

University of Dundee

Working together to improve perinatal mental health in Scotland

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DOI:

[10.20933/100001291](https://doi.org/10.20933/100001291)

Publication date:

2023

Document Version

Publisher's PDF, also known as Version of record

[Link to publication in Discovery Research Portal](#)

Citation for published version (APA):

Gray, N., Farre, A., Cumming, S., Biazus Dalcin, C., McFadden, A., Marryat, L., & Shinwell, S. (2023). *Working together to improve perinatal mental health in Scotland*. University of Dundee.
<https://doi.org/10.20933/100001291>

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Report: Working together to improve perinatal mental health in Scotland

August 2022



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Organisations involved:	
<p>Dads Rock, providing support to Dads and families across Scotland.</p> <p>Parenting Across Scotland, a partnership of charities supporting families across Scotland.</p> <p>HomeStart, supporting the most vulnerable families in a multitude of ways.</p> <p>NHS Tayside - Perinatal and Infant Mental Health team</p> <p>MECOPP Minority Ethnic Carers of People Project</p> <p>PND and Me, Perinatal Mental Health Peer Support and Awareness</p> <p>Alternatives Dundee, providing counselling and support for those affected by pregnancy choices, abortion, miscarriage, infertility or stillbirth.</p>	

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Background: Perinatal mental illness and distress: What is it and why is it important?

The period just after giving birth is a critical time for mothers, fathers, and babies. Estimates of the incidence of perinatal mental illness and distress suggest that 10-20% of women will experience mental health problems during pregnancy or in the 12 months after birth.¹⁻⁴ It is estimated that up to 10% of fathers may also develop mental health problems during this time,⁵ an issue that has recently been addressed by the [national media](#). The consequences of poor mental health and distress in women can be catastrophic: mental health disorders are the leading cause of direct maternal death in the 12 months after birth.⁶ Whilst for babies, poor parental mental health can lead to adverse childhood experiences, which may have far reaching impacts on the physical safety and mental development of children.^{7,8}

PNMH incorporates a wide range of experiences from pre-existing mental health disorders, to pre and post birth anxiety and depression, birth trauma and pregnancy bereavement. Early and appropriate intervention is desperately needed to help those at risk of developing mental health disorders, and those with existing mental health problems to prevent further deterioration.

A 2019 perinatal mental health services needs assessment report put forth a list of 28 recommendations.⁴ The recommendations included a need for all NHS boards to have community specialist perinatal mental health provision and a parent-infant mental health lead to co-ordinate evidence-based interventions. The Scottish Government (SG) committed £50 million to the improvement of these services and a Perinatal and Infant Mental Health Programme Board was established in March 2019 to drive forward the implementation of the recommendations and oversee and manage the £50 million investment. In addition, a parliamentary Inquiry into perinatal mental health⁹ published this year (February 2022) lays out 55 recommendations, with a particular focus on early identification of perinatal mental health issues and how services should be designed and delivered. The provision of integrated care, across sectors, provided by a well-trained workforce was deemed critical.

Clearly there is a societal, service, community and individual need for improved perinatal mental health care.

The issue: how to design, implement and evaluate service changes

NHS boards have been tasked with delivering better perinatal mental health care. Many have started to develop and implement changes in services, some more quickly than others. For these changes to be successful, by which we mean delivering better outcomes for families in a sustainable and scalable way, there is a need to understand the gap between what is needed and what is currently being delivered and the context within which these services are being delivered and received.

Intervention mapping and developing a logic model of the problem

Intervention mapping provides a framework for theory and evidence-based changes in health care planning and implementation, adopting an ecological approach to understand complex interrelationships across multiple levels (eg, individuals, organisations, communities).¹⁰⁻¹² The intervention mapping approach has six stages: 1) logic model of the problem, 2) logic model of the change, 3) programme design, 4) programme production, 5) implementation plan, 6) evaluation plan. We used an intervention mapping approach to help elucidate the key needs of stakeholders and to co-create a logic model of the problem (stage 1) by developing a stakeholder workshop event to discuss the main concerns around perinatal mental health in Scotland.

Summary of Workshop

We hosted a stakeholder workshop which included eight external representatives comprising representatives with lived experience of perinatal mental health problems, health providers and health professionals involved in the care of families, third sector organisations involved in pregnancy, family and early years support, and six research staff. The workshop was hosted on 8th June at the University of Dundee by the Mother and Infant Research Unit (MIRU).

The workshop used interactive activities including individual and collective analysis of perinatal mental health issues/challenges, storytelling, and discussing barriers, challenges, and possible solutions to address perinatal mental health needs. Graham Joe Ogilvie is a graphic artist who helped to capture these conversations as they happened, and later the images were used to stimulate reflection amongst participants and share their thoughts on the images. Some of the images are available in this report. Finally, participants were asked to identify those image(s) that they felt most reflected their thoughts and the conversations of the day.

The conversations led to the sharing of information, enabled networking, and collective examination of the issues, and all participants expressed interest in further collaborations with MIRU.

Workshops findings

The discussions focussed on issues around individual concerns related to revealing feelings and experiences, specifically feelings of fear of being judged, isolation, not meeting societal expectations, and peer pressure. There was also discussion around not feeling well enough informed about what to expect in the perinatal period or where to find help and support. Challenges related to breastfeeding, birth trauma, pre-existing mental health issues and medication, and relationships were also raised. The feedback from attendees was that the workshop was timely and that there is scope and a need for further work in the field of perinatal mental health.

This report uses some images produced by the graphic designer and direct quotes from participants to illustrate the main points of discussion. The main themes that emerged during the workshop discussions were: barriers to accessing support, the impact of barriers on marginalised communities, exploring solutions through collaborative working, peer support and a family centred approach.

Theme 1: Barriers to accessing support

Stigma

This stigma around mental health we need to break it, we need to break these barriers. (Participant)

Women are still dying, women are still dying by suicide. It is still the leading direct cause of death in the perinatal period and that just should not be. In this day and age, people should not be dying because they are too afraid to talk about their mental health and children are left without their mothers because women aren't talking about it. Because we're not talking about it. We're not talking about it because we're afraid to talk about it' (Participant)

Stigma around perinatal mental health was identified by participants as a significant issue. Stigma was located at a wider social level and in general stigma around mental health. In the context of PNMH, stigma was seen as related to the social expectations and pressures that many new mothers encountered. Social media was identified as a key factor in perpetuating unrealistic social expectations of parenting. False images of 'perfect parents' on social media cause parents to mask their struggles and real feelings, deepening the stigma with PNMH. Participants discussed the internalising of this stigma and social pressures of 'perfection' as creating a barrier to accessing support. Discussion focussed on the consequential culture of fear and shame around PNMH and the perception of 'failing' at parenting by 'not coping'.

Figure 1 - Impact of Stigma



Language Exclusion

A further barrier to support was rooted in language. Participants engaged in wide ranging debate around the potentially exclusive nature of maternity services due to the very word 'maternity'. The focus on heterosexual labels of mother and maternity services, automatically excluded the LGBT+ community, but also fathers and kinship carers. This barrier was discussed as significant in the searching for support phase. People struggling with mental health during pregnancy, or post birth, could potentially miss out on support by not 'seeing themselves' represented in either the images or the language of the service. This caused exclusion, as parents felt this was not a service they could access. The use of identifying pronouns in maternity care apps and forms was celebrated as a successful initiative to overcome language exclusion but honest conversations were still seen as lacking. The need to promote a culture of 'asking and not assuming' was discussed as essential in overcoming this barrier.

Figure 2 - Language and exclusion



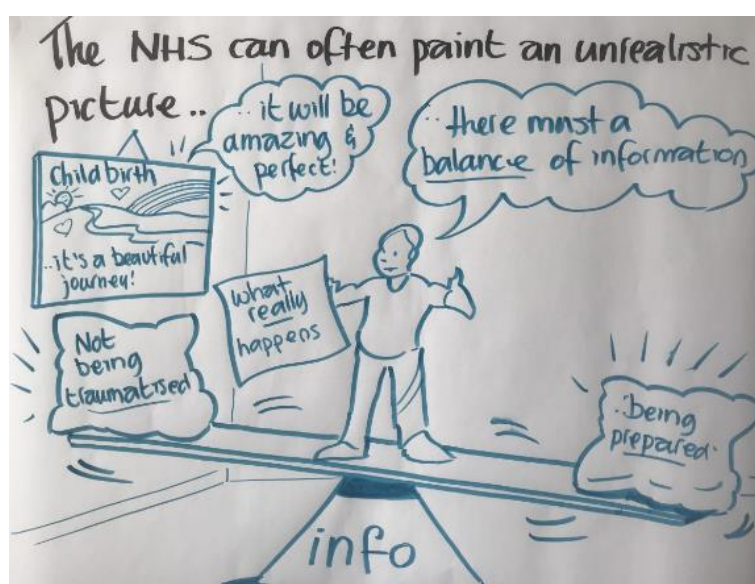
Inaccessible Services

Quite often we don't tell people what's available and then you expect an ill person to go out and find the support that they need when you're not in the position to go out and look for it. (Participant)

The NHS wants to paint this image that it will be a beautiful journey and they want to talk about the positives. And sometimes there's a sense that the NHS doesn't talk to parents as adults but talks them as these people who don't know anything and we're the specialists giving you some information and quite often families are really frustrated with the lack of information and a lot of families feel unprepared.....so there's a real balance between giving people enough information so we're not traumatizing them, but giving them information so that they've got knowledge and they're prepared. (Participant)

Inaccessible services was raised as a key issue for discussion. This inaccessibility was mostly discussed on a physical level with services being hard to access due to the onus being placed on the unwell birthing person to access support. Group discussion identified a lack of information from the NHS that was realistic and helped parents prepare for the possibility of developing perinatal mental health needs during pregnancy or post birth. This was thought to result in parents then having to 'go out' and find information and support, and access new groups at a time when they were feeling vulnerable. Solutions to overcoming this barrier were identified in simply ensuring all sources of support were discussed prior to birth so parents were aware of where to turn if needed. Additional physical barriers to support were discussed for those who live rurally, or digitally excluded, as well as the challenges of the 'postcode lottery' of services within the NHS.

Figure 3 - Inaccessible services



Family Exclusion

When we become pregnant, and I went to the booking appointment, I had made this stupid assumption to think that the NHS would come around us and cocoon us, naively, in this pregnancy thing that was going to happen. And I was amazed at how sort of hands off it felt at the time. (Participant)

It's not just about educating the pregnant person. It is about educating the entire family unit of what perinatal mental illnesses are. (Participant)

A cross cutting theme identified through the whole event was the notion of 'it takes a village to raise a child'. The family was seen as both affected by the problem and an important part of the solution (see theme 3 below). The absence and exclusion of the family as a consideration in PNMH was identified by participants as a barrier at the level of service delivery. PNMH was seen to impact all members of the family, including the baby, and therefore their exclusion from both analysis of the problem and the solution was seen as detrimental. Perspectives from the community PNMH team discussed the need to break the 'generational impact' of PNMH on families and their inclusion in treatment was centred on the notion of 'preventing future patients'. Promoting stable and secure

families was seen as essential to the creation of stable and secure children, especially with regard to infant bonding and development.

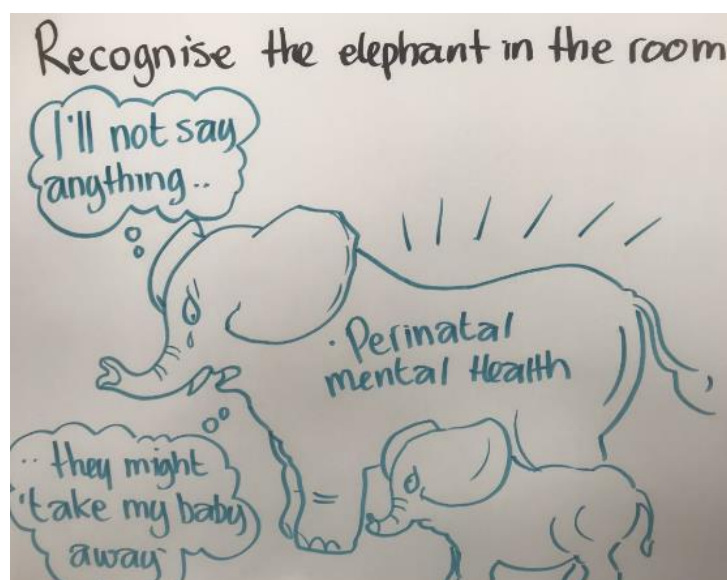
Figure 4 - Family exclusion



Fear of support

Families with existing social services involvement, especially those in the cycle of looked after child to future service involvement, were seen as especially vulnerable to fear of seeking support. Anonymous real-life examples were discussed where families were 'muddling through' for fear of seeking support with perinatal mental health in case this impacted their parenting capacity assessment with social services. Both third-sector organisations and members of the NHS PNMH team agreed that this only resulted in deteriorating mental health. Early intervention by breaking this stigma was identified by the participants as essential to improve perinatal mental health.

Figure 5 - Fear of support



Perception of not being 'ill enough'

I wouldn't have been eligible for the specialist services because I wasn't ill enough. But that that meant that I suffered for longer. (Participant)

At the level of the individual, there was strong agreement amongst participants that there was a gap in services for those deemed as having mild to moderate PNMH needs. This service gap resulted in individual perceptions of 'not being ill enough' to qualify for specialist service support. Real life examples were discussed where women were 'flying under the radar' because they were not deemed 'ill enough'. Continuing to function on a day-to-day level despite mental health challenges, was discussed as being related to earlier identified themes of social stigma and fear of being seen not to be coping. One participant shared her experience of not being 'ill enough' which resulted in suffering in silence and suffering for longer. However, from the community PNMH team perspective the need for strict criteria was seen as important to ensure service delivery to the most severe cases.

Figure 6 - The concept of not 'ill enough'



Theme 2: Impact of barriers on marginalised communities

There's still this idea within health services that you treat everybody the same, but it's not about equal care it's about equitable care, and sometimes you have to put in that bit more effort, even if it's a really small minority of people, because actually that's how they get lost in the system. That's how they have terrible outcomes because people don't understand them. (Participant)

In terms of Gypsy/Travellers and their mental health, they're twice as likely to have anxiety or depression. A mother is 20 times more likely to have lost her child. (Participant)

Good representation of the Gypsy/Traveller community was achieved at the workshop and specific cultural issues were explored in relation to their impact on PNMH. The MECOPP participants discussed the social expectations in the Gypsy/Traveller community on young women and the role of the mother as contributing to heightened fear and shame within the community with PNMH. Young girls are raised to 'expect' to be mothers as part of their social roles, and to admit they are not coping with this role is to challenge the core of their cultural identity. Even the language of PNMH was challenged as not easily understandable or culturally translatable to the Gypsy/Traveller culture as many women would not even identify themselves as struggling with mental health. Instead, it was suggested that women would be more likely to present with anxieties around housing, rather than identifying the underlying cause of social isolation.

This lack of identifying with the label of PNMH was also discussed from a cross cultural perspective within BAME communities where mental health was sometimes not recognised or culturally acceptable. Real life examples were given from the community PNMH team of working with BAME families from certain cultures that did not 'allow' mental health to be discussed. In one example of puerperal psychosis, the family did not want the woman to be admitted to a mother and baby unit due to the stigma and social shame within their wider community. The need for collaborative cultural working to break down barriers and have open discussions around these clashing frameworks was discussed as essential in delivering safe care.

As already identified above, the exclusion of certain groups through language poses an extra challenge to marginalised groups, especially the LGBT+ community who often feel excluded on the basis of the gendered language of services.

Furthermore, the fear of being seen not to be 'coping' was highlighted as a key issue, especially amongst marginalised communities perceived to have existing labels already such as young single mothers. A mother with lived experience of this shared her initial rejection of acknowledging her mental health struggles because she did not want to be fulfil the stereotype of being 'another young mum who couldn't cope'.

PNMH is a serious challenge for anyone, but those from marginalised communities were seen as especially vulnerable to all the identified themes of stigma, fear, exclusion and barriers to services. The recent 'five times more' survey¹³ after the 2019 MBRRACE report¹⁴, has placed structural racial health inequalities at the centre of maternity service provision debates and all participants echoed the need for building equity into PNMH services.

Theme 3: Exploring Solutions: Collaborative working, peer support and a family centred approach

As long as we continue to not see that the family the village are having a child, we're going to continue to have problems because we're excluding people. So I know it sounds madness to say that it shouldn't be called maternity services, but it's a birthing service, it's it's a family birthing service. (Participant)

This is where things like peer support come into place. Have people been there, done that? Got the T shirt? (Participant)

A key theme that cut across many of the participant discussions was the need to approach PNMH as a collective experience, not an individual one, both in prevention and treatment. The workshop explored how PNMH is *affected* by the wider context of society, culture, health inequalities and direct experiences of birthing and parenting in the pandemic. PNMH was also clearly identified by all participants as *affecting* the wider community of baby, family and the health of future generations in its long-term impacts.

The *solution* to promoting a more positive PNMH culture was therefore also located in the communal, wide reaching context of collaborative working, peer support and incorporating a family centred approach.

Examples of positive peer support projects were discussed as important in overcoming barriers to support through informal relations and shared experience. Collaborative working in NHS Tayside was identified with the current role out of the PNMH pathway that actively sought the input of parents with lived experience of PNMH to the service delivery and design. The need to include the family in both prevention and treatment was discussed as essential to positive PNMH, as families are the first to see the need for support in loved ones as well as feel its biggest impact. Education for families around PNMH was identified as a strategy going forwards alongside collaborative working between NHS and third sector organisations.

Figure 7 - Collaboration, peer support, person-centred approach



Impact: Timely and Important

The workshop brought together a wide range of stakeholders and captured a diversity of perspectives. The conversations led to the sharing of information, enabled networking, and collective examination of the issues around perinatal mental health from the individual, family, and service providers perspectives. All participants were unanimous that there was a strong need for PNMH services development that is inclusive and equitable and is incredibly timely in the post pandemic climate. The full impact of the stakeholder event is likely to be realised in future collaborative working and the development of research proposals that will benefit all.

Figure 8 - Improving Perinatal mental health in Scotland



Funding

The workshop was funded by the Innovation and Impacts Development Fund (IIDF), Research and Innovation Services (RIS), University of Dundee.

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