



mums and babies in mind

Supporting local leaders to improve perinatal mental health services

Leaders' Top Tips 4

User insight and engagement



Mums and Babies in Mind (#MABIM) is a Maternal Mental Health Alliance Project that is hosted by The Mental Health Foundation and funded by the Big Lottery Fund.

MABIM supports 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 parents 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 7 '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 fourth Top Tips document in our series. The first – on the topic of setting up a Specialist Perinatal Mental Health Community Service – was published in October 2016, the second on Commissioning Perinatal Mental Health Services – was published in February 2017, the third on the role of midwives and health visitors – was published in May 2017, and all three can be downloaded from the Mums and Babies in Mind website:

www.maternalmentalhealthalliance.org/mumsandbabiesinmind/mabim-tools



Our fourth Masterclass: User insight and engagement

The fourth MABIM masterclass, on 5 July 2017, looked at the importance, and valuable inclusion of, women's voices in relation to the development and improvement of perinatal mental health pathways and services.

We discussed how working with women and their families with first hand insight provides a huge amount of added value when commissioners and service providers are developing and improving perinatal mental health services across the whole pathway of care. We were joined by seven great speakers:

Dr Alain Gregoire: Consultant Perinatal Psychiatrist in the Hampshire Perinatal Mental Health Service, and Founder and Chair of the UK Maternal Mental Health Alliance

Trevor Hopkins: Asset Based Consultancy (www.assetbasedconsulting.co.uk)

Jessica Warne: Founder, Cocoon Family Support, North London (www.cocoonfamilysupport.org)

Maria Bavetta: National Champion Network Manager, Maternal Mental Health Alliance Everyone's Business Campaign (www.everyonesbusiness.org.uk)

Alex Corgier, Peer Support Manager, HomeStart Stroud (www.homestartsd.org/perinatal-project)

Natalie Nuttall and Ruth Eglin, Founders, SMILE Group (www.thesmilegroup.org)



The voice of lived experience ran throughout the day from a number of speakers.

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

It also includes links to useful documents and resources which may be helpful to anyone looking to enhance their inclusion of women and family voices in their service development and delivery processes.

"Keep your thoughts positive because your thoughts become your words.

Keep your words positive because your words become your behaviour.

Keep your behaviour positive because your behaviour becomes your habits.

Keep your habits positive because your habits become your values.

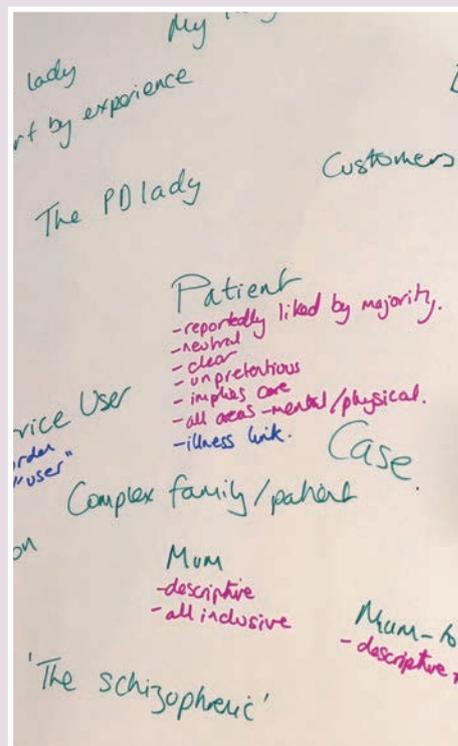
Keep your values positive because your values become your destiny"

Ghandi

What do we mean by 'user' in perinatal mental health?

As part of the Masterclass, delegates were asked to discuss the variety of terms used to describe those with lived experience.

A discussion about the words that could be used did not lead to one single phrase or word being chosen over another, but more to a collective of words that can be used sensitively depending on the context.



Head, hands and heart: taking an asset-based approach

Never do for a community what it can do better for itself.

Much of the data and evidence currently available to describe health and wellbeing is based on the deficit model. This focuses on the risks, problems and needs in individuals, families and communities, with professionals designing services to 'fix' the problems. This can be disempowering for recipients and can foster service dependency, with individuals and communities becoming passive recipients.

An asset-based approach values the capacity, skills, knowledge, connections and potential in individuals, families, communities and organisations. The approach highlights the factors that create and support resilience and wellbeing. However it usually requires a shift in attitudes and values, especially from professionals, who need to be willing to share power. Traditional organisational silos and boundaries can get in the way of people-centred outcomes and community building.

A key feature of using an asset-based approach is that you start with what is working and what people care about rather than focusing on the problems. Using appreciative enquiry, it starts with what you have – all individuals, communities, organisations have assets that support resilience and wellbeing. These will include resources, skills and knowledge. By giving support to identify and make visible these assets, citizens and communities can become the co-producers of sustainable outcomes rather than just the recipients of services. This

in turn empowers communities to control their futures and create tangible resources.

Broadly, asset-based working draws on three related strands of theory, evidence and practice:

- Salutogenic theory and the idea of positive health and wellbeing
- Concepts of assets and asset approaches
- The practice of asset-based community development and related approaches.

The key themes defining asset based ways of working are that they are place-based; relationship-based and citizen-led. They also promote social justice and equality.

Trevor explained the strands, which are detailed in the publication *Head, Hands and Hearts: asset-based approaches in health care* (<http://www.health.org.uk/publication/head-hands-and-heart-asset-based-approaches-health-care>). All three share a focus on working with people's capacities and resources, and all the approaches are interested in mobilising the whole community to create outcomes – rather than targeting those deemed to be most at risk, or with greatest need.

Sustainable outcomes are seen as a product of social action, with each approach putting a high value on a sense of belonging, capacity to control, and finding meaning and self-worth. They all start with a premise that strong communities



– whether of geography, identity or interests – generate resources, through fundraising, mutual aid, lobbying power, voice and empowerment.

Approaches to asset mapping described included:

- **Appreciative interviewing** (using reflection, affirmation and action)
- **Asset mapping** (for individuals, communities and organisations)
- **Open Space** (enables all kinds of people, in any kind of organisation, to create inspired meetings and events. Participants create and manage their own agenda of parallel working sessions around a central theme of strategic importance)
- **Theory of Change** (reframing towards a fresh perspective, developing a common agenda, recognising assets, making connections to mobilise assets, coproducing assets and outcomes)

Examples can be found here: <http://www.assetbasedconsulting.co.uk/Resources.aspx>

Case study – providing user voice within statutory systems

Women often describe their care as feeling 'like a baton in a relay race', and being 'dropped at every stage'.



North Central London



**Barnet - Camden - Enfield
Haringey - Islington**

Cocoon Family Support is a charity set up to support families affected by perinatal mental health conditions. They are run by a wide team of volunteers and small team of staff, all of whom have experienced perinatal mental health difficulties, and are supported by a team of Trustees.

Their services are wide ranging across the community and include:

- Awareness raising of perinatal mental health and reducing stigma
- Information for families
- Training for professionals and community organisations
- Antenatal education

- "Small Steps" Walking Group
- Chrysalis Course – transition to parenthood

The services provide:

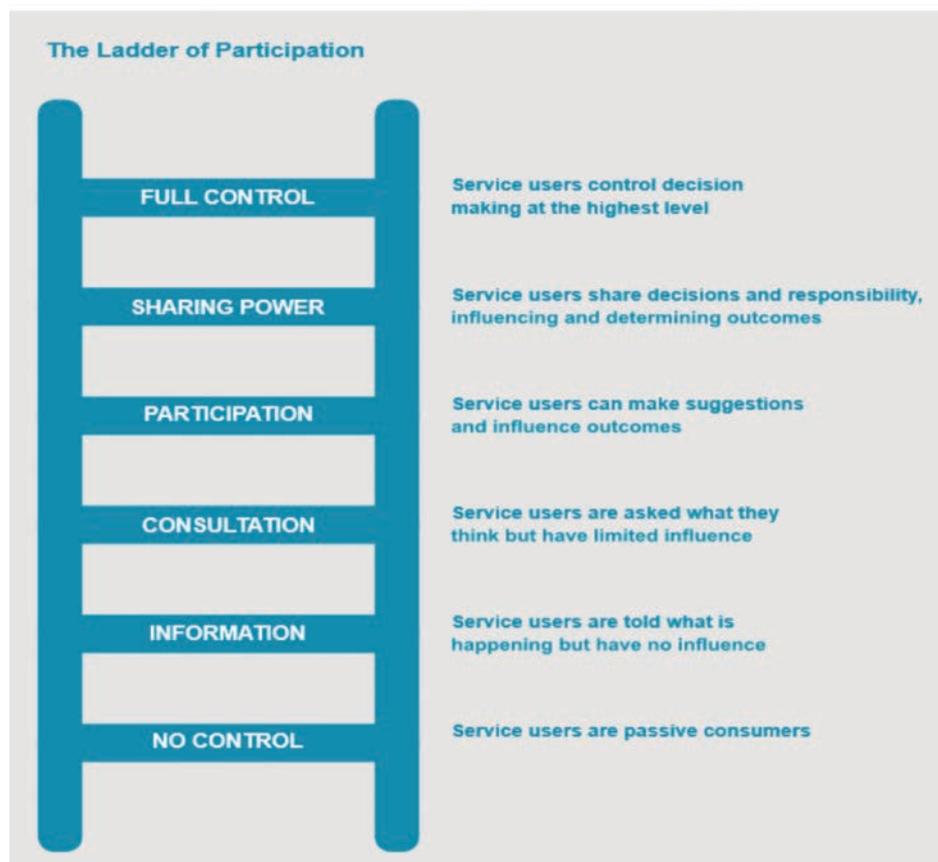
- Signposting
- Outreach support
- Partnership working
- Service Navigation
- Peer Support
- Creative therapies
- Support for fathers/carers
- Counselling

Across the work of Cocoon, the service user voice is integral to its development and ongoing growth. Involving service users benefits them by:

- Sharing experience to promote positive change
- Gaining confidence
- Turning a negative experience into a positive outcome
- Giving back to the community
- Providing the ability to recognise the power and impact of their own voice
- Enabling service users to shut the door and move forward to a happier, healthier future

The service benefits by:

- Ensuring services are as accessible as possible to all who utilise them
- Increasing satisfaction with services
- Improving relationships between staff and service users
- Having a greater insight into their service user needs



Sherry Arnstein – Ladder of citizen participation

A number of service users were keen to be formally involved in developing local perinatal mental health services for women and families. The local area was also looking to enhance the existing provision of care and were bidding for national money. They wanted to include the voices of women in their deliberations.

This is how the Cocoon Butterflies were created – a small group of women, who had utilised services and were willing to contribute to ongoing developments. They are supported by Cocoon, who act as an advocate where needed, provide a safe space to meet, support childcare needs to facilitate women attending meetings, provide training and supervision to enhance confidence.

Cocoon Family Support and its Butterflies have supported the local North Central London perinatal mental health team by:

- Participating in bidding process with NHS England
- Inputting on service design
- Creating consultation groups
- Participating in implementation groups
- Participating in interview panels

Involvement in the process has allowed women to express the issues with care they have experienced and to offer positive solutions to how these can be improved. This has ranged from practical examples within the pathway of care, to

awareness about specific conditions and how they are managed in the antenatal and postnatal period.

“A well organised, responsive and passionate organisation. An example to be followed in terms of ensuring the views of those with lived experience of mental disorder during the perinatal period are heard and acted upon in supporting the development of specialist and other perinatal mental health services.”

Andrew Smith – Project Manager,
NCL Perinatal Mental Health

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Case Study: Using lived experience to support other women



THE SMILE GROUP

SMILE group, Cheshire . “If we can make a difference to one family then we’re turning a negative experience into something positive.”

Natalie Nuttall and Ruth Eglin are the founders of SMILE group which provides weekly peer support to local mums. They shared their own personal experiences of perinatal mental health and how, through a thoughtful and proactive health visitor, they were connected locally and SMILE Group began!

Having started five years ago, the local support has grown and now provides peer support through a drop-in format at three Children’s Centres across Macclesfield, Congleton and Sandbach. Paid, trained and supported facilitators run these non-judgmental warm and friendly groups and 1-1 person-centred talk therapy is offered onsite. In addition, monthly family sessions are provided

which includes the wider family support. The group recently received game-changing financial support through Comic Relief which will be supporting 1-1 home visiting support which had been successfully piloted and evaluated.

Women attending the groups are supported by a welcome pack and the Little Book of Smiles. The Group has also developed a helpful checklist (<http://www.thesmilegroup.org/wp-content/uploads/2014/08/GP-Checklist.pdf>) for use when meeting with the GP, which is included in the RCGP toolkit.

The service is supported by robust policies and procedures around safety and safeguarding, and all facilitators

are trained and supported. The Board of Trustees provides advice, direction and accountability.

The organisation is part of the Perinatal Mental Health Partnership (<https://www.facebook.com/PerinatalMHPartnershipUK/>) and the North West Coast Strategic Clinical Network, as well as being embedded within local networks and providing user voice across these platforms.

Locally the group is recognised by health professionals and provides a community-based solution within the broader pathway of care for local women.

<http://www.thesmilegroup.org/>
<https://twitter.com/TheSMILEGroup>

Case Study – Using lived experience to support other women

Mothers in Mind peer support. Alex Corgier, HomeStart Stroud.

A volunteer can be the bridge between specialist and or statutory services. If a family can talk to a volunteer about how they are really feeling this creates a window of opportunity for the volunteer to support the family to seek specialist support.

HomeStart's core model of support is home visiting by trained volunteers who have been parents or carers themselves. The ethos of Homestart is to provide non-judgemental practical and emotional support to families. Providing a weekly listening ear to vulnerable parents is probably the most valuable thing that our volunteers bring to families.

Our volunteers are well trained and well supported. We work hard to build their confidence and skills so that they feel as appreciated and valued by us as an organisation. We spend a lot of time organising training, social get togethers, six-weekly supervision sessions and ongoing telephone contact to assist in developing them as volunteers.

For the Mother(s) in Mind project, the role has been enhanced by upskilling our volunteers to better understand perinatal mental health. By identifying what services are available for mental health, to understand cognitive behavioural therapy (CBT) and the importance of changing your relationship with your thoughts.

Their training looks at how, as volunteers, they might use simple and practical CBT exercises to better understand mental health. Particularly the differences between anxiety and depression and to hone in on how they can best support families in the two to three hours they spend with them every week.

The weekly support is non-time limited and can be flexible depending on the needs of the family/woman referred. So it can adapt to the ups and downs of mental illness and the needs associated with that. Also, based on the feedback from mums, we also developed a drop-in service to support local mums meeting each



other when they are ready, and these are led by volunteers.

The aims of the project (which are different to their core 'HomeStart' goals) are to:

1. Promote women's voices – what women had to say about their own experiences of perinatal support was central to the project;
2. Explore stigma – training professionals and volunteers, and creating a local leaflet that discussed the programme, and other local services we were linked to and are available locally;
3. Develop mental health wellbeing groups for women (ante and postnatal) with 2gether NHS Foundation Trust; and
4. Explore other forms of community support for families outside of Home-Start's core offer.

They also set up a pathway with 2gether NHS Foundation Trust into and out of Mental Health

Mothers in Mind – The Project Aims and Outputs



Intermediate Care Team (MHICT) / Let'sTalk Service to improve the links and access to advice for volunteers and professionals working with women in the perinatal period.

One aim of the pilot was that the groups would be for them to run in line with the Improving Access to Psychological Therapies (IAPT) CBT treatment model so that in future it could potentially be replicated across the county within the IAPT treatment programme.

The learning from the project, which remains ongoing following the pilot, is that it is crucial that any specialist community perinatal mental health services should be backed-up by holistic community-based support that includes peer support networks and groups run by the community and voluntary sector. This implies a continued financial commitment by local Clinical Commissioners (Gloucester in the example) to help support a spectrum of innovative practice in each locality.

Development of support in each locality needs a coordinated approach from all agencies and charities supporting women at this time and better referral pathways and communication between mental health intermediate care team (MHICT), primary health care workers including health visitors, midwives and GPs and all agencies working with pre-school families. The full evaluation of the project can be found at <http://homestartsd.org/mothers-in-mind-evaluation-report/>

MABIM sites pledge to include local voices in service development

The value of the voice from experience cannot be overestimated. The impact of timely, effective, compassionate care ultimately makes the difference between a supported and rapid recovery, or the potential for years of suffering by both mother, infant, and wider family.

The day ended with pledges for change made by participants across the four MABIM sites. The following ideas were shared:

- A local social media #Thunderclap to reach women across Blackpool who have experienced perinatal mental illness and invite them to help develop local services, bringing them together and generating awareness.
- Working with the Community Connectors in Blackpool to see what developments might be possible around perinatal mental health.
- Write to all women who engaged with the liaison service in the first six months of 2017 to see if they want to engage in service development and how that could work for them.
- Engage with Smile Group and other peer support groups to develop local support in Blackpool.
- Working harder to connect



with a wide range of local organisations to reduce the isolated pockets of work in Southend.

- See if organisations are already working to support perinatal mental health without realising it, and look to see if peer support is something that can be developed from within existing community-based organisations.
- Gloucester want to grow their peer support offer to more areas of Gloucester through meaningful co-design and production.

Resources

- SCIE: <http://www.scie.org.uk/future-of-care/asset-based-places>
- Royal College of Obstetrics and Gynaecology – Maternal Mental Health: Women's voices: <https://www.rcog.org.uk/en/patients/maternal-mental-health---womens-voices/>
- The Health Foundation – Head, hands and heart: asset-based approaches in health care: <http://www.health.org.uk/publication/head-hands-and-heart-asset-based-approaches-health-care>
- NICE guidance NG44 - Community engagement: improving health and wellbeing and reducing health inequalities: <https://www.nice.org.uk/guidance/ng44>
- The Kings Fund – Experience-based co-design: <https://www.kingsfund.org.uk/projects/ebcd>

Involvement standards for service users

“It is important to acknowledge that sharing your personal story is like being ‘mentally naked’ ”

The Maternal Mental Health Alliance campaign Everyone’s Business (<http://everyonesbusiness.org.uk/>) is now into its fourth year of Comic Relief funding, having received funding in 2013 and again in 2016.

The campaign has been a vital voice in the awareness raising of specialist perinatal mental health care with the public and professionals. It has also contributed to the commitment by government to pledge funding to increase the number of Mother and Baby Unit beds, and to support the development of specialist community perinatal mental health teams.

The campaign team to date have:

- designed maps highlighting the postcode lottery of services around the UK, which have driven conversations in all four nations about the provision of care for perinatal mental health.
- funded the review and publication of the financial and societal costs of not adequately caring for and the treatment of women affected by mental illness in pregnancy and early

parenthood (<https://www.centreformentalhealth.org.uk/costs-of-perinatal-mh-problems>).

- hosted policy level roundtables with government ministers to generate discussion and public commitments to improving funding and care in perinatal mental health.
- ensured the voices of people affected by perinatal mental health problems have been heard in a supported and constructive way by policymakers, health professionals, academics and the public (often through the media) to provide the powerful lived experience perspective.

As the campaign moves into its new phase, Maria Bavetta has been appointed as the Champion Network Manager, responsible for ensuring the lived experience voice plays a key role in delivering the campaign messages across the UK, within regions, so that user insight can contribute meaningfully and collaboratively alongside professionals and commissioners.

Maria is coordinating and supporting a network of campaign ‘experts by experience’ to support Everyone’s Business and who can represent the wider views of women and families affected by perinatal mental illness.

They will be supported in delivering their story, trained in providing consistent campaign messages, and empowered to use their voice to help improve services. Their contribution to ‘turning the map of specialist perinatal services green’ will be evaluated just as other elements of the campaign are.

The campaign team will create a suite of tools and resources to support the sharing of personal stories safely and to help services and organisations who want to include the user voice, how to do this constructively and appropriately. Maria is currently preparing a campaign protocol for safe, supported involvement of experts by experience which will be shared through the MMHA on completion.

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

www.maternalmentalhealthalliance.org/mumsandbabiesinmind

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