Leaders’ Top Tips 5

Reaching all communities affected by perinatal mental illness

Mums and Babies in Mind (#MABIM) is a Maternal Mental Health Alliance project supporting local leaders to improve services and care pathways for mums with perinatal mental health problems and their babies.

We work in Blackpool, Gloucestershire, Haringey and Southend, and capture and share our work to inform and inspire other commissioners and providers across the UK.

The MABIM Leaders’ Programme brings together leaders from a wide range of different services and professional backgrounds to:

- Learn from leading experts in policy, research and practice,
- Be inspired by those who are making a real difference to women’s lives,
- Talk to women with lived experience and hear their views,
- Meet and share experiences with peers from other areas, and
- Share learning and develop new solutions to difficult challenges.

We are organising 9 ‘Masterclass’ events for our leaders, each on particular themes relating to perinatal mental health. After each one we will produce a Top Tips document – like this one - to share the insights and ideas with a wider audience.

This is the fifth Top Tips document in our series. Others can be found on our website: www.maternalmentalhealthalliance.org/mumsandbabiesinmind/mabim-tools
Our fifth masterclass: reaching all communities

The fifth masterclass, on 25th October 2017, focussed on how we reach and support ALL parents and families affected by perinatal mental illness and work with them effectively to achieve better outcomes for women and their families.

The day was about recognising the huge diversity amongst those affected by perinatal mental illness and thinking about how we design and deliver services to ensure equality of access and care. “All communities” includes those who are marginalised; have additional needs and/or fall outside ‘normal’ pathways of care.

Our speakers covered only a very small sample of the communities that commissioners and practitioners must consider.

But they provided some wonderfully rich insights into the diverse needs and circumstances faced by families in relation to perinatal mental ill-health, many of which were generalisable to other sub-groups in the population, the needs of different families and plenty of ‘food for thought’.

We were joined by seven great speakers:

Louis Dunn from the Dads in Mind project at Bluebell Care talked about his experiences of perinatal OCD as a new father, and the support he now provides for other dads.

Sian Kilcommons, Perinatal Support Service Manager from Family Action told us about their work with diverse communities in Bradford.

Dr Camilla Rosan, Programme Lead at the Mental Health Foundation discussed the impact of complex trauma on women during the perinatal period.

Dr Alain Gregoire, Clinical Lead for MABIM and Chair of the Maternal Mental Health Alliance described the experiences of women and babies in the criminal justice system.

Dave Bennett and Liz Smith from the Jig-So team in Swansea told us about their work with young and vulnerable parents.

Catriona Oglivy, a mum, occupational therapist and founder of The Smallest Things charity shared her lived experience as a mum of a premature baby and insights from work with parents who have had babies in intensive care.

This document captures the key messages from our speakers and the discussions at the masterclass.

It also includes links to some useful documents and resources which may be useful to anyone considering how to commission, design and/or deliver services that meet the needs of the diverse range of families affected by perinatal mental illness.

Case study: Hillingdon specialist community perinatal mental health team

Hillingdon’s specialist perinatal mental health service is offering clinics in children’s centres around the Borough.

This increases the likelihood that many of the most vulnerable families will be able (and willing) to access the service. This approach aims to reduce stigma, increase accessibility and ‘join up’ with other services to provide a package of care to meet women’s needs.

The service has already seen a great reduction in the number of women who do not show up for appointments.
Reaching all communities

As commissioners and providers, we must ensure that all families affected by perinatal mental illness get the support that they need. However, the way that services are traditionally designed and delivered can make it particularly hard for some families with additional needs or more unusual circumstances to engage with or benefit from them.

These families have sometimes been described as ‘hard to reach’, but if our services are not working for the most vulnerable groups, then it is our services – not these people – who are hard to access. Our goal should be to design and deliver services that work well for everyone.

The aim of our MABIM masterclass was to discuss how best to reach, and improve outcomes for ALL families affected by perinatal mental illness. We wanted to understand more about:

• The experiences and needs of different groups, and any differences in their experiences of perinatal mental illness.
• How to make services accessible to, acceptable and effective for everyone who needs them.

Whilst a lot of attention was focussed on the need to address health inequalities and engage groups who are socially excluded and marginalised, we also recognised the needs of families who may not be marginalised in other aspects of their life, but may have characteristics or experiences which do not ‘fit’ with traditional perinatal pathways and services. For example, parents who have had still birth; a premature baby, or a disabled or poorly child have very different experiences of the postnatal period and may ‘fall out’ of traditional care pathways.

The word cloud above shows some examples of groups who are marginalised, have additional needs and/or fall outside ‘normal’ pathways of care. This is by no means exhaustive.

Other ways to describe this topic:
• Equality and diversity
• Treating everyone with respect and dignity
• Preventing discrimination
• Appreciating difference
• Inclusivity
• Understanding diverse needs
The risk of perinatal mental illness in different groups

Research shows us that the following factors increase a woman’s risk of perinatal mental illness.

However it is important to note that the causes of perinatal mental illness are complex and heterogeneous, and these are risk factors rather than determinants of illness.

- History of mental illness.
- Family history of mental illness.
- Childhood trauma/abuse.
- Lone parent or poor couple relationship.
- History of abuse or domestic violence.
- Low levels of social support.
- Adverse or stressful life events.
- Socio-economic disadvantage.
- Teenage parenthood.
- Unwanted pregnancy.
- Present/past pregnancy complications.
- Pregnancy loss.

Despite the increased risk of mental illness amongst some disadvantaged groups, we must not forget that women from all parts of society can be affected by mental illness.

Over half of the women who committed suicide during pregnancy or shortly after birth in the UK between 2006 and 2008 were white, married, employed, living in comfortable circumstances and aged 30 years or older.

Case study: reaching diverse groups

Sian Kilcommons from Family Action shared with the group the value of peer support in reaching marginalised communities. The Family Action service in Bradford provides perinatal peer support to women from 28 ethnic groups, of which 45% are Pakistani British.

Peer supporters provide 1:1 support to women and their families, and can also provide some group work interventions, such as Solihull and Theraplay.

A huge part of the service is to tackle distrust in and alienation from services and cultural stigma around mental health. This service has been very successful in breaking down some of the stigma around mental health and asking for help: One in every three referrals for the service is now made by service users themselves.

Most parents who are referred to the service are struggling with mental health issues for a number of complicated psycho-social factors that cannot be ignored. In particular, addressing domestic abuse and coercion and control is crucial but not easy.

Nearly 80% of Family Action’s volunteers are parents from the local area, many of whom experienced perinatal mental health issues themselves – and increasingly many of the volunteers were service-users themselves. Therefore volunteers are, in many ways, in receipt of a service and need investment too.

24 languages are spoken in the volunteer team and 15 ethnicity categories are represented. Many of the volunteers were service users themselves. This is critically important in reaching families.

Religion and belief systems are a big factor to consider within the support plan and can also impact on engagement rates.

This service aims to transform power structures and systems so that our health, community and social services are staffed, led, designed and developed by local people who have experienced some of the issues the services are there to address. The service also helps communities to find their own solutions and become more resilient by using peer support on an individual and group basis, strengthening support networks and decreasing social isolation.

‘The service was a “jump-start” of many changes in my life. I have started attending baby groups with my son, which helped me to make friends and overcome the feeling of isolation, discovered I am not the only one with such problems/feelings. I stopped feeling guilty/ashamed of my situation, thanks to my volunteer, I realised that there was a lot of mental abuse/controlling in my marriage and I finally found courage to say NO and think about introducing changes, I left my “comfort zone”, despite a lot of anxiety I found a job, put my son into a nursery, my life has completely changed.’
Understanding trauma

Understanding the impact of trauma is pertinent to this topic because people from socially marginalised and vulnerable groups are much more likely to have experienced trauma, particularly in childhood as well as in adulthood, which affects their wellbeing and ability to engage with services. Experience of trauma – particularly in childhood – impacts on every area of functioning, including physical, mental, behavioural and social.

Work on Adverse Childhood Experiences (ACEs) demonstrates clear associations between the amount of trauma, stress and maltreatment a child has experienced, and poor health and wellbeing in later life across a wide range of outcomes, including serious emotional problems, risky health behaviours, substance misuse, adult disease and disability and mortality, and the likelihood of becoming a victim of sexual assault or domestic violence. This is shown in this infographic (right) from the Robert Wood Johnson Foundation. It is also clear that the earlier ACEs were experienced, the greater the effect.

The adult effects of childhood abuse often manifest as, and can be known as, borderline personality disorder or complex PTSD. Adults who were maltreated as children can display particular behaviours, such as:

- Extreme lack of trust in others, including those trying to help
- Hypervigilance, fear, avoidance
- Minor triggers precipitate rapid and extreme changes in thinking, behaviour, mood, physiology;
- High stress/anxiety
- Intrusive thoughts, intensified mental and physical experiences
- Heightened sensitivity to somatic symptoms, sometimes labeled as somatization, or ‘medically unexplained symptoms’
- Self preservation through detachment from current reality: dissociation, non-psychotic voices
- Self blame and self harm
“I have learned to ask ‘what happened to you?’ not ‘what’s wrong with you?’

The impact of complex trauma in the perinatal period

At the Masterclass, Camilla Rosan from the Mental Health Foundation discussed the impact of adverse childhood experiences and complex trauma – particularly childhood sexual abuse - on women’s experiences of pregnancy, birth and parenthood.

Approximately 20% of women have experienced some form of childhood sexual abuse and between 74 and 96% of these women present with physical and emotional consequences.

Childhood trauma is associated with parenting difficulties, increased risk of mental health problems, pregnancy complications and pre-term birth. The prevalence of experience of child sexual assault is much higher in already vulnerable groups such as teenage parents.

Pregnancy is a major life transition and during this time memories of childhood and trauma memories can resurface. Experiences of services during the perinatal period in particular, such as touch during scans and genital examination; pain during childbirth; a sense of loss of control, and the power imbalance between patient and professionals, can trigger conscious and unconscious trauma memories in survivors of child sexual abuse.

Camilla advocated ‘trauma informed’ approaches across all aspects of care in the perinatal period. These approaches are based on the understanding that most people who come into contact with services have experienced trauma, and this understanding informs how practitioners interact with service users and how services are delivered.

Trauma-informed care involves taking into account past trauma and resulting coping mechanisms when understanding someone’s behaviour and the care that they need.

Trauma informed maternity care might involve:

- All maternity staff trained in trauma informed care.
- All women asked about child sexual abuse as part of a wider psychosocial assessment, to be followed-up with a supportive empowering response.
- Proactive normalising of child sexual abuse and its impacts ‘It is totally normal that pregnancy might bring up memories from our childhoods’
- Individualised maternity care plans for each survivor, including references to the staff team involved in their care, family or friends they may or may not want present during all appointments
- Continuity of care
- Integrated and joined up approaches to care, including joined-up physical and mental health care.

Dads’ experiences

1 in 10 new dads experience some form of mental illness. Dads are also an important source of support to mothers who get ill – between a quarter and half of new fathers with depressed partners are depressed themselves.

Louis Dunn from Bluebell Care talked about his experiences of perinatal OCD as a new father, and how he worked through this challenging period of his life. He also described the support he now provides for Dads through the Dads in Mind project. Louis’ story can be found here: http://www.bbc.co.uk/guides/zwgw4qt
Mothers and babies in the criminal justice system

Dr Alain Gregoire talked about the characteristics and needs of women in the criminal justice system.

For example:

- 61% of women in prison are mothers of dependant children. (Caddle & Crisp, 1997)
- Women in prison mother and baby units have high rates of mental health problems, mostly unrecognised (Gregoire et al, 2010).
- Women with babies who are refused a place in a prison MBU, and are forcibly separated from their babies, have the highest rates of mental health problems in the prison population - over 90% Gregoire et al, 2010; ONS Prison Study, 1998).
- On release, 70% of mothers who were in prison MBUs return to becoming main carers for their children, but only 20% of those separated from their babies in prison (Dolan et al 2013)

There are 70 places in prison mother and baby units in the UK, available for women who are pregnant or have young children at the time of incarceration, and meet particular criteria. Mothers in prison mother and baby units tend to have a lower rate of mental disorders than those who are separated from their babies. However women's mental health problems are rarely recognised and recorded.

“Some families experience a ‘double disadvantage’ when it comes to mental health services: their experiences of marginalisation, poverty, racism and/or violence can increase their risk of poor mental health and ALSO makes it harder for them to access the support they need to recover.”

Alain shared the following infographics from the NSPCC’s ‘An Unfair Sentence’ report.
The neonatal experience

Catriona summed up the experience of parents with a baby in neonatal care as: unexpected, unprepared and uncertain.

Being a mum in NICU is not a ‘normal’ experience, and neither is taking a NICU baby home. Catriona shared research by ‘The Smallest Thing’ charity, which showed that 1 in 3 mothers feel isolated following neonatal care, and their experiences are poorly understood by families and professionals.

Mums with a baby in NICU can be at heightened risk of poor mental health, and can feel particular feelings of guilt, trauma and anxiety connected with their babies’ birth and wellbeing.

Because their babies are in hospital for longer, these mums may not have the traditional postnatal contacts with midwives, GPs and health visitors and therefore opportunities to ask about their mental health may be missed.

Catriona recommended that more be done to:

- Raise awareness and increase understanding of the experiences and needs of families with a baby in neonatal care.
- Reduce isolation amongst these families.
- Provide timely and tailored support.
Case study: Baby Steps

The NSPCC Baby Steps service uses materials that were designed in consultation with learning disability charity and accessibility expert Change.

Easy read and accessible materials are not only useful for people with learning disabilities, they also make services more accessible for anyone who finds reading and writing difficult, perhaps because they had poor educational outcomes or have English as an additional language.

Case study – a DBT informed perinatal intervention

Dr Hannah Wilson, Consultant Clinical Psychologist in Winchester runs an Emotional Coping Skills course for women who have experienced childhood emotional adversity.

This is a 12 week, DBT informed skills course for mothers who demonstrate motivation for change, and low risk of self-harm or suicide. Women with various diagnoses attend: nearly 40% have complex PTSD; their diagnoses include bipolar, depression and anxiety.

The programme focuses on the acquisition, strengthening and generalisation of emotional coping skills, and covers mindfulness, emotion regulation, distress tolerance, interpersonal effectiveness. Compared to controls, the course programme has been shown to have a positive impact on clinical outcomes, mental health confidence and living with emotions scale.

Case study: Nelson Trust

The Nelson Trust in Gloucestershire run women’s centres which provide a “one stop shop” approach to the wide range of problems faced by women in the criminal justice system. They provide holistic, and trauma-informed care to women with multiple vulnerabilities.

Women can access some perinatal mental health support at the centre, along with services to address other needs, and a crèche for their children.
Case study: working with young parents

Dave Bennett and Liz Smith talked to the group about Jig-so’s co-parenting and relationship interventions for young families.

The JIG-SO TEAM is a multi-disciplinary and multi-agency initiative based across the City & County of Swansea. It consists of both family facilitators and midwives and nursery nurses. The project aims to provide services from conception to a child’s third birthday that provides additionality to core generic provision during the antenatal and postnatal period for parents aged between 14 and 24 years old.

The aim of the service is to provide a holistic support package for young parents to:

• promote the importance of early attachment and improve sensitivity between parents and infants.
• enable young families to take some control of issues affecting their parental couple relationship
• reduce isolation and improve the mental health and well-being of parents.

The team offers:

• 8 week midwifery-led programme that focuses on all aspects of becoming a parent and preparation for birth
• Home visits by midwives and/or nursery nurses
• The Cowan’s ‘Parents as Partners’ 16 week programme.
• Range of support such as peer support, breastfeeding support, dads group etc.

Individual beliefs, attitudes and perceptions
Eg. Does the parent perceive that they need help? Do they think the service will help them?

Social and cultural pressures
Will their friends, family and community support them to participate?

Structural barriers
Do the parents know when and where to go to attend the service? Is this possible for them?

Fit for purpose
Does the intervention suit the parent? Do they have things in common with other service users?

Nature of the programme
Does the style, content and timing of the intervention work well?

Personal Resources
Do parents have the material and emotional resources needed to attend? Eg. travel, childcare, confidence.

Experience of the service
Does the service/intervention meet parents’ expectations? Do they find it useful?

Quality of professionals
Do professionals have the skills, style and characteristics to engage with parents?

Risk factors
Are there significant stresses that prevent a parent engaging with support (eg. substance misuse, mental illness).
Other resources

There are many excellent resources that provide useful information and guidance about working with different groups. Here are some examples of reading that is relevant to this topic.


- More detail on what childhood maltreatment does to brains of adults (15 mins Harvard lecture). [https://www.youtube.com/watch?v=dxv3hareoQ8](https://www.youtube.com/watch?v=dxv3hareoQ8)

- Dramatic impact of childhood maltreatment on lifetime physical health (TED 15 mins.). [https://www.youtube.com/watch?v=95ovIJ3dsNk](https://www.youtube.com/watch?v=95ovIJ3dsNk)


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Themes arising from discussions

In discussions at the masterclass, our leaders identified the following ways to develop and deliver services that reach all communities:

• Attract and supporting a diverse work force
• Build women’s self-esteem, self-efficacy and confidence.
• Ensure resources are accessible or translated, and provide interpreters where necessary.
• Ensure the staff team is diverse.
• Help families to overcome practical barriers (finances, transport, cost etc).
• Improve staff training, understanding and cultural competence. Provide reflective supervision.

• Invest in good quality outreach and engagement.
• Link to community organisations other sources of support for the woman and her family.
• Offer flexibility within the service to meet different needs.
• Provide a holistic approach which understands women’s’ history and circumstances.
• Provide peer support.
• Tackle stigma.
• Treat service users with respect.

To download copies of Leaders’ Top Tips visit www.maternalmentalhealthalliance.org/mumsandbabiesinmind/mabim-tools

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