/uk/cases/UKSC/2015/11.html

9 See Emma Ashworth's article on the Montgomery ruling

10 NHS, 2021: 9; NICE 2010 www.nice.org.uk/guidance/cg110/chapter/1-Guidance#ftn.footnote_6

11 AIMS ED&I statement www.aims.org.uk/general/aims-equality-diversity-and-inclusivity-statement

Elements of Better Births have been trialed across England by the early adopter sites since 2017, but the findings of these trials, with regard to the implementation of personalised care, are absent from the Personalised Care and Support Planning Guidance document, for example, the 2018 'Personal care plans for Mums and Families'[12] information booklet developed by NHS North West London as part of the maternity early adopters project.

The main means by which the Maternity Transformation Programme intends to achieve personalised care now appears to be with the implementation of personalised care and support plans (PCSPs) as part of the NHS's Universal Personalised Care Model. However, the recommendations are vague and without clear targets or measures of success. Indeed, the recommended 'Audit tool' in the guidance document focuses on assessing the use of PCSPs rather than the actual implementation of personalised care as set out in Better Births. It is also unclear how these plans will link in with the 2020 Interim Ockenden Report's[13] Immediate and Essential Actions, in particular with regard to listening to women and families, managing complex pregnancy, risk assessment throughout pregnancy and informed decision-making.

What is clear from reading this new document is the interrelatedness of Better Births' recommendations. The plan for implementing personalised care is interwoven with the need for progress in improving choices, Continuity of Carer, unbiased information and safer care. As such, it will be interesting to see what guidance is issued next to continue moving forward with Better Births' implementation.

Actions for birth activists:

- Ask your LMS (Local Maternity System) how they are implementing personalised care in your area, and if it is in line with the recommendations in Better Births.
- Encourage women to learn about their birth choices and rights to support informed decision-making (AIMS has lots of helpful information here[14]).
- Share resources and talk to your maternity care colleagues about what it means to provide personalised care.
- Get involved with your local Maternity Voices Partnership[15].
- Let's talk! Join in the conversation around NHS maternity care online with AIMS on Twitter[16] and other groups such as National Maternity Voices[17] and the Midwifery Unit Network[18] on Facebook.

Author Bio: *Georgia Clancy is a research fellow at the University of Warwick. Her ESRC-funded PhD research explored women's childbirth preferences, decisions and outcomes in light of the Better Births policy in England today. Georgia is also a member of the AIMS Campaigns team.*

12 NHS North West London. (2018) *Personal care plans for Mums and Families*, available online at www.chelwest.nhs.uk/services/maternity/ccg-booklets/personal-care-plans-en.pdf

13 Ockenden, D. (2020) *Ockenden Report*, available online at www.donnaockenden.com/downloads/news/2020/12/ockenden-report.pdf

14 AIMS Birth Information page: www.aims.org.uk/information/page/1

15 Maternity Voices Partnership: http://nationalmaternityvoices.org.uk/

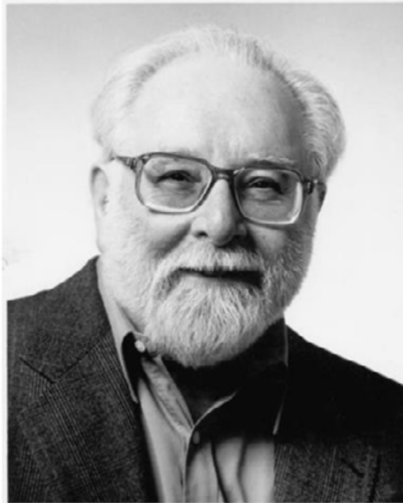
16 AIMS Twitter: https://twitter.com/AIMS_online

17 National Maternity Voices: www.facebook.com/groups/MaternityServiceUserReps

18 Midwifery Unit Network: www.facebook.com/groups/MUNet/

Obituary for Murray Enkin

By Tania Staras



Dr. Murray Enkin, 1924-2021
Photo credit: McMaster University

In 1992 I was a 23-year-old history master's degree student pregnant with my first child. In the days before the Internet I hunted around for books that would tell me about what was happening to my body and how I might experience pregnancy and birth. I bought a copy of Gordon Bourne's book *Pregnancy*. He was an obstetrician; the book was authoritative and authoritarian. As someone trained to critique everything I read, even from my position as an ignorant primigravida[1], I just wanted to argue with him. I tried other books from the library; I found Balaskas' work empowering and slightly overwhelming. And then I found *A Guide to Effective Care in Pregnancy and Childbirth* (Enkin et al 1989). I still have the copy I bought then. It was laid out in a clear and logical fashion, it wasn't emotive or bossy, it didn't make presumptions or think it knew my mind or body better than I did. It used clear and unambiguous language to discuss obstetrics and midwifery care and to set out the evidence underlying whole rafts of interventions and actions. It then sorted these into those which were harmful, those which were neutral (no evidence either way) and those which might do good or be efficacious. I found the book powerful and sensible. It also ignited my interest in maternity care; not simply as a pregnant woman who was part of the system, but as a researcher (at that time working on the history of fairgrounds) who had always vaguely assumed that medicine not only did what was 'right' but also knew what was 'right'. The book was a shock because it made clear the extent of practice based on custom, opinion and belief. It made the case for research and evidence to form the bedrock of care rather than rumour and assumption.

The co-author of *A Guide to Effective Care in Pregnancy and Childbirth,* Murray Enkin, a Canadian doctor who died in June aged 97, was a true polymath whose influence on maternity care and debate has been far-reaching and hugely significant. Most women and healthcare practitioners in the UK today may not recognise his name or may vaguely feel that they have seen it somewhere, but his thinking and writing around care and around evidence-based practice has helped reframe maternity. In the 1980s and 1990s his work with Iain Chalmers and Marc Keirse in producing *Effective Care in Pregnancy and Childbirth* (Chalmers et al 1989) and the paperback summary, *A Guide to Effective Care in Pregnancy and Childbirth* gave practitioners and women a language for understanding what worked and didn't work in maternity practice; and where the evidence was sound, equivocal or downright non-existent. As an extension of this work, he helped to develop the Cochrane Reviews as a way of standardising research synthesis reporting and linking it directly to current debates and policy. His work indirectly helped groups like AIMS to develop a confident and clear approach to issues in maternity care by highlighting the use of sound research and evidence. It also helped to develop a critique around areas of practice that were ill-informed by evidence.

Enkin was born in Toronto in 1924 and did his medical training there, graduating in 1947. He then undertook specialist training in obstetrics and gynaecology in New York before returning to Canada where his professional life was centred. He worked primarily in Hamilton and was one of the founding faculty members of the McMaster University Medical School. As a practitioner in women's health, Enkin very much believed in the minimisation of intervention, which should be used sparingly. He was a passionate believer in what, in modern parlance, would be described as human rights in childbirth and

1 Editor's note: A primigravida is a person who is pregnant for the first time.

which he saw as a humanitarian imperative. As has been noted above, he sought to achieve this through the lens of evidence. Working with both McMaster and the National Perinatal Epidemiology Unit at Oxford university, he created frameworks for evidence-based practice and developed the science and art of the randomised control trial, particularly for issues around the emerging speciality of perinatal care. I say 'art' deliberately because Enkin was most definitely not a stereotypical scientist. His understanding of broader ethical and philosophical issues was evident in the way that *A Guide to Effective Care in Pregnancy and Childbirth* was presented; even at the time, I was struck by the language used. Concepts such as 'harm' have deep ethical roots in medicine, going back to Hippocrates and the concept of 'first do no harm'. In harnessing this language Enkin both signalled the historical depth of his thinking but also issued a challenge to practitioners happy to use technology or intervention simply because they could without wider thought for the ramifications. The sophistication of his thinking was undoubtedly aided by his engagement with the reality of practice but also through the intellectual companionship of his wife. Eleanor Enkin (who died in 2019) was a birth photographer who joined Enkin in his sabbatical to Oxford and in his work with Chalmers in the late 1970s. Together they established the Murray and Eleanor Enkin Lectureship, on humanitarianism in health care at McMaster University. They were also involved in and very supportive of the re-development of midwifery as a profession in Ontario in the 1990s.

Enkin was always very clear that any intervention had to do good if it was to be acceptable and that the wishes and expectations of women were central to effective care, not an optional extra. The *Effective Care* work was pioneering in that it not only considered clinical procedures but also attempted to account for the influence of social factors such as partners in the birth room or one to one midwifery care. For example, evidence suggested that continuous support for women in labour was 'beneficial', respecting their choice of place of birth was 'likely to be beneficial', there was 'no evidence' for routine blood pressure monitoring in labour, directed pushing was 'unlikely to be beneficial' and routine shaving and enemas in labour were 'ineffective or harmful' (Enkin et al 2001). Enkin and the *Guides* had the confidence not just to say what did or didn't work, but also to be honest about where the evidence was lacking or unclear.

Evidence based practice has been a powerful positive force in maternity. It does, however, have issues and cannot solve every dilemma faced. As a midwife I am constantly aware of the paucity of 'good' evidence for much midwifery – as opposed to obstetric – practice. This is partly because RCTs (randomised controlled trials) and Cochrane, now seen as the gold standard of evidence, can only measure what can be measured. They leave to one side, unexplored, the huge areas of care which cannot be boiled down to figures and which rely on intuition and that nebulous concept, wisdom, rather than quantifiable data. Although indelibly associated with the concept of evidence and its use in practice, Enkin was aware of its limitations and later in his career began to explore other ways of understanding and developing practice which moved beyond counting and into the philosophy of science.

I still have the copy of *A Guide to Effective Care in Pregnancy and Childbirth* that I bought in 1992. Inevitability, and rightly, many conclusions have been refined or superseded by more recent research. But the clarity of the thought and the wisdom behind it are a lasting testament to Enkin as is the centrality of good evidence to good care.

Photo credit: McMaster University

Enkin M, Keirse M, Neilson J, Crowther C, Duley L, Hodnett E, and J Hofmeyr 2001 ' Care in Pregnancy and Childbirth: A Synopsis' Birth 28:1 41-51

Written by:
Tania Staras, PhD, RM,
Principal lecturer in Midwifery,
University of Brighton

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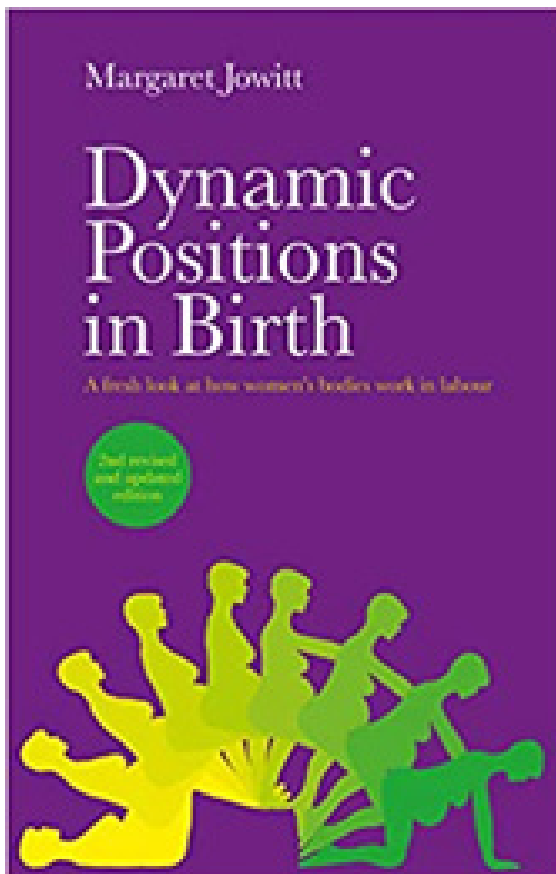


Review by Verina Henchy

Margaret Jowitt first published Dynamic Positions in Birth in 2014, and since then, Margaret has continued in her quest not only to understand why so many women birth in the supine position (when it is a commonly held belief that birthing 'upright and forwards' helps a birthing body to work efficiently and effectively), but also to do something about it. In this new edition, Margaret asserts that the majority of women in the UK still give birth in the semi-reclined position , thus not working directly with the force of gravity. As such, the book speaks to an issue which continues to demand attention.

Margaret suggests that current mainstream obstetric culture (where the word "obstetric" is derived from the Latin stet ob or "stand before") continues to place the bed centre stage of so many births today, pays only lip service to the emotional aspects of birth, and works with guidelines that are based on 'obstetric numerology' (Margaret's phrase to describe modern maternity care). This is not a recipe for success when it comes to offering high-quality maternity services.

The new edition of this book begins with an in-depth chapter on 'birth furniture,' which includes some interesting illustrations of ancient stools, chairs and tables all designed to support the process of birthing in upright positions, positions which subsequent academic research has shown to be beneficial to the mother. The very thorough chapter on research in this area explores the gap between physiological science as we know it and medical practices, concluding that researchers have very little interest in the physiology of birth and that physiology tends to be poorly understood, disregarded, unknown or forgotten. In further chapters, Margaret goes on to explain the function of the uterus and the mechanics and physiology of birth, and explores how obstetric technology may often be the very reason why the physiological process of birth so often goes awry in a hospital setting.

In my opinion, this updated version is not very different from the original, and as an owner of the original, I see no need to rush out to buy this replacement. The additional short chapter that has been added to discuss the potential role of the clitoris is based on supposition and challenges the notion that it has the function of giving female sexual pleasure, suggesting instead that its function is to activate the fetal ejection reflex in birth. If you don't know the full anatomy of the clitoris (and let's face it, the full anatomy of the clitoris wasn't thrust into the public eye until the Australian urologist Helen O'Connoll brought its wondrous structure to our attention in 2005 2), then this chapter is a worthy read. I draw my own conclusions about whether or not 'vaginal orgasm is relatively rare'!

Review by Jo Dagustun

Most people would perhaps assume that the UK maternity services base their work on a deep understanding of the physiology of reproduction. Margaret's book is an important reminder that this is sadly not the case. In this second edition

of her book, Margaret Jowitt – a self-declared lay person, albeit with decades of experience campaigning for improved maternity services – raises many important and interesting questions about the physiology of labour and birth in her mission to improve how the maternity services understand, and thus support, labour and birth. As such, she sets an important research agenda: indeed, it is rather disconcerting to realise that our maternity services seem to assume that they can operate well without answering the research questions laid out here.

Margaret has an authentic authorial voice: as a reader, if you are willing to follow her lead, she will take you on a journey of reflection, with many thought-provoking questions along the way. Margaret is not afraid to pose questions to herself and is upfront about how some of the background reading in this area is really quite complicated. You may find yourself disagreeing with the text at times or even a little frustrated, with questions that might have been attended to in the text (I made quite a list!). However, it is important to remember that this book is not intended to be an academic text: instead, it is a highly thoughtful "outsider" intervention in a research area that seems to have got well and truly stuck. I look forward to seeing how researchers take up Margaret's challenge to better understand birth physiology, to drive improvement in the maternity services.

For me, this book offered a first "tour" of birth furniture through the ages. I was fascinated by the idea that an unborn baby might have reflexes to aid its exit from the womb – I had previously only considered these reflexes in the context of breastfeeding. I am still doubtful about Margaret's assertion about the lack of knowledge about birth physiology as evidenced in medical textbooks – but there again, I hear this complaint too about midwifery education, and this would certainly seem to explain many of the everyday practices that we know are not conducive to supporting the physiological process of labour and birth. I became curious about the drivers of uterine rupture. I was pleased to read an account of early labour that considered the function of early contractions and how these could be more productive with some attention to maternal positioning, rather than an account that simply dismissed them as 'uncoordinated' (with the implication that they are useless!). I liked the way that Margaret was unafraid of offering controversial material: at one point, for example, she likens the requirement to lie in a supine position for foetal monitoring – when concerns have been raised about the unborn baby – as 'tantamount to fetal abuse' (p. 145).

Thank you, Margaret, for continuing to bring your passion and energy to this important topic. But most of all, thank you for valorising the skill, knowledge and agency of the mother-baby dyad. Birth physiology is too important an issue to be left to the "self-styled experts": they have let us down, and it is thanks to "ordinary women" asking "ordinary questions" that we will surely make progress on this important topic. AIMS campaigns for a physiology-informed maternity service, and reading this book certainly seems to confirm the need for this campaign.

Making informed decisions on childbirth

by Sophie Janters

Publilshed by Sophie Janters
ISBN 978-1532812989
224 pages
Current Price £10 on Amazon

Review by Georgia Clancy

Vantiers is, by her own admission, not a specialist on the topic of pregnancy and birth. She does, however, have a PhD in geophysics and scientific research experience, which she says has given her the confidence to carry out an exploration of the medical literature surrounding maternity. In Making Informed

Decisions on Childbirth: One Scientist's International Perspective (2016), Vantiers seeks to pass the knowledge of this personal exploration, as well as her own and others' experiences, on to expectant parents.

The book, which is an interesting and accessible read, is written as if a friend were recounting their childbirth story and uses the author's personal knowledge of pregnancy and birth as a launchpad from which to explore a myriad of topics. With the goal of facilitating informed decision-making, Vantiers discusses topics such as pregnancy and birth preparation, the tension between respectful care and 'best' care, consent, interventions, pain relief, gestation time, medicalisation and what happens after birth. The author references scientific and academic literature, but also offers the reader her own thoughts on many 'what if?' scenarios along the way.

Vantiers herself favours a 'natural approach' to childbirth and takes a cautious approach to medicalised practices:

I am not an advocate of 'natural is always better'. Rather my motto is 'natural is safer in the long-term unless significant benefits outweigh the possible unknown risks'. In other words, if the most recent (bio)medical research shows only a marginally better outcome or no difference at all for a certain intervention, don't use it! (p.7).

Just as it is worth cautioning against the use of interventions in birth, it is also worth cautioning against the privileging of natural childbirth ideology, which can make women who do not, or cannot, fit in to this discourse feel like failures if they have medicalised care. Indeed, Vantiers herself acknowledges that she would have asked for an epidural if her labour had been slow and the pain had been set to continue (p.32), highlighting the subjective nature of decisions in pregnancy, birth and motherhood and how perspectives can change depending on the circumstances.

In lieu of being an 'expert' in birth in the traditional sense, Vantiers strives to provide relevant and current references to support her writing and thus offers the reader a springboard from which to engage in the scientific literature itself. Her discussion and consideration of scientific evidence is based on her time living in the UK, US, France and Belgium. Peppered throughout the book are musings from Vantiers's husband and stories from her "international group of friends and family" (p.5) stemming from eight Western countries.

The stories from Vantiers's friends and family have clearly had a profound effect on her perspective, though unfortunately we do not find out much about this group, such as whether their experiences represent distinct or diverse communities and so in turn how their experiences might relate to the experiences of others. Vantiers focuses on the difficult births of two friends in particular, one in Canada and one in France. Whilst these stories help to bring the writing to life, they are, of course, individual experiences, which may or may not be indicative of practices in particular countries, and are infused with the author's own thoughts. Rather than adding to the 'international perspective' of the book, they serve to highlight some of the complex and often competing ideologies and practices of birth which women must navigate and negotiate whilst on their own maternity journey.

The overwhelming take-home from this book is that women will encounter a myriad of choices and options during pregnancy and birth and that Vantiers feels that it is "always better to be prepared for the worst and hope that it doesn't happen" (p.25). Whilst equipping yourself with information is empowering for some, the expectation that women should be doing this may be overwhelming for others at a time when they are undoubtedly already doing the best they can. Indeed, the onus must not just be on women to learn how best to work the system, but also on the system and those working within it to improve. There may be limitations on how many different situations women can mentally prepare for and the technical information they can consume in order to continuously be making informed decisions about their care, especially if they are already in labour experiencing pain and fatigue. This is why a key element of a well-functioning maternity service is to support informed decision-making, so that women can feel in control of their birth and positive about their experience, regardless of how plans might change.

Verina Henchy and Jo Dagustun are both AIMS Volunteers

Introducing Paternal Mental Health Support

by Scott Mair

Scott Mair is a husband, Veteran, dad to 7 boys and founder of PMH Support[1]: a Facebook page offering guidance and advice and practical tips – educating parents on parental mental health through pregnancy, birth and beyond.

He is a member of the Paternal Mental Health alliance, a mental health campaigner, peer to peer leader trained, a team member of the perinatal training CIC and a qualified Beyond Birth mental wellbeing practitioner. He works locally and nationally speaking to expectant parents.

My experience of becoming a dad was an absolute rollercoaster – very difficult, anxious pregnancy and traumatic birth, mixed with sheer joy, as we had talked about kids when we were only 16. We got married at 18 and my first son was born when we were 20. From the beginning we knew our future involved children. Even so, I wasn't prepared for how the birth itself would impact me and my mental health. As with many parents, and most definitely dads, it's later on in life that we realise the impact that events have had. It was our seventh son that caused me to hit rock bottom. I found it hard because I knew I was struggling but I didn't have enough education to know what it was. I just had this sad numbness that you hear everybody describing and I wasn't able to connect the dots on what was causing it. I experienced it over about eight years, and at first they put it down to me being in the military and being injured. They just kept giving me antidepressants. And then I realised that all these spirals around my mental health were around the time of pregnancies because of the anxiety of traumas happening. We have had suspected miscarriages, traumatic deliveries, emergencies… everything you can think of, we have experienced it. And not once did anybody think that watching those things is going to affect you. The births were simultaneously the best and worst days of my life. It can go wrong so quickly, and dad is just standing there in the corner thinking oh my god… and then once it's unfolded you're just supposed to move on.

When I was talking to dads on zoom groups it just kept highlighting the fact that my story wasn't unique. There is this idea that dads don't talk, dads won't share but actually it's that nobody asks. I'm a firm believer that we have to support both parents. We need better postnatal mental health care. 6000 men take their own lives in the UK every year and the statistics say that 1 in 10 new dads will experience postnatal depression[2]. We need a proper pathway for dads to get support and understand what they're experiencing. Society has this idea of what a man should be – men don't cry. And if we do talk – where do we go, how do we get the support? Due to the fact I really struggled to find support or any information, I set up PMH Support.

Most people think I campaign just for Dads. I talk about dads based on my experience, but I push for better support for all parents. The hope is that society and services will see the family as a unit and support it as one, not just as individuals.

All too often, in a situation where you only have the two parents and times get hard, it's just each other that they have to lean on! I know so many of you hear me say this often, but if not for my wife Sarah I wouldn't be doing what I'm doing; in reality without her I wouldn't be here period, and that's not what I think, it's what I know. I also know how much I helped her in times of need. That's what we do as family after all, yet we are continually treated as individuals. Support all parents' mental health; it's not rocket science. It's better for the family and, while some people don't agree, there is evidence to prove it's better for the child's development[3]. So that means everyone has a part to play and family member's views and opinions

1 PMH Support: www.facebook.com/pmhsupportforparents/

2 Tommys (2017) Postnatal depression in men. Available at: www.tommys.org/pregnancy-information/blogs-and-stories/after-birth/tommys-midwives/postnatal-depression-men

3 National Research Council (US) and Institute of Medicine (US) Committee on Depression, Parenting Practices, and the Healthy Development of Children; England MJ, Sim LJ, editors. Washington (DC): National Academies Press (US); 2009

are important and should be respected, even when they don't fit with society's expectations. And family services, anyone involved with family services has to see the importance of both parents and, in my case, what a father has to offer. His views and opinions, but really those of all non birthing partners, have so much to offer in regards to babies development but crucially in regard to the birthing person. They know them best. Why can't they all see this, a fountain of knowledge left untapped all too often.

We have experienced three extremely traumatic births, with each birth worse than the last. I have never been so scared in my life. The three pregnancies had been straightforward but the births were far from it. It was after the birth of our sixth son, where both my wife and son were at risk of dying during labour, that I lost all control. I stood in the delivery room as it filled with a lot of people before my wife was rushed for an emergency c section. I stood outside the theatre not knowing what was happening. I could hear my wife crying, and doctors saying we need to get this baby out now. I was in the corridor with my head in my hands not knowing if they were going to be ok. After what felt like an eternity, I was allowed into the operating theatre. My son was born and rushed past me as he wasn't crying and needed help to breathe. My heart felt like it stopped. My wife was not well, my son had been rushed away, there was so much going on. Thankfully my son was ok and I was able to see him after about 20 minutes. My wife recovered physically, but mentally she developed PTSD. She received therapy and is now well, but that took a long time.

Our seventh son was born at 36 weeks. This was planned due to the severity of the 6th birth. We were told that 'anymore after six (babies) and Sarah would "die"'. This was the exact way it was put in recovery, then never talked of again or even explained, despite multiple attempts to figure out what happened and why and what it meant, until fifteen months later when baby number seven was discovered! So it was hard to be overly excited early on as my concern for her was matched by her concern for her unborn child!

When our seventh son was born, he needed NICU care as he could not breath on his own and in a short period of time my life seemed to fall apart around me. My wife wasn't well from the minute he was born and for three days I constantly raised my concerns and was told to listen to the experts, but in this woman, I am the expert and everything I knew told me something was very wrong. I questioned and raised concerns, convinced she had an infection! It turned out she had multiple infections and it was sepsis that almost took her from me. If I was listened to, my wife would never have suffered quite like she did. Post c section she was critically ill, but it took 3 days of me being ignored before they listened. I really thought that I might be saying goodbye to the love of my life. That experience broke me in a way I don't think I ever fully recovered from. This is why I started my webpage.

It was only after Sarah recovered that I began to notice things were not right. I was not happy, easily irritated, no patience, avoidance, no tolerance. I could not find joy in anything. I was depressed. I could not understand why; I have my wife and I have my beautiful boys, but these feelings were getting worse. I was at breaking point; I could not go on. My wife recognised something wasn't right but it was my health visitor who told me what I could be experiencing and suggested speaking to someone. I went to see a private counsellor where I was diagnosed with PTSD. It was found that it had been there since the birth of my first son 18 years ago and the fear and anxiety had carried over to the next pregnancy until it became all too much. The breaking point was attributed to witnessing or experiencing a life-threatening event. Well let me tell you now – nothing is more traumatic than thinking your wife and or child might die! The thought that I might be saying goodbye to the love of my life, while knowing my son was fighting for his life on another ward, broke me in a way I still can't fully articulate and in a way I will never fully recover from. Time isn't a healer. It's how you use the time, and what you learn over time, that helps most – not just the time itself.

So rather than being bitter, the PMH Support page gave me a way to try and help others. I'm no Mary Seacole or Florence Nightingale, but I did manage, as so many on here did, to find a bit of peace in helping others and by giving the advice I wish someone had given me. I felt we needed to have conversations that we just don't have about the realities of pregnancy, birth and parenting, as it's hard, really really hard. We can love being a parent and adore our children but still find it challenging. We have 7 boys and I'm still trying to figure it out day by day. Nobody has it sussed in my mind. Some may say they do, but trust me they don't! The best thing you can ever do can also be the hardest – it can be both; it's not one or the other. If we had these conversations more frequently and openly we would see that everyone struggles at some point. Nobody said life was easy, so it's ok to find it hard!

MBRRACE report: racial inequalities in maternity outcomes continue

by Megan Disley

Scott and his PMH support can also be found on his instagram page. https://www.instagram.com/p_m_h_support/

On the 14th January 2021, the latest MBRRACE-UK report was released[1]. This annual report from the Maternal, Newborn and Infant Clinical Outcome review programme looks at data from the UK and Ireland confidential enquiries into how many women had died during childbirth, and the 12 months after, for the three years 2016 to 2018. The report provides statistics on these deaths as well as summaries on the circumstances around them; and makes suggestions on prevention and lessons to be learnt. The report can be read in full[2], or an infographic is available[3]

Important findings from the 2020 MBRRACE report include:

- The significant increase in Sudden Unexpected Death in Epilepsy.
- 90% of those that died in the three year period from 2016-18 had multiple problems suggesting a constellation of biases are preventing women from receiving the care that they need.
- There continue to be racial disparities in maternity care, with Black, Asian, and mixed ethnicity women significantly more likely to die than their white counterparts.
- Women living in the most deprived areas were almost three times more likely to die than those who lived in the most affluent areas.

What does the report say?

It is important to remember that pregnancy in the UK remains very safe. In the UK, 2,235,159 women gave birth during the three-year period from 2016-2018. Of these, 566 died from either direct causes (deaths related to obstetric complications during pregnancy and up to 12 months after birth) or indirect causes (deaths associated with a disorder which is exacerbated by pregnancy) during and up to the first year after pregnancy. 217 of these deaths occurred within pregnancy or up to six weeks after giving birth[4].

Cardiac disease remains the leading cause of indirect maternal death in the UK. Epilepsy and stroke together are the second most common indirect cause, and third commonest cause of death overall, due to the statistically significant increase in Sudden Unexpected death in Epilepsy (SUDEP)[5]. This refers to deaths in pregnant women with epilepsy that are not caused by either injury, drowning, or any other known causes[6]. The exact causes of these deaths are not known and there may not be any one single explanation. The report does go on to detail that, in many incidences, these deaths are related to inadequate medication

1 Editor's note: For anyone not familiar with it, 'Information about MBRRACE-UK for Parents and Health Service Users' can be found here: www.npeu.ox.ac.uk/mbrrace-uk/service-users

2 MBRRACE-UK (2020) Saving Lives, Improving Mothers' Care: Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2016-18: www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2020/MBRRACE-UK_Maternal_Report_Dec_2020_v10_ONLINE_VERSION_1404.pdf

3 MBRRACE-UK (2020) infographic and lay report. www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2020/MBRRACE-UK_Maternal_Report_2020_-_Lay_Summary_v10.pdf

4 MBRRACE- UK (2020) Saving Lives, Improving Mothers' Care.

5 Sudden Unexpected Death in Epilepsy (SUDEP) is when a person with epilepsy dies suddenly and prematurely and no reason for death is found. https://sudep.org/sudden-unexpected-death-epilepsy-sudep

6 Angus-Leppan H. (2019) 'Epilepsy-related deaths and SUDEP'. Epilepsy Action. www.epilepsy.org.uk/info/sudep-sudden-unexpected-death-in-epilepsy

management for these women either before or during their pregnancy. Due to the doubling in cases of SUDEP, it has become the key focus of this year's report.

Thrombosis and thromboembolism (blood clots) remain the leading cause of direct maternal deaths during or up to six weeks after birth. Maternal suicide sadly remained the leading cause of direct deaths that occurred within a year of pregnancy.

The report states that 90% of the 566 women who died had multiple problems which included both physical and mental health problems. The infographic version and Lay report, talk about a constellation of biases (figure 1) that lead to the maternal deaths. Figure 1 shows how systemic biases due to pregnancy, health and other issues prevented these women with complex and multiple needs from receiving the care that they needed.

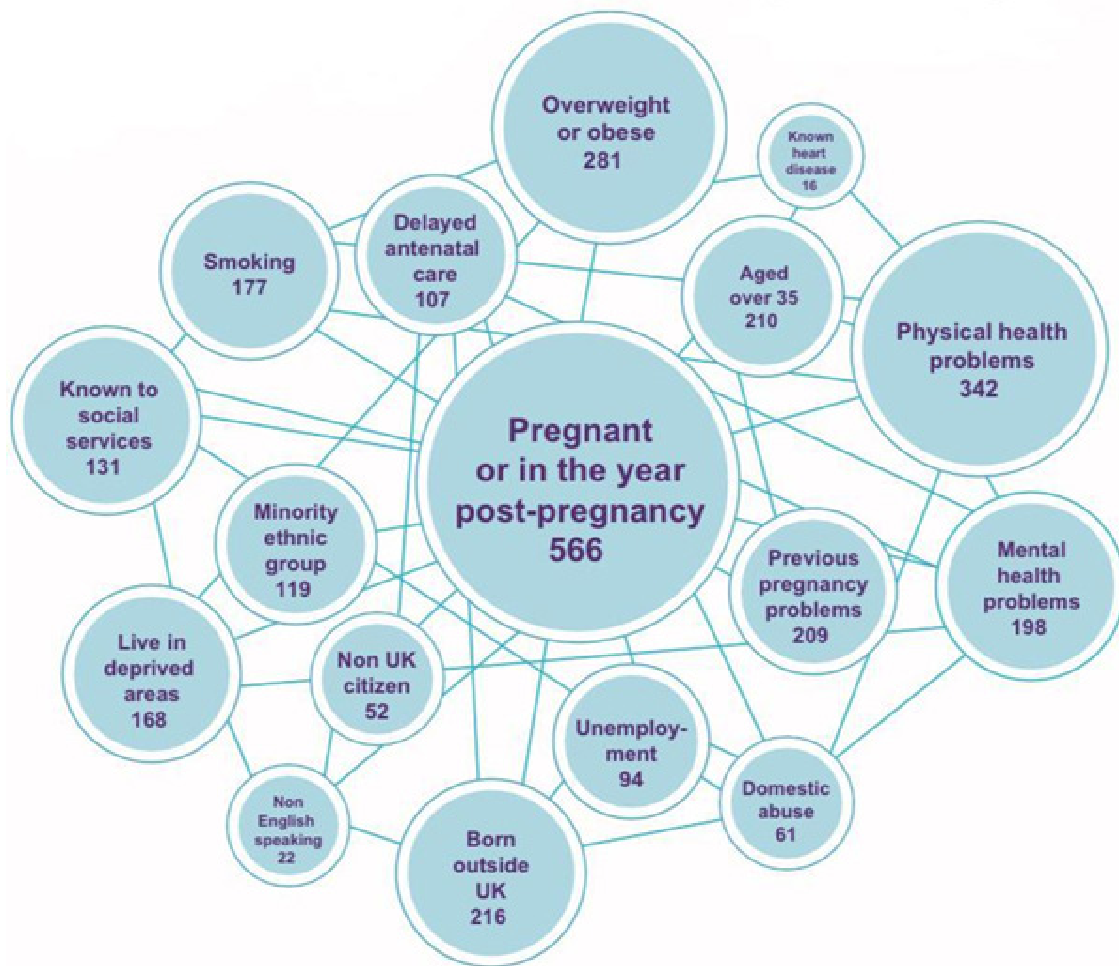


Figure 1. Constellation of biases leading to maternal deaths. MBRRACE infographic

How does this compare to previous years?

Overall, there was a non-significant increase in the overall maternal death rate in the UK between 2016-18 compared to 2013-15.

Outcomes for women from different racial groups are not equal. There remains more than a four-fold difference in the mortality rates amongst women from black ethnic backgrounds, a three-fold difference for mixed ethnicity women and almost a two-fold difference in women from Asian ethnic backgrounds compared to white women.

Figure 2. Disparities in maternal deaths in Black, Asian, and Mixed ethnicity women.

26% of the women who died (in the perinatal period, up to six weeks after the birth) between 2016-18 were born outside of the UK, 36% of whom were not UK citizens. People born in certain countries had a significantly higher risk of death compared to those born in the UK. Table 1 is taken directly from the MBRRACE report which shows the number of deaths from certain countries, those with the highest number of deaths. It is very clear here that the relative risk is higher for those women from specific countries.

Woman's country of birth	Maternities 2016-18	Total Deaths	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
UK	1,630,796*	144	8.83	7.45 to 10.40	1 (Ref)	-
Outside UK	604,363*	50	8.27	6.14 to 10.91	0.94	0.67 to 1.30
Specific countries						
Bangladesh	22,662‡	3	13.24	2.73 to 38.68	1.50	0.31 to 4.47
China	10,479‡	3	28.63	5.90 to 83.64	3.24	0.66 to 9.67
India	41,262‡	4	9.69	2.64 to 24.82	1.10	0.30 to 2.87
Nigeria	19,326‡	10	51.74	24.82 to 95.14	5.86	2.75 to 11.09
Romania	41,683‡	3	7.20	1.48 to 21.03	0.82	0.17 to 2.43

*Estimates based on proportions of births to UK and non-UK born mothers applied to number of maternities

‡Estimates based on ratio of maternities to births applied to number of births recorded to mothers born in stated country

Table 1. Maternal mortality rates according to the mother's country of birth (selected countries) 2016-18

There remains a difference in mortality rates in different areas and ages. Women living in the most deprived areas are almost three times more likely to die compared to those living in the most affluent areas of the country. 8% of those who died experienced severe and multiple disadvantages, which is an increase of 2% from the last report. The main elements being substance abuse, ill health, and domestic abuse.

20% of women who died were known to social services, a proportion that has increased steadily over time since the 2012-14 report. This further highlights the vulnerability of many people who died.

Let's talk about SUDEP

As previously stated, epilepsy was a key focus for this year's report. SUDEP occurred nearly twice as often in 2016-18 compared to the previous three years. Most of these women who died had clear risk factors, but did not have risk or prevention methods discussed with them or put in place, or even pre-pregnancy counselling. Some of those who died were either living or sleeping alone. As pregnancy is a known risk factor for SUDEP, it is imperative that strategies are discussed with the pregnant women and people, and their families, and prevention measures are put in place.

Currently, there are no specific recommendations about the discussion of SUDEP and risk minimisation within the RCOG (Royal College of Obstetricians and Gynaecologists) green-top guideline on epilepsy on pregnancy. The report recognises that

this needs to change and there needs to be guidance developed to ensure SUDEP awareness. It recommends that there should be clear standards of care for joint maternity and neurological services which would allow for a simple referral process, and prompt reviews. Other recommendations include all maternity units having access to an epilepsy team, having a maximum referral time of two weeks, and, where necessary, involving social services to ensure that pregnant women and people have safe accommodation arrangements in place.

What has been actioned since the previous report?

On a positive note, conversation has finally now begun to change. It is now recognised that the disparities in maternal mortality just because of a mother or birthing person's ethnicity is quite simply not acceptable. AIMS is currently in the process of developing a position paper on this important topic.

The report discusses the first Black Women's Maternal Health Awareness Week which was organised by the Five X More campaign in September 2020. The campaign is effectively working to raise awareness by supporting and empowering Black women to make informed choices throughout their pregnancies. The campaign was set up in response to the racial inequalities experienced by two black mothers and the findings in the 2018 MBRRACE report (Please see the AIMS Journal article 'MBRRACE and the disproportionate number of BAME deaths' for more information on the 2018 MBRRACE report.[7]) Subsequently, AIMS teamed up with Five X More on a joint project to make sure that Black women know their rights within pregnancy and childbirth, to help achieve better outcomes for these women (https://www.fivexmore.com/do-you-know-your-rights). AIMS and Five X More are volunteer organisations which are entirely independent of MBRRACE. However, MBRRACE have used data from Five X More. This shows that there is a change in conversation, which is a success of sorts, but it also feels as if the report has used this success to show actions which haven't come from partners/sponsors of the report themselves.

RCM (Royal College of Midwives) and RCOG (the Royal College of Obstetricians and Gynaecologists) have said that they are working to address racial disparities in the maternity services. The RCM have set up the 'Race Matters' initiative that sets out a five point plan which includes supporting research and championing positive change for those affected by racism in maternity. RCOG has set up a task force which aims to highlight where health care disparities exist and improve the understanding of these inequalities. They also aim to collaborate with the government to create meaningful solutions and improve the outcomes that are currently seen and experienced. It is not clear what these initiatives entail or what they have achieved so far.

NHS England/Improvement are in rapid development of a chart for use in England similar to the consensus Modified Early Obstetric Warning Signs (MEOWS) which monitors physical parameters for women and allows for early recognition of the deterioration based on these factors. These already exist and are in use in other parts of the United Kingdom. They are also creating clear response pathways to ensure appropriate escalation of care. It begs the question, why not just adopt the MEOWS strategy, particularly if there is evidence this is being successfully used?

Due to the SARS-CoV-2 pandemic, a rapid review was conducted of the care of all women who died with confirmed or suspected SARS-CoV-2 infection during or up to one year after pregnancy. This also included any women who died from mental health-related causes, or domestic violence which may have been influenced by the public health measures that were put in place to control the epidemic. Therefore, the MBRRACE report also included the actions following this rapid review. The rapid report showed evidence that Black and other women from ethnic minorities within the UK were disproportionately severely affected by COVID-19. NHS maternity units in England were requested to increase support, create tailored communications and discussions of nutrition, and to record ethnicity as well as other comorbidities on maternity information systems. However, no data was given on this in the MBRRACE report and also no evidence to show that this has in fact been actioned.

It is stated that other reviews have been actioned, however this is for information gathering only and none are currently funded to assess any outcomes or recommendations. It is, therefore, so important that campaigns are carried on by committed individuals and organisations in order to drive forward the much needed changes.

7 McKenzie G. (2019) 'MBRRACE and the disproportionate number of BAME deaths'. AIMS Journal. Vol 31. No 2

What does the report recommend?

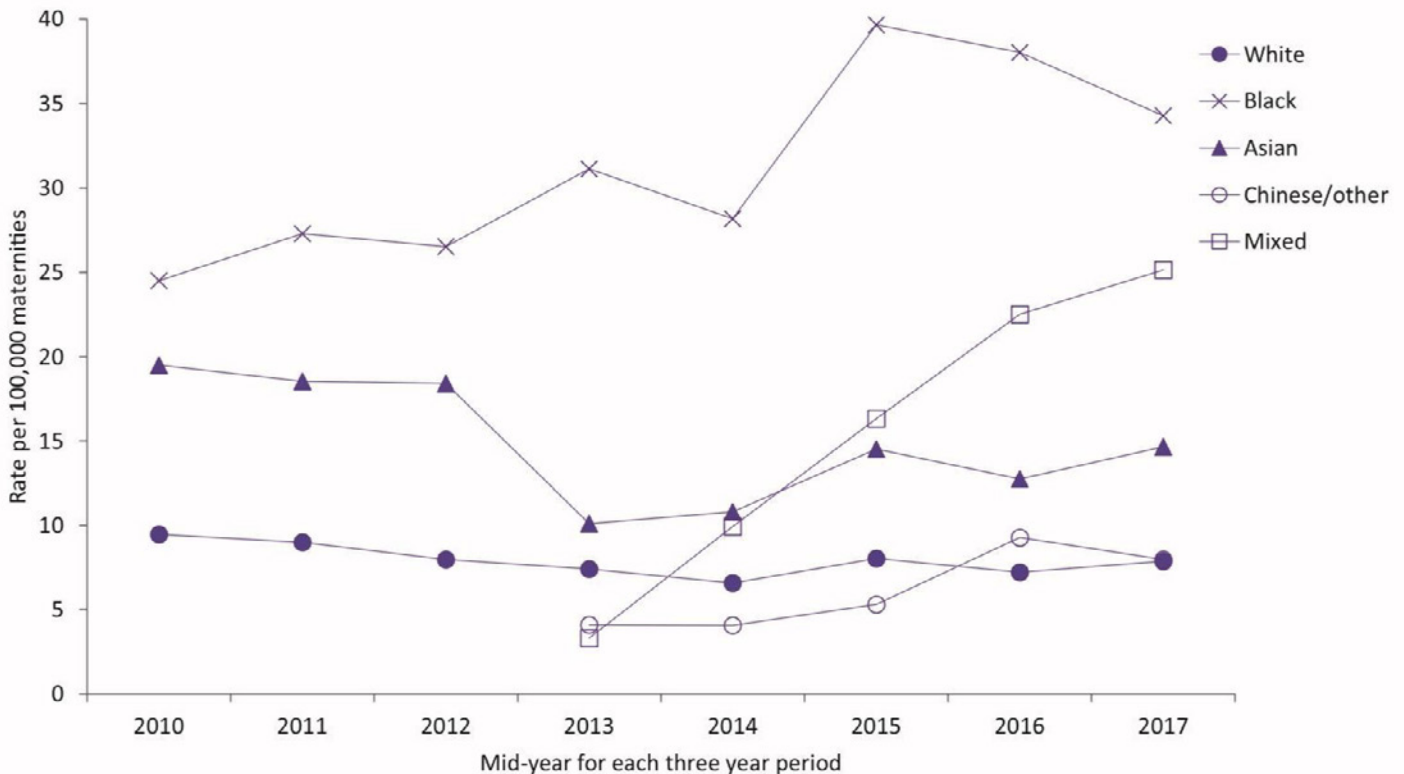
Maternity care needs to improve in order to save lives. The recommendations from the MBRRACE assessors have been drawn directly from already existing guidance and reports. They have identified areas where the existing guidance needs to be strengthened and recommended actions where national guidelines are currently not available.

This report has gone back to focusing on the direct and indirect causes in a medicalised sense. It focuses on guidelines and ensuring that member organisations and professional groups support healthcare professionals in delivering these recommendations. Findings showed that almost three quarters of those women who died during or up to six weeks after pregnancy in 2016-18 had pre-existing physical or mental health conditions. One of the most concerning factors of the 2020

MBRRACE report is that there is very little discussion regarding pre-existing mental health conditions considering 198 of those 566 who died from 2016-18 experienced pre-existing mental health conditions. Maternal suicide is the fifth most common cause of death during pregnancy and up to six weeks after birth, and is the leading cause of death over the first year after pregnancy. There are no suggestions made in this report on how to improve access to services for pregnant women and people suffering with mental health conditions and how best to support them, and it is hard to determine from the report whether or not the type of birth was a risk factor for mothers.

Although conversations around disparities in maternity care are improving and we are seeing campaigns from organisations such as Five X More raising awareness, it is extremely disappointing to see that this report has shown very little focus on continuing to reduce the maternal mortality rates and disparity by improving culture, attitude, and quality of care for non white people. While there has been a decrease (although not statistically significant) in the number of Black and Asian women who have died, there was an increase in the number of deaths of Chinese/other and Mixed Race people as shown in figure 3. We are still a long way off from seeing an actual reduction in mortality rates. Changes in conversation are not enough, action needs to be taken. There are no suggestions or comments in the report to work towards this change. It is only discussed that reports are being commissioned, meanwhile racial disparities in maternity care continue.

Figure 3 Maternal mortality rates 2009-18 among women from different ethnic groups in the UK



There also remains a statistically significant difference in maternal mortality rates between those living in the most deprived areas and those in the least deprived areas of the UK. It is suggested that this inequality gap is also increasing. Suggesting further research to fully understand the reason behind these disparities and develop actions to address them is a positive step, but suggestions are not enough.

Focusing on the physical causes of both direct and indirect deaths, the report makes numerous suggestions on changes in guidelines for all healthcare professionals. This is necessary and important for obvious reasons. Preventing the avoidable deaths of hundreds of pregnant women and people is what MBRRACE sets out to do. Hopefully the suggestions made will be implemented and achieve changes. It is important to remember that pregnancy and birth are generally very safe in the UK, but this report makes it clear that there is room for improvement.

Conclusions

Whilst assessors judged that 29% of the women who died had good care, they identified that in 51% of the deaths, had there been improvements in care, it may have made a difference to the outcome. It is clear that the level of care pregnant women and people are receiving simply needs to improve in maternity services within the UK.

There is a clear constellation of bias going on in maternity services within the UK. With 90% of those that died having other pre-existing physical and mental health conditions, there is systemic bias in the system that has led to these people failing to receive 'good' standards of care.

Additionally, there is no mention of anything in the recommendations to continue work on decreasing the disparities between Black and other ethnic minority pregnant women and people compared to their white counterparts. This has only been raised when comparing it to the new conversations about those with pre-existing medical conditions receiving a lower standard of care, and how this is not acceptable simply because they are pregnant.

The NHS and maternity services are facing continued constraints and challenges with increased births and health complexities of these, increased demand from policy changes, and the vicious cycle of staff shortages[8], all exasperated by the COVID-19 pandemic. The level of care that pregnant women and people receive will inevitably be affected. The RCM put forward solutions for these challenges but we are yet to see any improvement from the NHS and UK governments.

Guidelines and policies alone are not going to reduce mortality rates and disparities in these deaths. The constellation of bias, and racial and social disparities pregnant women and people are experiencing needs to change. Hopefully we will see in the next MBRRACE report that meaningful solutions have been put into practice, and that not only are we seeing a change in conversation, but also in positive action.

Author Bio: ***Megan is just beginning her journey as a student midwife and advocate for birthing people. She volunteers for AIMS on the Birth Information and Health Inequalities Teams. She lives in Essex with her young son.***

8 Royal College of Midwives (2017) 'The gathering storm: England's midwifery workforce challenges'. www.rcm.org.uk/media/2374/the-gathering-storm-england-s-midwifery-workforce-challenges.pdf

AIMS Commentary: the OASI care bundle debate

by the AIMS Campaign team

The prospect of sustaining perineal trauma during birth remains a topic that has, until recently, been seen as relatively taboo; an issue seldom shared socially, with the consequences of severe perineal trauma rarely discussed. Tears, of course, vary in severity and the subsequent management and treatment for this injury is dependent on accurate clinical identification and recognition, followed by the offer of appropriate treatment. On that basis, the Royal College of Obstetricians and Gynaecologists (RCOG) and the Royal College of Midwives (RCM) have come forward with 'an OASI care bundle',[1] with OASI standing for 'obstetric anal sphincter injury'. This article explores some of the controversy surrounding this bundle.

Estimates of the incidence of perineal trauma vary, with an estimated 90% of first-time labouring women and birthing people sustaining some degree of tear, graze or surgical incision (episiotomy)[2], reducing in incidence in subsequent pregnancies. Most of these injuries will not be severe and will heal without long term consequence. These are classified as 1st or 2nd degree tears.

However, some injuries will be identified as a 3rd or 4th degree tear, affecting the tissue around the anus. These are commonly associated with long labours, instrumental birth and prolonged pushing, although they may also occur during spontaneous births. Approximately 3.5 out of 100 tears (6/100 in first time labours, <2/100 in subsequent births) will be classified as a 3rd or 4th degree tear.[3] These Obstetric Anal Sphincter Injuries (OASI) require accurate identification, specialist repair, and post birth support and rehabilitation. This usually includes obstetric follow up appointments and physiotherapy.

Sustaining an OASI can have profound implications for those experiencing them, both from an emotional and physical health perspective, with many women and birthing people reporting chronic and acute pain, sensitivity, faecal and flatus incontinence, bladder and bowel dysfunction, sexual dysfunction, anxiety, depression, post-traumatic stress disorder and tokophobia[4]. Support networks and charities, including AIMS, Birthrights, The Birth Trauma Association and the MASIC foundation, exist to provide specialist support and information to women and birthing people in this regard, as well as to support decision making and to offer practical advice.

Criticism has been levelled against national healthcare policies and guidelines and this continues to gain momentum. Concerns exist around their failure to provide appropriate antenatal education about the risks and consequences of sustaining not only OASI, but perineal trauma as a whole. There are concerns about the clinical detection of, and the prevention of OASI across maternity systems, and about the provision of suitable support for those having sustained an injury. The stigma associated with the range of consequences of perineal tearing, is also a concern.

Urgent action was therefore needed not only to contribute to reducing OASI across the childbearing population, but also robust information and antenatal support that enables informed decision making. It is for this reason that the OASI care bundle was launched in 16 maternity units between January 2017 and March 2018. The bundle has become a troublesome area of debate across disciplines with regards to not only the evidence upon which it is based, but the way in which the bundle has been introduced and the omission of robustly evidenced interventions such as warm compresses and massage. This has left many clinicians, academics and birth workers scratching their heads as there is evidence that these simple measures reduce the incidence

1 OASI Care Bundle Project Team. (2018) Implementation guide for maternity sites in the roll-out phase 2017-2018. RCOG London. www.rcog.org.uk/globalassets/documents/guidelines/research--audit/oasi-care-bundle/oasi-care-bundle-guide-final-_-050118.pdf

2 COG (2019) Perineal tears during childbirth. Available at: ww.rcog.org.uk/en/patients/patient-leaflets/perineal-tears-during-childbirth/

3 RCOG (2021) Third- and fourth-degree tears (OASI). Available at: www.rcog.org.uk/en/patients/tears/third-fourth/

4 Editor's note: Tokophobia is a morbid fear of childbirth and/or of the experience and consequences of medicalised birth care.

of third- and fourth-degree tears.[5 6 7]

Based on a set of interventions brought together and intended to be applied to all women and birthing people, the OASI Bundle includes:

- Antenatal information about OASI and what can be done to reduce the risk of sustaining an OASI. This is limited to advising midwives and doctors that the bundle is used, and to explaining its elements. There is no discussion of the risk factors for OASI, for positioning or for the evidence (or lack thereof) for or against manual perineal protection (MPP) . Importantly, there is no reminder about the absolute right of the woman or birthing person to decline the intervention and/or to be supported to give birth in a way that they consider will increase their chance of avoiding an intervention, such as episiotomy, that may in itself increase the risk of OASI. the bundle was published[8] to complement the publication of clinicians' perspectives on the bundle[9]. This showed a decrease in OASI rate from 3.3% to 3.0% after implementation of the bundle. Whilst acknowledged as a small effect, the paper's authors suggest that the pre-bundle figure of 3.3% may have been an underestimation of the incidence of severe perineal trauma (with perineums previously not checked as thoroughly), and that therefore, the reduction in trauma brought about by using the bundle, may be bigger than it appears. However, there is no evidence to support this.
- Documented use of manual perineal protection (MPP). The bundle works on the basis of applying this unless "the woman objects" and in all cases of operative vaginal births. We note that the evidence upon which MPP is founded is limited, a point acknowledged by the authors of the evaluation paper (see footnote 9).
- Episiotomy when indicated. The bundle just says it should be used when indicated, so this adds no change to current normal practice. However, the bundle has changed the angle at which this is performed, something that isn't included in the antenatal evidence for the woman or birthing person and lacks robust evidence.
- Full and thorough examination of the perineum including a rectal examination even if the perineum appears to be intact. Although this is important in detecting tears and classifying them for appropriate management there remains little evidence of the number of OASI identified by per rectum examination in the presence of an intact perineum.

In August 2020, a quantitative evaluation of the bundle was published to complement the publication of clinicians' perspectives on the bundle . This showed a decrease in OASI rate from 3.3% to 3.0% after implementation of the bundle. Whilst acknowledged as a small effect, the paper's authors suggest that the pre-bundle figure of 3.3% may have been an underestimation of the incidence of severe perineal trauma (with perineums previously not checked as thoroughly), and that therefore, the reduction in trauma brought about by using the bundle, may be bigger than it appears. However, there is no evidence to support this.

This again sparked discussion and debate across disciplines around the true impact of the interventions, challenging the evidence upon which the bundle was based as well as the interpretation of data collected as part of the bundle, and the evidence gaps that remain.

This again sparked discussion and debate across disciplines around the true impact of the interventions, challenging the evidence upon which the bundle was based as well as the interpretation of data collected as part of the bundle, and the evidence

5 Magoga, G., Saccone, G., Al-Kouatly, H.B., et al., 2019. Warm perineal compresses during the second stage of labor for reducing perineal trauma: a meta-analysis. Eur. J. Obstet. Gynecol. Reprod. Biol. 240, 93–98. doi:10.1016/j.ejogrb.2019.06.011

6 Aasheim V, Nilsen ABV, Reinar LM, Lukasse M. Perineal techniques during the second stage of labour for reducing perineal trauma. Cochrane Database of Systematic Reviews 2017, Issue 6. Art. No.: CD006672. doi: 10.1002/14651858.CD006672.pub3.

7 Pierce-Williams R. A. M., Saccone G. and Berghella V. (2019): Hands-on versus hands-off techniques for the prevention of perineal trauma during vaginaldelivery: a systematic review and meta-analysis of randomized controlled trials, The Journal of Maternal-Fetal & Neonatal Medicine, www.iris.unina.it/retrieve/handle/11588/804108/333468/199%20Hands%20on%20-%20JMFNM%20-%20Pierce%20Williams.pdf

8 Gurol-Urganci I, Bidwell P, Sevdalis N et al (2020). Impact of a quality improvement project to reduce the rate of obstetric anal sphincter injury: a multicentre study with a stepped-wedge design. BJOG doi:10.1111/1471-0528.16396.

9 Bidwell, P. et al. (2020) 'Exploring clinicians' perspectives on the "Obstetric Anal Sphincter Injury Care Bundle" national quality improvement programme: a qualitative study', BMJ Open, 10(9), p. e035674. doi: 10.1136/bmjopen-2019-035674.

gaps that remain.[10 11 12]

It was not until January this year, in the International Urogynecology Journal[13], that the qualitative data of the views of the women was published. This provided an evaluation of women's experiences of the bundle. Sadly, it did not seem to answer the anticipated questions surrounding the acceptability of the bundle in a way that truly represented the wider population upon which the bundle was imposed. 19 women out of a prospective 55,060 (accepting that qualitative research is neither representative of an entire population nor aims to capture everyone's perspective), responded to questions that seemed neither to capture the elements of the bundle, nor to reflect the available evidence.

It is clear that the implementation of the bundle comes from a place of good intentions. No one would deny that there would be huge benefit in being able to reduce the incidence of OASI. **However, the history of maternity care is littered with the implementation of seemingly well-intentioned innovation and interventions that later have been found to be problematic, ineffective and/or harmful.** Care bundles, themselves, are intended to draw together a variety of evidence-based interventions, in order to achieve improvements in outcomes, that are greater as a sum of the parts, than individually. [14]
It is important that scrutiny should therefore be applied to all care bundles and interventions, no matter how well intentioned, before they are implemented and during implementation, as once embedded into clinical practice, it can be hard if not impossible to de-implement.

There continues to exist professional disagreement in relation to the bundle, and it is these same issues that lead AIMS to continue to be concerned:

Lacking a physiologically informed approach – The bundle aims to standardise practice in relation to reducing OASI with a focus on the application of the invasive intervention MPP across a whole birthing population but without consideration of the physiological variations of women and birthing people or of the mode or place of birth, and is therefore lacking a physiologically informed approach to reducing serious tears.
Place of Birth – Evidence already exists around the preventative effect of out of hospital birth on perineal tearing.
Position in Labour and Birth – The authors of the bundle's original paper explored risk factors for OASI and identified instrumental birth as a 'key determinant' in increased risk of severe perineal tears.[15] And Bidwell's evaluation of clinicians views of the bundle[16] and its unintended consequences found, amongst other things, that the position the birthing person needed to adopt in order for someone to apply manual pressure to the perineum, may in itself be a cause of OASI.
One size fits all – The application of the bundle takes a one size fits all approach rather than offering individualised care, possibly for fear of being drawn into a blame culture should any serious trauma occur. The homogenised approach once again reflects the mechanised, pathologised and defective view of women's birthing bodies[17 18], failing not only to acknowledge individual uniqueness, but reinforcing the belief that every birth must be medically managed in order to 'save the mother

10 Moncrieff, G. and Dahlen, H. (2020) 'The UK OASI Care Bundle: the results are out but so is the jury', All4Maternity Blog, News & Views. Available at: www.all4maternity.com/the-uk-oasi-care-bundle-the-results-are-out-but-so-is-the-jury/.

11 Thornton, J. and Dahlen, H. (2020) 'The UK Obstetric Anal Sphincter Injury (OASI) Care Bundle: A critical review', Midwifery, 2020(90). doi:10.1016/j.midw.2020.102801.

12 Alexander, S. and Langhoff-Roos, J. (2021) 'Intra-partum care of the perineum matters: new knowledge and remaining gaps', BJOG : an international journal of obstetrics and gynaecology, 128(3), pp. 593–593. doi: 10.1111/1471-0528.16560.

13 Bidwell, P. et al. (2021) 'Women's experiences of the OASI Care Bundle; a package of care to reduce severe perineal trauma', International Urogynecology Journal. doi: 10.1007/s00192-020-04653-2.

14 Institute for Healthcare Improvement (IHI) (2015). Bundle up for safety. www.ihi.org/resources/Pages/ImprovementStories/BundleUpforSafety.aspx

15 Gurol-Urganci, I, Cromwell, D, Edozien, L, Mahmood, T, Adams, E, Richmond, D, Templeton, A, van der Meulen, J. (2013) Third- and fourth-degree perineal tears among primiparous women in England between 2000 and 2012: time trends and risk factors. BJOG 120: 1516– 1525. doi:10.1111/1471-0528.12363.

16 Bidwell P, Thakar R, Gurol-Urganci I et al (2020). Exploring clinicians' perspectives on the 'Obstetric Anal Sphincter Injury Care Bundle' national quality improvement programme: a qualitative study. BMJ Open https://bmjopen.bmj.com/content/10/9/e035674

17 Davis-Floyd R. (2001) The technocratic, humanistic, and holistic paradigms of childbirth. Int J Gynaecol Obstet. Nov;75 Suppl 1:S5-S23. PMID: 11742639.https://pubmed.ncbi.nlm.nih.gov/11742639/

18 Beech B. (2011) Challenging the Medicalisation of Birth. AIMS Journal. www.aims.org.uk/journal/item/challenging-the-medicalisation-of-birth

and baby'. This is perhaps illustrated in the failure to fully acknowledge the dehumanising effects of rectal examination in the absence of evidence and visually identified trauma, and the psychosocial effects of labial tears, which increase when using MPP.[1] Whilst labial tears have less long-term implications compared to OASI, this does not negate the personal effects of this type of injury.

Birth Practices – More work is needed, not only to inform clinicians and birthing women and people around which birth practices are associated with intact perineum or severe tears, but to reach a consensus and to resolve clinical issues. The ongoing debate and conflict serves only to underline the dysfunctional nature of the current system which will benefit very few in the long term.

Antenatal Information – It goes without saying that women and birthing people have an absolute right to clear, unambiguous and evidence-based information antenatally to enable informed decision making regarding their care, and this includes the OASI care bundle. Currently the bundle information pack provision extends to advising the content of the bundle rather than the evidence around prevention of tears, and any other options for care. More must therefore be done in terms of the provision of appropriately tailored antenatal education and discussion of perineal tearing including risk factors that extend beyond the individual including mode and place of birth, as well as discussing acceptability of interventions including MPP, rectal examination etc.

AIMS would like to remind all clinicians that the birthing person's wholehearted and fully informed consent is needed for any examination or procedure and they must be aware of all their options before agreeing to any part of the OASI care bundle.

1 Naidu M, Sultan AH, Thakar R (2017). Reducing obstetric anal sphincter injuries using perineal support: our preliminary experience. International Urogynecology Journal 28:381-9 dol:10.1007/s00192-016-3176-4.

Birth Activist Briefing

Why it's important for you to get involved in your local (MVP) Maternity Voices Partnership

by the AIMS Campaign Team

Maternity Voices Partnerships (MVPs) are a key element of the landscape for maternity service improvement in England.[2] In order for them to function effectively, they require sustained input from committed local 'service user representatives', who are willing to work hard for the interests of maternity service improvement in their local area. And that's where you – or someone you know – might come in. In this article, we will brief you on the key role of Maternity Voices Partnerships and encourage and support you to get involved.

England has long prided itself on having a decent national maternity policy, much of that thanks to an impressive maternity service improvement community (of which AIMS – for the last 60 years – has been a key member). But we also know that structural problems persist and that good policy doesn't always translate well to every encounter that local service users have with the maternity services. This is where local MVPs can be vital. So that there is no postcode lottery when it comes to high-quality maternity services. So that we leave no one behind.[3]

So what are Maternity Voices Partnerships ?

Maternity Voices Partnerships are "independent formal multidisciplinary committees" which bring people together "to influence and share in local decisions" about maternity services. Better Births guidance (2017)[4] asks Local Maternity Systems to ensure that all service users in their area (and their partners

2 Different arrangements exist in Scotland; Wales and Northern Ireland retain the MSLC structure.

3 unsdg.un.org/2030-agenda/universal-values/leave-no-one-behind

4 NHS England (2017), 'Implementing *Better Births*: A resource pack for Local Maternity Systems': https://www.england.nhs.uk/wp-content/uploads/2017/03/nhs-guidance-maternity-services-v1.pdf.

and families) are able to participate in a Maternity Voices Partnership, either by giving feedback or by becoming service user members of a partnership. And according to that national guidance, maternity service users and their families should make up a third of the members of each MVP.

Some of our English readers may be more familiar with the idea of a Maternity Service Liaison Committee (MSLC). Since the Better Births report (2016),[5] most local Maternity Service Liaison Committees have transitioned to become Maternity Voices Partnerships. But it's not simply a change of name. The MVP concept is now very well embedded into the national framework for maternity service improvement work, in a way that MSLCs never were. Another key change is that MVPs should now be led by a paid and independent Service User Chair. Neither of those changes in themselves necessarily mean that your local MVP will be an effective one, of course. However, they do mean that your input on an MVP is likely to be more worthwhile than similar work on an MSLC. Those who are there to represent the service user perspective should now have a key ally in the Chair, if that was not the case previously. This is because the Chair can no longer have a role in the maternity services you are there to improve (whether within the Trust or within the local CCG). Rather, the Chair will be there to ensure that those Trust and CCG members of the MVP will continue to play an important role in the Partnership, but not one that is in any way superior to the Service User Representative members. The leadership of the Chair – to ensure that this is the case – is crucial.

So what's the problem? AIMS has heard from our Members and Volunteers over the years that being a Service User Representative on an MVP (and previously on an MSLC) can be hard: really hard, actually! It can be hugely stressful to feel that you are one lone voice against 'the system', where even the Chair can sometimes seem like part of the system you're trying to 'speak up' to. Whilst AIMS hopes that this position will change in the coming years, as MVP chairs find their feet and come to appreciate the vital contribution of Service User Representatives and how to support them, we aren't going to lie to you about the difficulties you might face. For some of our members, being on an MVP and trying to speak up on behalf of service users has, quite frankly, been the hardest work challenge they've ever faced. But please, don't make this a reason not to step up, or maybe step up again.

AIMS is keen to play our part in supporting the success of MVPs, in particular by supporting isolated local Service User Representatives. In that context, we would like to publicise a new AIMS-led space for MVP Service User Representatives. We envisage this as a one hour monthly zoom call where you can come together with other Service User Representatives and share experiences and learning in a mutually supportive way, so that you can each engage more productively at a local level. We hope that sounds like the support network you need to make that decision to step up to a role on your local MVP!

So … Please consider taking part in your local MVP. MVPs are a key space for engagement and a key space for you to help to deliver the AIMS mission. Yes, it requires a keen interest in maternity service improvement (which you surely have already in reading this Journal!) and a commitment to being present in the discussions and to putting in the necessary work, but if we don't step up and show up, we risk MVPs that fail to reach their potential. AIMS believes that MVPs must play their part in tackling the everyday trouble that people encounter with the maternity services, some of which translates into truly unacceptable experiences and outcomes. For MVPs to stand a chance, they are crucially dependent on the engagement of people who have experienced the system first-hand and who are committed to seeing improvement for all those who come after us. We are here to support you!

Action for Birth Activists:

1. Find your local Maternity Voices Partnership. You should be able to find details of your local MVP via your local Trust or CCG website. Alternatively, visit the National Maternity Voices website and use their 'find an MVP' service.[6]

2. Sign up as a Service User Representative. Get involved.

3. If you would like to share your experience and/or join the AIMS network for MVP Service User

5 NHS England (2016), 'Better Births: Improving outcomes of maternity services in England': https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf.

6 National Maternity Voices website, 'Find an MVP': http://nationalmaternityvoices.org.uk/find-an-mvp/.

Representatives please email campaigns@aims.org.uk

Further reading

If you would like to understand the role envisaged for MVPs in National Maternity Transformation, section 4 of this national guidance document might be a good place to start:
nhs-guidance-maternity-services-v1.pdf (england.nhs.uk)
This AIMS Journal article should also be helpful in explaining the role and ambition for MVPs:

Implementing Better Births: Why Maternity Voices Partnerships (MVPs) are key | AIMS

There is also lots of really useful information about Maternity Voice Partnerships and the role of Service User Representatives on the National Maternity Voices (NMV) website. National Maternity Voices is the national group of Maternity Voices Partnerships in England. They support and advise the service user chairs of MVPs. You may want to start with this document, which offers a really good sense of the role of the service user chair:
Service User Rep Info Pack (nationalmaternityvoices.org.uk)

What has the AIMS Campaigns Team been up to this quarter?

(June – Aug 21)

Covid-19:

We have continued to be involved in the But Not Maternity Alliance[7], campaigning for the lifting of restrictions on partners/supporters being admitted throughout the maternity services. We have also been updating our website resources regularly, with the latest guidance for maternity service users in all four nations of the UK.

New campaigns development work:

We are supporting groups of Volunteers to develop our work around our desire to see an end to obstetric violence and our concern that race inequalities in the maternity services are effectively tackled.

Written outputs:

We continued the conversation on 'Shared Decision Making', with a blog written by one of our volunteers[8] which was shared across the National Voices community via their website[9].

We wrote to NHS England's Maternity Transformation Programme[10] team about the quality of NHS antenatal preparation provision and the related issue of the criteria for paid-for maternity services within the NHS.

We wrote to NICE[11] to get them to address our concerns about the initial publicity surrounding the Draft NICE

7 www.butnotmaternity.org/

8 Improving healthcare: is it time to ditch the terminology of 'shared decision making'?: www.nationalvoices.org.uk/blogs/improving-healthcare-time-ditch-terminology-shared-decision-making

9 National Voices: ww.nationalvoices.org.uk/

10 Maternity Transformation Programme: www.england.nhs.uk/mat-transformation/

11 NICE (The National Institute for Health and Care Excellence): www.nice.org.uk/

Induction of Labour guideline (which they did), and also responded to the consultation[12]. We have been active on social media on this issue, encouraging others to read and respond to the consultation, and sharing our draft response to support and inform other potential respondents.
We wrote to NICE to highlight our concern that some of their draft guidance put out for consultation does not seem to reflect their own principles[13].

We responded to the NICE consultation on their new proposed guidance on pelvic health.[14]

We co-signed a letter by Professor Lesley Page; Heed Maternity Care Evidence[15] to the Guardian editor in response to the article 'No evidence and little research - it's no wonder that women and babies continue to die'.[16]

Conferences and meetings attended:

We participated in a special workshop organised by the Maternity Transformation Programme's Stakeholder Council, to feed into the recently-launched evaluation of the Maternity Transformation Programme (England).

We continue to keep ourselves updated on a wide-range of current issues of relevance to the maternity service improvement community by regularly participating in the thought-provoking weekly Maternity and Midwifery Hour[17] hosted by Sue Macdonald.

We participated in the first quarterly meeting of a Royal College of Midwives Re:Birth Project Oversight Group.[18]

We participated in a meeting organised by the Association of Radical Midwives[19] to discuss the proposed update to the **NICE guidance around the induction of labour**, and were particularly pleased to hear an international research-based perspective at that meeting provided by Hannah Dahlen.
We participated in the inaugural meeting of a **Task Force on Decision-Making for Women in Childbirth** organised by Open Justice20 to write some guidelines about how decisions should be made for women who may lack capacity to make their own decisions in childbirth.

We continue to be regular participants in the informative and thought-provoking weekly meetings organised by Caroline Flint as part of the Facebook-based **Practical Continuity – setting up continuity of carer in maternity services**[21] community of practice, as well as other events that help us to keep updated about the implementation of #ContinuityofCarer.

We continue to attend research seminars organised by Care Opinion[22], seeking to improve understanding about **patient feedback** and how it can lead to improved services.

We attended an informative online seminar called **"Women's Choice in Childbirth. Really?"**, organised by Stella Villarmea in collaboration with The Collaborating Centre for Values-based Practice in Health and Social Care[23].

We attended an informative NHS webinar on their guidance about personalised care and support planning[24].

We attended a seminar hosted by the Midwifery Unit Network[25], with speakers from the Keep MLU Midwives campaign[26], considering the interplay between the rollout of #ContinuityofCarer and the preservation of the option for labouring and of giving birth in well-managed birth centres.

We participated in an interesting Twitter Q&A event hosted by National Voices, on the issue of co-production[27].

12 AIMS – NICE Inducing Labour Guideline - Consultation on Draft July 2021: www.aims.org.uk/campaigning/item/nice-iol-comments

13 NICE – The principles that guide the development of NICE guidance and standards: www.nice.org.uk/about/who-we-are/our-principles

14 NICE – Pelvic floor dysfunction: prevention and non-surgical management - Draft guidance consultation www.nice.org.uk/guidance/indevelopment/gid-ng10123/consultation/html-content-3

15 Final version of letter by Professor Lesley Page to Guardian Editor: www.theguardian.com/theobserver/commentisfree/2021/jul/11/letters-diana-dream-and-reality

16 Sonia Sodha's article for The Guardian: www.theguardian.com/commentisfree/2021/jul/04/as-long-as-sexism-lies-at-the-heart-of-childcare-babies-and-women-will-continue-to-die

17 Maternity and Midwifery Hour: www.maternityandmidwifery.co.uk/the-maternity-and-midwifery-hour/

18 Royal College of Midwives Re:Birth project: www.rcm.org.uk/what-is-the-rebirth-project/

19 Association of Radical Midwives - www.midwifery.org.uk/

20 Open Justice Court of Protection Project - Promoting open justice in the court of protection: https://openjusticecourtofprotection.org/

21 Practical Continuity - setting up continuity of carer in maternity services: www.facebook.com/groups/maternityCoC/

22 Care Opinion: www.careopinion.org.uk/

23 The Collaborating Centre for Values-based Practice in Health and Social Care: https://valuesbasedpractice.org/

24 NHS England: Personalised care and support planning guidance: Guidance for local maternity systems - www.england.nhs.uk/publication/personalised-care-and-support-planning-guidance-guidance-for-local-maternity-systems/

25 Midwifery Unit Network: www.midwiferyunitnetwork.org/

26 Campaign to Keep MLU Midwives: https://twitter.com/keepmlumidwives

27 National Voices: Co-production - www.nationalvoices.org.uk/wellbeing-our-way/co-production

What we have been reading:

The House of Commons Health & Social Care Select Committee's latest call for improved maternity services in England.

Julia Cumberledge's address to the recent national event on Better Births Five Years On.

The NMPA's (National Maternity and Perinatal Audit) Sprint Audit on NHS maternity care for women with a Body Mass Index (BMI) of 30 or above.

The NMPA's Clinical Report 2019: Based on births in NHS maternity services between 1 April 2016 and 31 March 2017.

The recruitment material for the next wave of NHS England's service user voice representatives on the Maternity Transformation Programme.

Thanks to all the AIMS campaigns Volunteers who have made all this work possible. We are very keen to expand our campaigns team work, so please do get in touch with campaigns@aims.org.uk if you'd like to help!

There for your mother

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0300 365 0663