VCSE health & wellbeing alliance

Insight report: Understanding lived experience of suicidality during the perinatal period

Introduction

Latest MBRRACE-UK data shows that deaths from mental health-related causes account for nearly 40% of deaths occurring between six weeks and a year after the end of pregnancy with maternal suicide remaining the leading cause of direct deaths in this period[1]. Women were 3 times more likely to die by suicide during or up to six weeks after the end of pregnancy in 2020 compared to 2017-19, with multiple adversity being an extremely common pattern in women who died by suicide and substance misuse[2]. Risk factors for suicide and mental illness in the perinatal period include domestic abuse, substance use, baby loss and pregnancy loss, childhood and/or adult trauma, and experience of children's social care involvement.

As part of the VCSE Health and Wellbeing Alliance, the Tommy's and Sands Maternity Consortium has delivered a range of projects which have engaged with women and birthing people from groups at risk of poorer maternal and neonatal outcomes to understand and share with healthcare professionals the barriers to accessing support and how services can be improved to meet their needs. We have also worked with Birth Companions to understand the lived experience of children's social care proceedings during pregnancy and early motherhood which found a significant impact on women and birthing people's mental health and wellbeing and their ability to trust healthcare professionals[3].

Building on our previous work and in recognition of MBRRACE UK's findings, this project engaged with women and birthing people who have self-harmed, had suicidal thoughts and/or attempted suicide who also have lived experience of domestic abuse, substance use or other forms of trauma to understand these experiences in relation to how support in the perinatal period can be improved and the risk of self-harm and suicide reduced.

1. MBRRACE-UK (2023) *Saving Lives, Improving Mothers' Care 2023* – Main Report https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2023/MBRRACE-UK_Maternal_Compiled_Report_2023.pdf
2. MBRRACE-UK (2022) *Saving Lives, Improving Mothers' Care 2022* - Core Report https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2022/MBRRACE-UK_Maternal_CORE_Report_2022_v10.pdf
3. Birth Companions, Maternity Consortium (2023) *Understanding women's lived experience of children's social care proceedings: An insight report* https://www.birthcompanions.org.uk/resources/understanding-women-s-lived-experience-of-children-s-social-care-proceedings

Our approach

A total of 49 participants were interviewed by the Maternal Mental Health Alliance, The Nelson Trust and YogiBirds between January – March 2024. Participants had experienced suicidal ideation and/or self-harm during the perinatal period and had experiences of domestic abuse, substance use and/or other forms of trauma.

The safety of participants and facilitators was a key priority throughout the project. The Maternity Consortium and all of the organisations involved delivered the engagement work according to an agreed safety protocol, developed with key experts working in the perinatal mental health and suicide prevention space. This included a process of sharing accessible information about the project with participants, asking readiness questions, and discussing together whether participation felt safe and appropriate. In some cases, it was jointly agreed by facilitators and potential participants that it was not safe to continue involvement in the project.

Participants were asked about the support and services they received during the perinatal period and what could have been improved. They were also asked about the barriers to suicide prevention and what good suicide prevention would look like in the perinatal period.

All of the experiences shared in this report have been anonymised and participants have consented to inclusion of their stories in this report.

Who did we hear from?

To decrease barriers to participation in the project, we did not ask participants to complete a demographic form and therefore do not have a full breakdown of participant demographics. A summary is provided below of the information we have on participants' backgrounds to provide context to the findings shared in the report.

Many participants received formal diagnoses from clinical services of depression, anxiety, eating disorders, postnatal psychosis, post-traumatic stress disorder (PTSD), autism, and ADHD. Some instances of depression and anxiety developed postnatally.

A range of lived experiences were disclosed, including baby loss, pregnancy loss, removal of a child, domestic abuse, sexual abuse (including in childhood), and substance use. For some participants, suicidal ideation first occurred before they were pregnant and for others their first experience was during pregnancy or postnatally.

A range of services and support were accessed by participants, including: perinatal mental health teams; duty crisis nurses; counselling; psychiatric inpatient care; Mother and Baby units; acute psychiatric wards; antenatal groups; mum and baby groups; home birth teams; midwives; consultants; GPs; health visitors; third sector support; domestic abuse services; drug and alcohol services; and children's social care.

This report is focused on experiences of accessing support and services in England however, one participant accessed support in Wales. We have included their experience in the report as it provides additional evidence to understand the needs of women and birthing people with complex needs in the perinatal period and how suicide prevention can be improved.

Key findings

Education and awareness raising

The first key theme identified by participants was the need for specific training for all professionals who come into contact with pregnant women and birthing people around suicidality and, more broadly, perinatal mental health, to improve safeguarding responses and processes.

One participant noted feeling dismissed by maternity staff (midwives and health visitors) due to the assumption that the severity of her low mood was down to the *'baby blues'* and would *'sort itself out'* with no formal therapeutic intervention. Another participant shared that she made a GP appointment to discuss her poor mental health and traumatic labour however, the GP dismissed her concerns as she had a '*healthy baby'* which she described as '*so damaging'* to her mental health. Participants felt that if the professionals they had been in touch with were more aware of the prevalence of maternal mental health issues, more support would have been offered at an earlier stage, and potentially reduced the risk of their health worsening.

Other participants shared that, before they reached specialist perinatal mental health services, there seemed to be a lack of understanding as to how to respond to disclosure of suicidal thoughts, with a notable lack of empathy and compassion. One participant shared that, despite professionals knowing of her previous suicide attempts, there was no specific support around this, and she felt that she '*did not exist'* and the risk of suicide was higher because of the lack of support available to her. Another participant described how services avoided using the word '*suicide*' when talking about mental health which made her feel like she could not talk about it either, increasing feelings of isolation.

> *"More knowledge [is needed] from professionals so they don't panic when they hear this is how you feel. You can be a good mum and feel these feelings at the same time."*

All participants shared the vital importance of being taken seriously, noting the potential for increased severity the longer that symptoms are left unaddressed. Early intervention was also felt to be critical, not just for the safety of the mother, but for the safety of the baby and other children as well as the maintenance of the relationship between mother and baby.

Many participants spoke about the need for conversations about suicidality and mental health needs to be opened up to reduce stigma, build trust and provide a safe space for disclosure. However, they felt it was also important that action is taken once disclosure takes place:

> *"Doing something rather than just talking about it. E.g. Find someone who is depressed with something to do, set a routine for them. Showing more action would have been beneficial to me as I found it hard to build those trusting relationships and do these things on my own."*

Some participants also felt that if these experiences were talked about more openly and they knew what to expect, they may have been able to advocate for themselves more when they were not receiving the support they needed. They felt that those with complex needs may find it more difficult to speak up and that this has an impact on care. Those with key workers described the benefit, particularly when domestic abuse was involved:

> *"My keyworker helped to keep everyone updated if I couldn't talk."*

> *"For me, not having my support worker would have made it harder for me to share my feelings with other professionals about how I was feeling. She was able to help them to understand what things were like for me, so without that, I think that would be a massive barrier. I think more people supporting you to have your voice heard and advocating for your needs was such a massive help to me, this would be helpful for every mum to have. Especially if things are hard or go wrong."*

Two participants who used Crisis/Home Treatment Team services noted that there was a lack of understanding about perinatal mental health and the perinatal experience overall. One participant noted that she was given advice that felt '*impossible*' to follow whilst taking care of a new baby, including '*you just need to have a good sleep'*. A different participant, who accessed crisis services when she was pregnant commented:

> *"I was told that it was 'just my hormones', and not offered any support apart from medication. I didn't want to take medication, that was my choice during pregnancy, but it felt like beyond that they just didn't know how to help."*

Participants also felt that professionals focused more on the baby's health, and they would have liked there to be an equal focus on their own physical and mental health and to feel '*seen as a person*' that exists as well as their identity as a mother.

Participants also noted the need for professionals to have an increased understanding of different aspects of their lives that could exacerbate suicidality and create further challenges to disclosure. This includes neurodivergence, particularly the difference between how someone presents vs how they are actually feeling. Much suicide awareness education is focused around recognising a list of 'common' signs to look out for. Although these signs can be true for some, particularly those who are neurotypical, it is of particular importance to be mindful that neurodivergent mothers may not 'perform' emotional distress in the same way that many professionals are trained to recognise. This in turn creates a missed opportunity for intervention.

> *"There are so many ways to have a mind. It's about understanding the way people experience their feelings differently and express their feelings differently. Being suicidal doesn't look the same for everyone."*

Several participants spoke about their experiences of domestic abuse and how professionals need to be aware of the challenges they face as a result, such as finding it difficult to go to appointments and struggling to open up.

One participant described how details of her abuser were written on the first page of her notes by healthcare professionals, serving as a constant reminder and evoking feelings of shame and a need to hide her notes from her current partner. She was told by healthcare professionals that mental health support was not needed and had to explain her traumatic experience multiple times despite information being available in her notes and her requests for no vaginal examinations.

Participants felt that more training was needed for professionals to understand domestic abuse more, be able to signpost to support to help them leave their relationship safely, and to adapt ways of working to respond to these complex experiences.

> *"It all just felt like a very overwhelming time that was frightening. I felt trapped during and after my pregnancy and my relationship was affecting my mental health. I didn't always feel like I could speak to someone as I couldn't always get away from my partner."*

> *"Professionals being consistent and keeping on to try and contact me, even if I couldn't always get back to them because of my partner. I think some services close people if they can't get hold of them and that would have been really difficult for me."*

Participants wanted healthcare professionals to know that they need to feel understood and safe to build trusted relationships with professionals, despite what may be going on in their lives such as domestic abuse, substance use, or involvement from children's social care. This was highlighted by a participant in Birth Companions' 2023 report who shared that women feel 'marked' once they've had a child removed, affecting their ability to disclose their feelings and concerns to professionals.

Participants felt it was a struggle to achieve trusting relationships as appointments were rushed, conversations were '*like a checklist exercise*', and they had to share their trauma with every professional because information was not passed on. However, those participants that had positive experiences described the impact this had:

> *"When I was able to speak up, I always felt supported and felt like people cared. I felt like professionals wanted to help me which helped me to feel less alone in things."*

Judgement, stigma and guilt

Many of the participants spoke about the stigma that exists both when speaking about mental health in the perinatal period and the lack of awareness in mothers and families themselves of what they may experience.

> *"Once I'd had my baby, my suicidal thoughts decreased. But initially, during my pregnancy, I was so scared to speak to someone as I didn't really understand what was happening to me. I think that could be a barrier for lots of mums."*

Participants discussed how mental health is still often spoken about very cautiously within pregnancy with professionals sometimes avoiding the subject, particularly those conditions and experiences that are more severe. One participant with PTSD described feeling like professionals were not listening to her and did not understand how she felt, exacerbating feelings that no one cared.

The difference between awareness raising of physical conditions in the perinatal period, and awareness raising of mental health conditions is notable.

> *"At every midwife appointment I was reminded about the symptoms of pre-eclampsia, told what to look out for in terms of reduced movements, and given information on countless 'what-if' scenarios related to my physical health. Never did anyone tell me what to look out for in terms of my mental health. If they had, maybe my story would have been different."*

Following on from this, participants felt that if they had understood more about what support is available to mothers experiencing perinatal mental health difficulties, they may have felt more reassured about reaching out for help.

> *"I was so terrified that if I said I was feeling suicidal social services would be called, that I never told anyone until I was really unwell. If I'd had known about how much support was available, and how common mental health [difficulties] can be, I'd have spoken up sooner."*

It was also noted that there is often a missed opportunity to raise awareness of poor mental health and support available at an early stage in the maternity journey. One participant had never experienced any mental health difficulties prior to giving birth, and her experiences shocked her so profoundly that she refused support for a long time due to the stigma associated with mental illness. She felt strongly that if mental health had been discussed openly at each contact with maternity services throughout her pregnancy, she would have felt more able to reach out for support when her mental health did start to suffer.

Many participants shared that they felt judged by healthcare professionals due to children's social care involvement, mirroring findings from the Maternity Consortium's 2023 report. They felt that they were being treated differently which directly impacted their care and stopped them from disclosing mental health needs as they feared that their child would be removed. This was exacerbated when substance use was involved with many professionals taking an accusatory and presumptive approach rather than a supportive one.

> *"I was so worried my baby would be removed from my care, it made me want to stay quiet, but also felt like there was no one I could always trust to speak about what was happening when I did want to talk. I felt isolated. Less judgement and reassurance from professionals that if I shared that I was feeling suicidal, they'd support me, not take my baby away. I received support from The Nelson Trust, social services and health visitor. Sometimes I didn't always feel listened to by my social worker and felt worried about sharing."*

> *"…Every experience is different… just because I use drugs, doesn't mean that I'm the same as every other mum who might use drugs. Or the same as another mum who might have mental health issues. I think sometimes judgement from professionals happens because they think they know what I might be going through or my needs already – but they don't. Being able to explain what my needs are and have them heard as an individual made a big difference to me."*

In addition to stigma, several of the participants spoke of the strong sense of guilt they felt whilst battling mental health challenges, particularly postnatally.

> *"I found being pregnant really challenging and sometimes it felt like there was pressure for me to be happy all the time when I wasn't. It got better after I had my baby, but there were still really difficult moments and I felt a lot of shame around this from some professionals."*

Much of the judgement participants experienced was also related to their transition into parenthood with some describing how they struggled to pick their baby up and did not know how to change them. One participant's baby was born with some health issues and struggled with feeding, the baby cried throughout the night during their stay in hospital which made her feel anxious and guilty for keeping others awake. The mother felt that she and her baby did not receive adequate support which impacted her mental health and made her feel like she was not coping. She described feeling like she was '*no longer human*' as she was not offered mental health support, despite her previous experiences with suicidal thoughts and mental health issues.

Another participant spoke about feeling that she was *'a nuisance'* and *'creating trouble'* when she was engaging in self-harming behaviour and feeling actively suicidal. On reflection, she believes that the pervasive stigma around mental health, led her to feel this way, and now reflects*:*

> *"I wasn't being 'trouble', I just had a troubled body and mind."*

The combination of judgement, stigma and feelings of guilt meant participants did not always feel safe to disclose their needs and seek help. Almost all of the participants spoke about pervasive feelings of guilt in sharing their reality, that became a significant barrier to receiving the right support at the right time. They mentioned feeling like *'a burden'* to others and fearful of the outcome of disclosure of suicidality.

> *"When I finally told a health visitor how I was feeling she looked so horrified and panicked that I immediately backtracked and felt I had to convince her that I was fine. I wasn't fine."*

Many wanted to be asked by professionals how they were feeling and coping, particularly during the postnatal period, but either were not asked at all or were not asked in a compassionate manner. In some cases, the inability to disclose reinforced feelings of isolation, creating a vicious cycle:

> *"Feeling judged or that no one cares. Also, when I isolate, this gets harder to open up."*

Participants felt that clear and compassionate communication about the realities of mental health difficulties during the perinatal period, the support and services available to them, and the creation of a safe space to disclose would have helped them.

> *"…Although I love my baby, it has been a really challenging time for me… I wish I didn't need professionals involved at times, as it makes me feel like people feel I'm not coping. So sometimes some reassurance can be helpful that you're doing a good job. That it's okay to feel difficult things and it doesn't mean you're not a good mum."*

> *"…all women struggle and that support there is there for a reason – it's there to help. I struggled so much during my first pregnancy, because I didn't feel like I could be honest. In my second pregnancy, this has felt so different. I've felt able to open up to those who want to help me. Having a professional ask those open questions without judging me has helped me to open up without judging myself. During my first pregnancy, my barrier was my own feelings about opening up. I felt so badly about what I was feeling and so much judgement on myself, that it put me off. That was my biggest barrier."*

Those participants that felt supported with their mental health spoke of professionals around them being '*so Kind*', '*really understanding*', '*compassionate*' and that there was continuity in their care.

Trauma awareness

Trauma awareness was a topic which was frequently raised, with participants discussing historical trauma, as well as birth trauma. It was generally felt that there was a lack of understanding of the deep impact of this and, again, calls for improved training to raise understanding and awareness in this area.

> *"My pregnancy was referred to again and again as being a 'risk factor' for me, and the reason I felt the way I felt, but no-one bothered to look at what else was going on in my life, and the reason why my mental health was so fragile to begin with."*

The need for individualised holistic care was mentioned by most participants, with a focus on understanding that someone's mental health could be impacted by a multitude of events, many 'hidden' and not just the obviously presenting transition to parenthood. This included experiences of pregnancy and baby loss; marriage breakdown; domestic and sexual abuse; substance use; children's social care involvement and financial difficulties. Participants noted these experiences as having a significant impact on mental health, however there was little to no exploration of this as being a contributing factor to suicidality.

For healthcare professionals, exploring the reality of someone's life, beyond being pregnant or postpartum, is vital to understanding the *'bigger picture that might have been building up for some time'.*

> *"Mental health is rarely the only factor. You have to dig deeper."*

> *"I was really frightened during my pregnancy. I'd had children removed from my care previously, due to my mental health and an abusive relationship I was in. I was scared that the same would happen again. I felt really anxious through my pregnancy and felt that there was a lot of judgement about my previous experience as a mum. I felt frustrated that this was being used against me. My suicidal feelings didn't go away when I was pregnant and I felt frightened about how I was feeling, as I didn't want to lose my baby. I wish I felt safer to share how I was feeling and get the right support, instead of feeling like a failure."*

One participant described how she was scared that her baby would be removed from her care despite there being no social service involvement in either of her pregnancies or after birth. However, her previous experience of being fostered herself as a child, traumatic births and mental health challenges meant that she struggled with this fear.

Another participant's GP had records of previous trauma, self-harm, depression and suicidal ideation which was not shared with her maternity team. She felt she was treated poorly because she is a Muslim woman and '*fobbed off*' when making requests based on her history of sexual abuse, such as asking for female healthcare professionals and for her husband to stay with her. Once her self-harm scars were exposed, she was moved to a private room and some of her requests were accommodated despite previous rejections. Despite this, she was not asked about her mental health and was discharged after birth with no further support.

Pregnancy and baby loss was also identified as a traumatic experience which needed to be handled better. One participant had a previous traumatic miscarriage which made her anxious during her pregnancy. She did not receive any support or further information about her 'high-risk' pregnancy, heightening her anxiety. Another participant who experienced depression, PTSD, suicidal ideation and anxiety in relation to baby loss felt there were quite a few occasions when a healthcare professional had said something '*that* stung' without realising because information had not been passed on:

> *"It just feels that there must be a better way than it needing to come down to the patient to explain what has happened; I have been working with a baby loss councillor who provided cards that you can fill in to handover when you get to an appointment to explain your history and any different requirements you may have, I haven't used them (and perhaps I should have!) but my expectation is that it would be clear and easy for someone to see on my records."*

Despite this, she felt that there were unexpected moments of people taking time to be compassionate that really stood out to her:

> *"One was when my consultant came to see us while we were waiting for the induction to kick in, I wasn't expecting that and it meant a lot. The other was the lady bringing us food, it was something silly like sneaking me some extra biscuits and bringing loads of flavours of yoghurt as she really wanted me to like it… thinking back about this has actually made me cry because I think sometimes people don't realise the positive impact they have from seemingly small acts."*

Another participant described how a previous miscarriage was discounted by a healthcare professional leading to them feeling '*invisible*'. Participants who experienced pregnancy and baby loss described how being in waiting rooms and on wards was '*traumatic*' and *'undignified'* and felt they needed a dedicated space so as not to be re-traumatised. Those who had been supported by baby loss specialist mental health practitioners and community-based groups felt they could heal safely and expressed a desire information about pregnancy and baby loss and how they might feel to be made available.

With regards to birth trauma, participants noted the importance of healthcare professionals having improved understanding that although a birth may look *'straightforward on paper'*, that does not mean that the experience of it is not traumatic for someone.

One participant did not get offered a debrief even though her birth had been extremely traumatic for her and had a significant and lasting impact on her mental health. Another participant noted, on reading their maternity notes at a later date, they were referred to as '*managing pain well*' which shocked them:

> *"I didn't feel I was managing the pain well at all. I felt terrified and that fear didn't leave me for a long time".*

One participant described how they felt unprepared for their traumatic birth, and this led them to feeling '*like a failure'* and that they '*had done something wrong'*. Another noted the surprise they now feel that the impact of a traumatic birth, and the potential for PTSD was never raised with them in the aftermath of the birth and subsequent severe mental health difficulties they experienced.

> *"Even after my car-crash of a birth, PTSD was never brought up. No-one ever spoke about it."*

Empathy and compassion

Participants noted the importance of *'soft skills'* in professionals such as empathy and compassionate communication. Compassion was seen as the biggest factor in feeling seen, safe and supported. Participants spoke of the vulnerability they felt at the time they were experiencing suicidal ideation, and the profound impact that kindness and authentic connections had on them.

> *"I still remember now being offered a cup of tea and a touch on the hand, and the kindness I felt in those gestures when I was at my lowest ebb."*

While participants provided examples of one-off interactions that were compassionate and empathetic, many noted consistency in careas being essential to invest in and build positive relationships, however the challenges of doing so were recognised.

> *"I saw four or five different midwives during pregnancy, and then when I was referred to the crisis team after giving birth it was someone different almost every day. It was impossible to build a relationship with any of them, and the trust was never there. So I never shared how I really felt."*

> *"I think more consistent contact from professionals to help me while I was struggling. I feel like I wasn't able to be honest about what was happening and how I was feeling. Sometimes it didn't always feel like they were interested in how I was doing, just about the baby – this was hard."*

Several participants noted the importance of looking beyond risk assessment within a contact. Some shared that it felt like during each appointment with mental health services (some specialist perinatal, some general mental health), although generally positive overall, could feel like *'tick box'* exercises.

> *"They felt very result driven at times, as though the staff just wanted me to say that I was able to keep myself safe, and not interested in continuing the conversation beyond that. People didn't often try to understand why I was feeling the way I was feeling in the first place."*

This was also evident for participants experiencing domestic abuse with one participant being asked questions about her abuser such as '*Have you seen him?*' and '*Do you know what to do if you see him?*' rather than '*How are you doing?*' and *'Are you feeling OK?'*. This made her feel invisible and in '*constant fear of social services*'.

Throughout all of the conversations, the importance of being listened to, and *'truly heard'*, came up frequently.

> *"I feel that it depends on what is going on with them, professionals can approach them based on their needs and understanding what each of their needs are. Also, having patience and understanding with them is important. Being kind and giving them time, hearing how they feel, listening to them and understanding how they are feeling. Not making them feel that they are a failure and not making them feel wrong about their decisions. The right and consistent support. Especially for women who lose their child at birth. You need to allow them time. Being kind and understanding what the person has been through, the support you get makes a massive difference."*

Participants noted the stark difference in outcomes when they were treated with compassion and empathy at their most challenging moments.

> *"I was always more likely to self-harm if I felt I wasn't listened to or understood".*

A participant with experiences of domestic and sexual abuse described a wide range of experiences with different healthcare professionals during labour. Some midwives were compassionate and kind, helping her to feel safe and relaxed, whereas others made her feel that she was '*a nuisance, alone and unsupported*'. This was exacerbated by different responses to her history of sexual abuse:

> *'The midwife that took the pessary out was really rough, I felt assaulted. She wanted to do a vaginal examination and I was very uncomfortable, she said 'If you don't let me do it, someone else will'. It felt threatening, like maybe a man would do it, I let her reluctantly. I felt coerced again, it was tense and painful – I felt worn down, I felt scared and intimidated, that's why I let her. I ended up going down for a c-section – the team were amazing, made me feel so safe and relaxed, laughing, a nurse whispered in my ear 'don't worry, you'll get a catheter, I will do it, no one else' I knew she had seen my notes – it is the only time I had felt seen – I still remember her face, she was so kind and I felt so safe…the team they made me feel like I mattered.'*

Another participant shared the impact of the relief they felt when they finally reached a professional (a mental health nurse) who took the time to really listen, when they presented at A&E.

> *"I had spent so long asking for help, and not being heard, that to be listened to, believed and taken seriously was such a wonderful relief, and that was the point I knew we were going to be okay."*

Inconsistent support and complex referral pathways

Inconsistent support and a lack of clear and consistent referral pathways was noted as being a significant barrier to receiving the right support at the right time.

> *"I needed quick access to mental health services and active listening from professionals was impactful for me. This is something I think all mums need. I think there are too many rules and regulations for mums. I also think there's too many processes and protocols to follow, which can be confusing. I also think safeguarding can be poor and often confusing as to why professionals make the decisions they do. I think that a mum should be allocated straight to a team, so they don't have to wait. I think professionals need to act fast - go and see the person, listen to their needs. That has been helpful for me when it has happened."*

Some participants shared that, before they reached specialist perinatal mental health services, there seemed to be a lack of understanding as to how to respond to disclosure of suicidal thoughts; where they ought to be referred to, when, and how.

> *"I went in front of two healthcare professionals, and said exactly the same thing, and had two totally different responses and outcomes."*

Although it should be acknowledged that all participants received care at different times, and in different localities and service variables should be accounted for, the variation in response to a first disclosure of suicidal thoughts remains notable.

One participant was told by their GP that a letter would be written to a psychiatrist in a general mental health team, other participants were advised by health visitors to present at A&E for assessment, and one was immediately referred by a midwife to the crisis team.

> *"Getting a service that would help. All I had was an assessment in the hospital, I was then told referrals would be made and someone would get back to me within a week, but no one did. I felt totally isolated and alone."*

At a time when early intervention is vital, complex and lengthy waiting times as well as poor communication between services and healthcare professionals can make a significant difference to outcomes.

> *"We were stuck waiting because the referral pathways were such a mess. I went to A&E and was told by a nurse 'you need to go to an MBU, but I can't send you there, but I have got you an appointment with a psychiatrist in the morning'. So I went to see the psychiatrist and was told 'you need to go to an MBU but I can't send you there, I've got to refer you to the HTT'. I went to the HTT and was told 'you need to go to the MBU, but that can only be done by another member of staff'. When I finally got to an MBU it was two whole weeks later."*

The lack of consistency in mental health support only exacerbated a scary and vulnerable time. When services did not follow-up with participants, provide adequate support, or had a long waiting list, some participants felt worse and wished that they had not disclosed their needs.

> *"I was told I would be referred to a nursery nurse, this still hasn't happened 8.5 months now. I also have been told I was being referred to support groups and a psychologist and have not heard anymore, it's a struggle with my anxiety when you are waiting and it doesn't happen."*

Examples of good practice involved professionals acting quickly. One participant who was pregnant for a second time after experiencing postnatal depression after the birth of their first child shared:

> *"I felt very anxious when I found out I was pregnant with my second child, after what I went through the first time. When I told my GP, I was referred straight away to the perinatal mental health team. I had regular appointments in the lead up to the birth and we worked on a care plan that would be put in place if I felt suicidal again. Although I did experience PND again, it was not as severe, and I felt well supported throughout."*

> *"The care post-birth was less consistent, a couple of months in I had thoughts of harming the baby. I immediately informed the perinatal mental health team and I received a home visit from a specialist who was very helpful and encouraging."*

Another began to have suicidal ideation during her pregnancy and felt safe enough to disclose to the home-birth team who were described as '*amazing'.* The duty nurse then called her, and she felt seen and safe through regular check-ups.

However, many participants described not being asked about their mental health and wellbeing at all; not receiving any mental health or parenting support despite their being a need; not being told what support and pathways are available; and care dropping off in the perinatal period. One participant described how even when support was put in place as a response to knowing about mental health issues before pregnancy, at time it was felt that it was lacking due to a lack of resources, particularly low staff levels, and therefore support didn't always feel effective.

Many felt that safe and appropriate support needed to be available and that this should be in place before the baby is born.

> *"I only started to experience suicidal feelings during my pregnancy, and hadn't really had them before. My pregnancy was hard. I think support for me was reassurance that what I was feeling was validated and that I wasn't 'crazy'. Support to understand more about how to cope and things I could try to help myself, as well as support from others."*

> *"I now have the mental health team involved in my care and I think it would have been helpful to have more support from them during my pregnancy."*

> *"I've had scares and struggles postnatally, I didn't bond with my baby or love her immediately. I have tried to speak to perinatal mental health to express my concerns, I was told 'because you were ok in pregnancy you are not a cause for concern' trying to get an appointment is a nightmare, I have been waiting 10 months."*

One participant who experienced varying levels of support in her pregnancies described the difference in outcomes:

> *"…Having as much support around you as possible is helpful, especially if you're a single mum. Previous pregnancies I had no support, but this time I had a lot of people around me who really cared. That helped so much on hard days. It helped me to feel like I could open up."*

Flexible consistent support tailored to individual needs was found to be crucial for women and birthing people with traumatic backgrounds experiencing suicidal ideation during the perinatal period. Existing models of care and types of support were not always felt to meet the complexity of need presenting in this group of women and birthing people, particularly as needs and risk change over time.

> *"Keep asking mothers questions. Someone's support needs change all of the time and everyone needs different support. Sometimes risks change and things get worse, sometimes things get better, support should adapt to this."*

One participant described how 'traditional' support such as talking therapy did not work for them:

> *"I hate talking therapy, it feels too intense and I feel really uncomfortable. I did not feel relaxed or safe."*

Support from the third sector, including keyworker support and peer-support groups, was described by participants as extremely beneficial, highlighting how these services need to be funded and seen as a key part of the referral pathway. Notably, building friendships and connections in groups were described by participants as promoting safety and healing.

> *"I have felt suicidal on and off for a very long time and for me, it's encouragement to join into things that helped, otherwise I keep myself away from everyone, which is when it gets worse. Being able to attend groups at the women's centre, which helped me to build confidence going to other groups."*

> *"Groups were the best thing, they really helped me feel supported, walks and chats with other mums and talking to other mums who have been through it, getting out of the house…being compassionate to others helps you."*

What needs to change?

> *"Honest and curious professionals who want to understand what's going on for me and my baby, not just my baby. Supporting me to be a good mum, whilst addressing my needs."*

Participants were asked for their views on changes needed to improve suicide prevention during pregnancy and the first year after birth. It is important to note that throughout these interviews, there was an understanding and an appreciation that the vast majority of individual professionals are doing the best job they can, with the resources and time that is available to them. No one apportioned blame on any one individual or service, instead there was a broad understanding that many services are underfunded, understaffed and under resourced. This is, ultimately, a 'big system' issue which needs to be addressed.

> *"It goes all the way to the top. Staff cannot provide the standard of care that is needed with the pressures they are currently under."*

In addition to seeing services properly funded, staffed and resourced, participants identified specific actions they felt would hugely improve care if implemented:

1 Improved training for professionals

This training should look at improving awareness of suicidal ideation in the perinatal period for all professionals that come into contact with pregnant women and birthing people and new mothers. Topics of particular importance include understanding trauma, substance use, domestic abuse and neurodivergence, and the skills of compassionate communication. This is particularly important when it comes to creating an environment where open and honest conversations can be held, free from stigma and judgement.

Crucially, any training that is developed should be co-created and co-delivered with people with lived experience of suicidal thoughts and/or attempts in the perinatal period, to ensure authenticity.

2 Improved education for mothers and families

An 'everyone's business' attitude should be adopted, with all professionals connected to maternity services understanding the role they can play in raising awareness, reducing stigma and encouraging early intervention for those experiencing suicidal thoughts and behaviours in the perinatal period.

Rather than feeling anxious about 'scaring' new mothers by sharing facts around maternal mental health and suicide, open and authentic conversations should be had at a frequency whereby speaking about mental health becomes the norm.

3 Analysis / evaluation of current support and referral pathways

Throughout the report, we have shared how participants felt that they needed more and consistent support tailored to their needs and prior experiences. It was also felt by participants that effective multi-agency working would improve consistency and help manage transitions between services throughout the perinatal period.

It is therefore recommended that an analysis and evaluation of current national policy, referral and support pathways, and multi-agency working related to suicide prevention in the perinatal period take place. This would help to better understand what already exists and needs to be built on and embedded further as well as where future work may need to be focused to ensure that the risk of suicide and self-harm in the perinatal period is reduced. Mothers and their support network should be clear on where they can seek support if their mental health or suicidal thoughts and feelings do cause concerns and, although the third sector cannot be over-relied upon, professionals should also be able to signpost to voluntary organisations using existing tools such as the Hearts and Minds Partnership map of services.

Accessing support

Samaritans

When life is difficult, Samaritans are here – day or night, 365 days a year.
You can call them free on **116 123** or visit samaritans.org.

Whoever you are and whatever you're facing, they won't judge you or tell you what to do.
They're here to listen so you don't have to face it alone.

Tommy's

If you would like to speak to a Tommy's midwife about your pregnancy, or need support and advice following a pregnancy loss, you can contact the team at midwife@tommys.org.
You can also call them for free on **0800 014 7800** (Monday to Friday, 9am to 5pm).

Sands

The Sands National Helpline provides a safe, confidential place for anyone who has been affected by the death of a baby. Whether your baby died long ago or recently. Call **0808 164 3332**. The team are available to speak to from 10am to 3pm Monday to Friday and 6pm to 9pm Tuesday, Wednesday and Thursday. The helpline team can also be contacted at helpline@sands.org.uk.

Acknowledgements

We would like to thank the participants for giving their time to this project and sharing their experiences with us to inform policy and practice development which supports women and birthing people experiencing suicidal ideation in the perinatal period.

About the Health and Wellbeing Alliance

In 2021, the Voluntary, Community and Social Enterprise (VCSE) Health and Wellbeing Alliance was established. It is a partnership between sector representatives and the health and care system, led by the Department of Health and Social Care, NHS England, and the UK Health Security Agency.

The Health and Wellbeing Alliance is a key element of the Government's VCSE Health and Wellbeing Programme, enabling the voluntary sector to share its expertise at a national level with the aim of improving services for all communities.

About the Tommy's and Sands Maternity Consortium

As part of the Health and Wellbeing Alliance, Tommy's and Sands co-lead the Maternity Consortium which aims to use our collective expertise to join up national and local voices behind a common agenda: to reduce health inequalities for families throughout the whole pregnancy journey from pre-conception and through the first year of a baby's life. Our members include: National Maternity Voices, the Pregnancy and Baby Charities Network, Five X More, LGBT Mummies, and the Muslim Women's Network UK. The Maternity Consortium is funded until March 2025.

About the Maternal Mental Health Alliance

The Maternal Mental Health Alliance (MMHA) is a UK-wide charity and network of over 130 organisations, dedicated to ensuring all women and families affected by perinatal mental health problems have access to high quality compassionate perinatal mental health care and support. We believe we have most impact through collective influencing and our national network spans community grassroots organisations, academics, national charities, clinical experts and Royal Colleges, and always includes our Lived-Experience Champions – a UK-wide network of people impacted by perinatal mental illness. We support our Champions to share their experience to raise awareness and influence changes in policy and practice.

The MMHA is a convenor, bringing this community of individuals and organisations together; a movement to build agency, leadership and capacity to make change for the better.

About The Nelson Trust

The Nelson Trust's Women's Community Services span across Gloucestershire, Wiltshire, Somerset, Bristol, and Wales. We also have a first-of-its-kind Women's Centre inside HMP Eastwood Park. Services are trauma-informed, gender responsive, and provide holistic support for women and their families.

As part of our women's centre in Gloucester, we have a Peri-Natal Mental Health project. We provide intensive wellbeing support to women through their pregnancy and postnatally until their child reaches age two. We work closely with partner agencies, including midwifery and social care, to provide wrap around support to mums who need it.

About YogiBirds

YogiBirds Yoga & Mindfulness is run by Kate Forde, a trauma - informed yoga & mindfulness teacher and perinatal Senior Birth Educator. YogiBirds offer pregnancy, postnatal and mum & baby yoga group sessions within the local community as well as workshops and retreats. All are dedicated to supporting women and their families through the perinatal period and beyond and working to improve the health and outcomes for all women.