



National Mental Health
Development Unit

NATIONAL PERINATAL MENTAL HEALTH PROJECT REPORT

**Perinatal Mental Health of Black and Minority Ethnic Women:
A Review of Current Provision in England, Scotland and Wales**

Author: Dr Dawn Edge, Research Fellow, The University of Manchester
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Contact Details	Cathy Freese National Mental Health Equalities Programme - NMH DU 11-13 Cavendish Square London W1G 0AN www.mentalhealthequalities.org.uk
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FOREWORD

This report is a welcome addition to the knowledge base regarding the position of women from black and minority ethnic (BME) communities. Its importance also lies in the light it sheds more broadly on the perinatal needs of all women. As the author states: *“Relatively little is known about whether and to what extent current provision meets the needs of black and minority ethnic women ... and available information makes it difficult to determine whether even the needs of women from the majority population are being met.”*

The report discusses issues of need that arise out of the overlapping aspects of ethnicity, culture, language and gender with mental health. This represents a useful approach for influencing commissioning and provision of services. This, in turn, can mean that services are better able to respond to the presenting needs of all women.

To underpin this, the report calls for better pre- and post-registration training in order to strengthen the understanding and skills of practitioners. It also highlights the importance of a stronger evidence base in terms of clinical as well as service evaluation. Critically, it underscores the requirement to develop and improve care pathways in primary care and in non-statutory provision, as part of an overall framework for improvement.

Particular note is made of the importance of addressing issues in relation to women from refugee and asylum-seeking communities. This necessarily places the focus on communicating more effectively, not only through better provision of interpreting and translation services, but also via strategies that promote incorporation of a cultural dimension within the therapeutic relationship. Adopting such approaches would help, for example, to improve access to services such as talking therapies, which, it is acknowledged, currently do not adequately meet the needs of people from BME communities.

I am pleased it has been possible for the Mental Health Equalities Programme to commission this work through the National Mental Health Development Unit. Not only does it add to the legacy of the programme's work; it also strengthens the evidence base in a key area. It is hoped that practitioners will read it, use it, and find ways of incorporating its messages into everyday practice.

Melba Wilson
National Programme Lead
Mental Health Equalities Programme

October 2010

EXECUTIVE SUMMARY

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Mental ill health during pregnancy and early motherhood, or 'perinatal mental illness', is a serious public health issue with potentially deleterious consequences for women's life-long mental health and the health and wellbeing of their children and families. For example, postnatal depression (also known as postpartum depression, particularly in North America) is the most common of the potentially serious perinatal mental illnesses and can precipitate relapse or recurrence of previous mental illness. It can also herald the onset of long-term mental health problems and is associated with increased risk of maternal suicide¹⁻².

Postnatal depression has also been linked with depression in fathers and with high rates of family breakdown³. In addition, depression in mothers appears to increase the risk of poor birth and child outcomes. These include higher rates of spontaneous abortion, low birth weight babies, developmental delay, retarded physical growth, and physical illnesses such as chronic diarrhoeal illness⁴⁻⁷. There is also evidence that children born to depressed mothers do less well educationally, experience higher levels of behavioural problems and are more likely to develop psychological problems in later life⁸⁻¹⁰.

The relationship between ethnicity/culture and mental illness is highly contested and falls outside the scope of this report. In terms of perinatal mental illness among black and minority ethnic (BME) women, evidence on aetiology, course of illness and effective interventions is lacking and/or poorly understood. This may be because research into mental illness and ethnic

minorities in the UK has mostly focused on black men¹¹⁻¹² and evidence about perinatal mental illness is based largely on research among white Western women¹³. Although there is emerging research about perinatal mental illness in BME women¹⁴⁻¹⁶, this area of psychiatry remains relatively under-explored.

What is known is that there is a strong correlation between social and material deprivation and onset of perinatal mental illness – particularly depression¹⁷⁻¹⁸. Limited clinical and research evidence indicates that, despite high rates of community-level morbidity¹⁹ and disproportionate exposure to psychosocial risk factors, fewer than expected BME women receive diagnosis and treatment. This may be for a number of reasons. BME communities' fear and mistrust of mental health services might reduce the likelihood of women from minority groups either self-referring or being referred to services by their families²⁰. Additionally, BME women are more likely to live in the most deprived communities in the UK²¹⁻²². Such communities tend to have poorer access to health care.

The confluence of structural factors, such as unavailability of BME therapists and lack of 'culturally-sensitive' care pathways, with personal and cultural factors, such as attitudes and beliefs about mental health and illness²³⁻²⁶ might represent significant (sometimes insurmountable) barriers to accessing care for BME women²⁷. Further research is needed to understand the complex relationships between these issues and to devise effective strategies for reducing the inequalities in access, care and treatment experienced by some communities.

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Rationale

The National Mental Health Development Unit has commissioned this report to begin this process. The report and the studies on which it is based are part of 'The National Perinatal Mental Health Project'. The remit of this report and related studies is to facilitate better understanding of how and to what extent current and planned perinatal provision is capable of meeting the needs of BME women.

This information will support development of a national strategy to improve perinatal mental healthcare via regional managed clinical (care) networks, which will act as mechanisms for planning and delivering more holistic and responsive models of care. It is essential, therefore, that these networks address the needs of all women – including the most vulnerable, who are often marginalised and/or deemed 'hard to reach'. Failure to recognise and address the barriers to accessing care that such women might experience could result in their needs being unrecognised and/or unmet. Those who may be particularly vulnerable to 'falling through the net' in this context include women:

- from BME groups
- with previous or ongoing mental health problems
- in the criminal justice system
- who are visually or hearing impaired
- with learning disabilities
- with long-term physical health problems and/or physical disability.

Aims of the report

This report focuses on the first of these vulnerable groups – women from BME groups. The purpose of the report is to gather information that will enable national and regional mental health commissioners and service providers to:

- map current/ proposed perinatal mental health provision for BME women
- identify gaps in provision
- identify and share good practice.

Method

A number of strategies were used to gather information to compile this report:

- 1 A review of the literature (August 2009–June 2010) was completed to place the studies in the context of what is known nationally and internationally about ethnicity and perinatal mental illness.
- 2 A national survey of current perinatal mental health provision was undertaken using a questionnaire developed for this study. Data was collected between September 2009 and March 2010.
- 3 Mother and baby units in England, Scotland, and Wales were surveyed about the ethnic backgrounds of women using their services between May and July 2010 and in the previous 12 months.

Due to the sample size, quantitative data was analysed using only simple descriptive statistics. A limited amount of qualitative data was collected from questionnaires and follow-up telephone conversations with consenting participants. Their qualitative responses have been used to illustrate the quantitative findings. To protect respondents' identity, their quotes are reported using the numbers assigned to the completed survey questionnaires.

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Survey 1: Review of current provision

- Of the 45 completed questionnaires received, 31 (69%) were returned by secondary care professionals. Only 20% (n=9) were completed by primary care practitioners. Consultant psychiatrists (n=15) were most likely to return questionnaires.
- Altogether, 27 different professional groups were named as members of perinatal mental health teams. Specialist nurses (n=16) and doctors (n=17) were the additional team members most commonly cited by participants. With the exception of specialist health visitors (n=11) and social care staff (n=11), primary care practitioners were not mentioned.
- More than half the respondents (53%, n=24) stated that they currently had no services specifically for BME women, although 13% (n=6) had plans to develop services in the future.
- Some respondents stated that they adopted an overtly 'inclusive'/'universalist' philosophy of care. This means that they actively encouraged BME women to integrate while working to provide individualised care. These services emphasised the important role of community-based, voluntary sector provision for ensuring that women's cultural needs were met.
- While acknowledging that the needs of BME women were often unmet, some respondents pointed out that this was also the case for white women. In this context, perinatal services were described by a number of respondents as 'patchy' or 'poor' for the majority of women, irrespective of ethnic background.
- Among the services specifically designed to meet the needs of BME women, 'assessment and treatment' (n=28), 'liaison' (n=25), 'education and training' (n=15), 'support' for women and colleagues (n=13) and 'consultancy' (n=11) were most commonly reported by respondents.
- Definitions and understanding of the construct 'BME' varied among respondents, ranging from those who knew the term referred to 'black and (other) ethnic minority groups' (40%, n=18) to those who were unable to define the acronym. Some respondents highlighted the importance of recognising hidden minorities such as white Irish people, Jews and travellers. Others stated that 'BME' refers to those who are 'visibly ethnically diverse from the majority population' or those who are 'not white British'.
- 16% of respondents (n=7) were unable to estimate the proportion of their client/patient group who were from BME backgrounds.
- Among those able to do so, South Asians (44% (n=20) were the largest ethnic group identified, and almost one third of respondents (31%, n=14) had caseloads that included Eastern European. The largest black group was African women (n=8).

Survey 2: Survey of mother and baby units (preliminary findings)

In May 2010, questionnaires/data collection sheets were distributed via email to managers of the mother and baby units (MBU) in England, Scotland and Wales. To date, 13 have been returned – one of which is incomplete.

As these are preliminary findings from an ongoing study, they should be interpreted with caution. However, findings from this survey (the first of its kind) raise important issues about MBUs in general and their accessibility to BME women in particular.

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- The 13 participating units provide a total of 91 beds. This is 76% of the national total of MBU beds (n=120) available in England, Scotland and Wales to women with severe perinatal mental illness. At the time of the survey, 71 women were inpatients within the participating services. While this represents 79% bed occupancy, there was a wide range of occupancy rates, with some units operating at or under 50% capacity.
- Two thirds of the women (66%, n=47) in MBUs in May 2010 were white British. The next largest ethnic group were Eastern European women (n=6), of whom four were classified as recent migrants.
- According to respondents, a total of 380 women had occupied the 91 available beds in the previous 12 month period. This suggests a high throughput, with each bed having been used by four women in a 12 month period.
- Over 12 months, occupancy rate by ethnicity was similar to that recorded by cross-sectional data. However, occupancy levels for white British and Irish women were even higher (75%) than in the cross-sectional survey. South Asian (n=36) and African (n=20) women were the biggest ethnic minority groups. Among South Asians, Pakistani women (n=9) were the largest sub-group. Apparently no Chinese or Middle Eastern women had been admitted to any of these MBUs during the 12 month period covered by the survey.

Observations and conclusions

Findings from both studies highlight a number of important issues.

1 Definitions of BME

There was a lack of consensus on definitions of 'BME' among respondents. Indeed, some health professionals were unable to define the acronym. To do so, others focused on obvious differences such as skin colour, clothing and language, suggesting a somewhat narrow perspective on ethnic and cultural issues. This has potentially important implications for delivering culturally-appropriate patient care.

2 Service provision and inter-professional boundaries:

The majority of questionnaires in Survey 1 were completed by secondary care practitioners. As levels of morbidity are known to be higher in primary than in secondary care, response rates might reflect perceptions of perinatal mental illness as a secondary care issue. Alternatively, they might reflect the fragmentation of services. To illustrate, respondents in this study were asked to cascade information to colleagues in their wider networks. However, according to primary care and voluntary sector providers, the information did not reach them. Lack of information flow might be indicative of more significant issues in partnership working, both across different sectors of the NHS and between statutory and voluntary providers. This is an area worthy of further study. In addition, cross-boundary, inter-agency work might be needed to establish sustainable, joined up care pathways.

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Twenty seven (27) different professional groups were identified as members of perinatal mental health teams. Previously reported inter-professional boundary issues and lack of ownership of perinatal healthcare²⁸ were reflected in respondents' comments. This endorses their concerns that, if these issues are not properly addressed, they may impede rather than enhance delivery of holistic care.

3 Service provision for BME women

Half the respondents stated that their services made no specific provision for BME women. Where such services existed, they tended to focus on providing interpreting and translation services. While acknowledging that communication is a vital component of effective patient care, focusing on language issues might obfuscate important cultural differences in areas such as child-bearing and attitudes to mental illness. This issue might gain increasing salience as the population becomes increasingly diverse – for example, among English-speaking settled migrants who do not have obvious language difficulties.

4 Education and training

A number of respondents raised concerns about their ability to manage the range and complexity of mental health needs of some BME women. This was especially so in respect of refugees and asylum-seeking women. Practitioners felt that neither pre- nor post-registration training had equipped them to deal with the impact and consequences of these women's experiences. This suggests that greater emphasis on equipping healthcare professionals to work with an increasingly diverse patient/client population is required in initial training, postgraduate education and Continuing Professional Development (CPD).

5 Evidence based practice

The absence of good quality ethnic data means that the clinical evidence for the under-representation of BME women in services remains largely anecdotal. Research is urgently needed to strengthen the evidence base – both to determine levels of morbidity and related need and to develop appropriate service responses.

Findings suggest that the evidence base for current services needs to be strengthened. Only one of the 45 respondents to Survey 1 stated that any form of service evaluation had been undertaken within the services they provide. To build more responsive, accessible and sustainable services, further research is required into:

- whether and what interventions are clinically effective and cost-effective
- how such interventions work and in what context
- how to evaluate, share and implement good practice across all levels of service.

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In terms of perinatal mental health, the evidence base for BME women in the UK is currently relatively poor. It is therefore difficult to advocate effectively for and/or implement the kind of services that would best meet the needs of BME women on the basis of evidence-based practice. Evaluation of current provision and new research to establish levels of morbidity and unmet need among BME women are urgently required to bridge the evidence gap.

There is an inherent tension in developing services without a robust evidence base – even where this is in response to obvious need, such as exists among women who have experienced violence, trauma and other events that might adversely affect their perinatal mental health. Increasing national and international evidence about the potentially deleterious consequences of perinatal mental illness for some women's long-term mental health and the close inter-relationship between maternal and child health^{4,29} suggests that urgent action is required to develop/improve care pathways and interventions.

Response rates to the surveys of perinatal mental healthcare for BME women and the sources of the responses to Survey 1 might indicate wider issues within and between levels of service provision. Since the majority of women experiencing perinatal morbidity would require care in the community, the virtual absence of primary care participation is particularly concerning.

More positively, indications that obstetricians, health visitors and social care staff are part of some perinatal mental health teams suggest that strategies

to develop more holistic, joined up services are having some impact – albeit in isolated pockets. It is important to evaluate and cascade these examples of good practice in order to improve services in all areas.

One of the recurring themes among respondents was that, while BME women might have specific, and often urgent, unmet needs, perinatal mental health services were fragmented and patchy at best and were poor or virtually absent in some areas. Inadequacies in service provision adversely affect women from all backgrounds. However, it was acknowledged that BME women's greater exposure to psychosocial risks, coupled with inferior access to care, might increase the likelihood of their needs remaining unrecognised and/or unmet²⁰. This is contrary to policy initiatives designed to improve the mental health of the population as a whole and those specifically aimed at addressing the needs of women and BME groups³⁰⁻³².

In summary, these findings, together with previous research, suggest that proposals to improve perinatal mental health provision by developing more holistic care pathways are timely. An important part of this work is facilitating development of models of care that incorporate all levels of service provision so that the full spectrum of perinatal mental health need can be addressed. Ensuring that BME and hidden minority women such as travellers and English-speaking non-White women do not continue to fall through the net is integral to the success of these strategic developments.

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- 1 According to respondents, new initiatives are needed to improve perinatal mental healthcare for all women. While acknowledging the particular needs of BME women, participants asserted that perinatal mental health services are 'poor', 'patchy' or 'virtually absent' for all women. In light of evidence about the deleterious consequence of perinatal mental illness for women and their children, and a number of policies to improve the mental healthcare of women and BME communities more generally, this work remains under-developed and is now urgently needed.
- 2 Proposals to develop Regional Managed Clinical (Care) Networks as delivery mechanisms for a national perinatal mental health strategy might be an effective means to address poor, absent or inconsistent provision. However, further evidence for the clinical and cost-effectiveness of these networks is required. Additionally, from the example included in this report and anecdotal reports about plans to develop other such networks, it appears that they are often built on the passion and energy of key individuals. This clearly has implications for their sustainability.
- 3 A surprising number of professional groups were reportedly involved in delivery of perinatal mental healthcare provision. Inter-professional roles, relationships and boundaries need to be clarified as there was evidence of the potential for misunderstanding. Addressing such issues is important if effective care pathways that transcend levels and sectors of service are to be developed.
- 4 For truly joined up services to become a reality, these findings also suggest that more needs to be done to improve the links between primary and secondary care and between statutory and voluntary sectors. In light of evidence that BME women currently favour community-based models, perhaps greater emphasis should be placed on creating care pathways in which non-statutory provision is more formally integrated into mainstream services. Such a strategy might also go some way towards addressing voluntary sector agencies' concerns about their financial viability – especially in financially-straitened times.
- 5 Further research is urgently need to:
 - a improve the evidence base on perinatal mental health in BME women, both for producing accurate denominator data in order to assess prevalence and incidence of morbidity and for developing effective interventions. Without better evidence, it is likely that provision will continue to fail to achieve anticipated benefits and that good practice will remain confined to isolated pockets rather than being shared across all levels of provision.
 - b improve understanding of the factors that might account for low levels of diagnosis and/or engagement with mental health services among BME groups. This is exemplified by the relatively low number of minority women accessing MBUs, despite their disproportionate exposure to known psychosocial risks.

INTRODUCTION

This report has been commissioned by the National Perinatal Mental Health Project. The project was established by the National Gender Equality and Women's Mental Health programme and is part of a wider Mental Health Equalities programme within the National Mental Health Development Unit (NMHDU) at the Department of Health (DH).

The primary purpose of the project is to improve perinatal mental healthcare by facilitating the development of a national perinatal mental health strategy to be delivered via regional managed care (clinical) networks. These networks would serve as mechanisms for providing joined-up services capable of meeting the mental health needs of women during pregnancy and after childbirth. Additionally, the project aims to support work that addresses wider issues related to perinatal mental health (such as the inter-relationship between maternal and child mental health) and to provide a forum for sharing good practice.

In establishing this project, the National Mental Health Development Unit (NMHDU) acknowledges that the historical and contemporary location of some groups of women means that, without conscious and concerted efforts, their needs may remain unrecognised and/or unmet. Women who may be particularly vulnerable to falling through the net include women who:

- belong to black and minority (BME) groups – including hidden minorities such as travelling communities, Irish women and Jewish women
- have experienced previous episodes of perinatal or other forms of mental illness that might increase their vulnerability to perinatal mental illness
- are or have recently been in prison
- belong to other marginalised groups such as:
 - hearing or visually impaired women
 - women with learning disabilities
 - women with life-long physical illnesses and/or other forms of physical disability.

As part of the Mental Health Equalities Programme's response to facilitating development of responsive and accessible perinatal mental healthcare for under-served groups, this report focuses on the needs of BME women. The report was commissioned to gather information about current and planned perinatal mental health provision for BME women. However, reflecting the programme's commitment to developing more joined up services, the needs of BME women are considered within the wider context of provision for all women.

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The National Perinatal Mental Health Project and BME women

The aim of the National Perinatal Mental Health Project in relation to BME women is *to develop strategies for addressing the specific needs of women from black and minority ethnic (BME) groups and to introduce these strategies to the regional networks.*

Report format

Section 1

A review of the literature is presented in this section of the report. Its purpose is to place perinatal mental health provision for BME women in the UK in the wider international context.

Section 2

This section of the report presents evidence on provision for BME women in England, Scotland, and Wales. This information was collected via two surveys completed by service providers and commissioners.

The first survey collected data using a questionnaire (Appendix 1), which was distributed via perinatal mental health networks and the National Perinatal Mental Health Lead at the Department of Health. It was designed to ascertain the views of commissioners and providers about current and future provision for BME women in their localities – including their perceptions about:

- a whether and where such services are currently available
- b how well services for BME women are working where they exist
- c the relationship between such services and wider provision
- d plans to develop services for BME women where these do not currently exist.

The second survey, which was undertaken in collaboration with the Royal College of Psychiatrists' Centre for Quality Improvement (CCQI), collected information about the ethnicity of women who have been inpatients in mother and baby units (MBUs) in England, Scotland and Wales. This study was undertaken in part because of the high response rates and levels of engagement among secondary care providers in Survey 1. It was conducted electronically (via email), using a data collection sheet (Appendix 2).

Section 3

This part of the report summarises the main issues from both studies. It concludes by making recommendations for the provision of perinatal mental health services for BME women.

Section 4

The final section of the body of the report provides examples of good practice from a range of services, all of which are committed to sharing their experience and expertise with others wishing to improve and/or develop similar services. This section of the report also signposts the reader to:

- contact details of good practice examples
- policy and practice documentation.

SECTION 1: BACKGROUND

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Perinatal mental health definitions and terminology

Consequences of perinatal depression

Risk factors for perinatal mental illness

Black and minority ethnic women and perinatal mental illness

Rationale for the study and report

Depression in women is a serious public health issue³³. It is generally agreed that women are twice as likely as men to be affected by depression³⁴⁻³⁷.

Despite debates and discussions about whether depression during pregnancy and the early postnatal period, or *perinatal depression*, is either quantitatively or qualitatively different from depression at other times³⁸⁻⁴⁰, this area has been the focus of much policy and research activity since the 1960s and increasingly in the last 30 years⁴¹. This is partly because a growing body of evidence highlights the deleterious and potentially life-long consequences of perinatal mental illness for the health and wellbeing of mothers, their children, and their families⁴²⁻⁴⁵.

Perinatal mental health definitions and terminology

As *perinatal mental health and perinatal mental illness* are emergent concepts, international consensus has not yet been reached on key issues such as diagnostic criteria and temporality⁴⁶. Indeed, agreed definitions and diagnostic criteria do not currently exist for postnatal/postpartum depression, despite the condition having been the subject of much academic and media focus in recent decades⁴⁰.

The 10th revision of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10) defines the perinatal period as commencing at 22 completed weeks (154 days) of gestation and ending seven completed days after birth⁴⁷. In the fourth edition of the *Diagnostic & Statistical Manual* (DSM-IV), the American Psychiatric Association makes no mention of perinatal or antenatal (prenatal/pre-partum) mental illness. Postpartum or postnatal depression is included, but only as a specifier for major depressive disorders and it carries a strict delimiter of four weeks after birth⁴⁸. While some academics

and clinicians suggest that the perinatal period and associated illnesses might be extended into the early years after birth⁴⁹⁻⁵¹, it appears that, for most practitioners and academics, the perinatal period encompasses pregnancy and the first three to 12 months following birth^{13,52}.

Perinatal mental illness is therefore an umbrella term⁵³ that refers to a group of syndromes and conditions related to pregnancy and the early postnatal period. The most common of these conditions are briefly summarised in the following paragraphs.

Baby blues is said to be a relatively mild, transitory condition or mood state. Recognised by clinicians, academics and lay people alike, it affects up to 80% of women following normal delivery⁵⁴⁻⁵⁶. As 'the blues' are so commonplace and considered relatively benign, the condition is often dismissed as trivial, both by lay people and healthcare professionals – a natural response to massive fluctuations in hormonal levels associated with pregnancy, childbirth and the onset of lactation^{54,57}. However, dismissing maternity blues as the natural sequelae of childbirth potentially negates women's distress and also fails to optimise opportunities to identify women at risk of more serious postnatal mental illnesses⁵⁸.

Puerperal psychosis is characterised by sudden onset of psychotic symptoms within the first few days after delivery^{46,59-61}. It is the most severe of the postnatal mood states and affects one or two women in every 1000 live births in Western, industrialised countries^{57,62}. Because of the nature of its symptomatology (such as severe behavioural changes and psychotic episodes, which may include auditory and visual hallucinations), puerperal psychosis has very high detection rates^{61,63}.

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Rationale for the study and report

In terms of severity, duration and prevalence, **postnatal depression** falls somewhere between 'the blues' and puerperal psychosis. Although levels vary according to the strictness of diagnostic criteria⁴⁶, meta-analyses of international research suggest that postnatal depression affects around 15% of women giving birth to live babies^{64,65}. Postnatal depression, or PND, has been defined as 'a non-psychotic depressive episode that begins or extends into the postpartum period'⁶⁴. Both DSM-IV⁴⁸ ICD-10⁴⁷ have sought to narrow this rather broad definition. DSM-IV uses a postpartum onset specifier while ICD-10 categorises postnatal depression as one of a group of mental disorders associated with the puerperium and commencing within six weeks of delivery. However, the Marcé Society (a special interest group dedicated to improving the care of women with perinatal mental illness) defines postnatal depression as a condition occurring in the first six months following delivery, and others suggest it may occur at any time in the first year after childbirth or persist for several years^{49,64,66,67}. Still others suggest that the condition may have its onset during or even pre-dating pregnancy^{68,69}.

In contrast to 'the blues', puerperal psychosis and postnatal depression, **antenatal depression** is a relatively new concept. It does not appear as a separate condition in either DSM-IV⁴⁸ or ICD-10⁴⁷ and there is relatively little research about it, except where the focus is on predicting postnatal depression and developing prophylactic interventions. This may be because common perceptions of pregnancy as a time of emotional fulfilment and physical wellbeing during which women 'bloom' means that, even if the condition is recognised, 'unhappy pregnant women... are likely to be told that their feelings are of little significance and that all will be well when the baby

arrives'⁷⁰. While some researchers and practitioners assert that antenatal depression is a separate, distinct and diagnosable condition^{68,71}, others are less certain, suggesting that it is unclear whether antenatal depression is 'specific to pregnancy, coincidental with pregnancy, or exacerbated by pregnancy'⁷².

The development, evolution, and adoption of the term **perinatal depression** into clinical and academic lexicon has its roots in the 1980s and 1990s, when a number of seminal studies appeared to establish a strong correlation between depression during pregnancy and following childbirth⁷³⁻⁸¹. For example, the late Professor Channi Kumar and his team found that, while most new cases of first-trimester depression resolved by term, half the women who were having psychiatric consultations four years after delivery either reported onset of symptoms during pregnancy or had a history of chronic mental health problems at the beginning of pregnancy⁵⁰. In a large, longitudinal study of 1,272 women, Green and Murray reported that 42% of the women who were depressed antenatally were also depressed postnatally, endorsing the view of some clinicians and researchers that depression during and after pregnancy represents a continuum of psychological morbidity rather than distinct conditions⁷⁰. However others, like Professor Michael O'Hara, contest a direct link between antenatal and postnatal depression. Findings from his longitudinal study of depression during and after pregnancy among 99 American women showed that those who developed postnatal depression were not the same women who were depressed during pregnancy. This led him to conclude that 'prepartum and postpartum depression appeared to be independent' of each other⁸².

Section 1: Background (continued)

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Risk factors for perinatal mental illness

Black and minority ethnic women and perinatal mental illness

Rationale for the study and report

Consequences of perinatal depression

Perinatal depression* is associated with increased likelihood of recurrent episodes and the primary onset of mental ill-health^{50,64,79}. It is also associated with increased risk of serious mental illness and increased risk of suicide in the perinatal period⁸³⁻⁸⁵. Indeed, one of the key findings of the triennial reports of the Confidential Enquiry into Maternal and Child Health (CEMACH) is that, until the most recent review, perinatal suicide was persistently the leading cause of maternal mortality in the UK⁸⁶.

Maternal depression has also been linked to onset of depression and emotional disorders in fathers^{3,87-89}, marital conflict, breakdown of families and institutionalisation of children^{8,50,90}. It has also been shown to directly and indirectly impact on all domains of child health. For example, perinatal depression is associated with poorer mother–infant interaction, which has implications for children’s emotional growth and development^{10,91}. There is also evidence to suggest that perinatal depression contributes to psychological morbidity in children, which can persist into adulthood^{8,9,92}. Other researchers have found that the children of depressed mothers do less well behaviourally, cognitively and academically^{45,93}.

Research has also found that maternal mental health can impact on babies *in utero* as well as after delivery^{94,95}. Among disadvantaged groups, there is growing evidence that perinatal depression increases risk of birth complications and poorer birth outcomes, including higher rates of spontaneous abortion, low birth weight babies, developmental delay, retarded physical growth and higher incidence of physical conditions such as chronic diarrhoeal illness^{4-7, 96,97}.

There is also evidence that *anxiety* (either in its own right or, more commonly, co-existing with depression) might be a significant and largely under-researched component of perinatal mental health morbidity, with potentially serious implications for maternal and child health both in the immediate and longer term^{10,92,94,97,98}. For example, the Avon Longitudinal Study of Parents and Children (ALSPAC) found a correlation between maternal anxiety and children’s behavioural and emotional difficulties at age four⁹⁹. Similar associations between maternal anxiety and poorer maternal and child outcomes have been reported elsewhere, reinforcing calls for more research and better interventions to reduce morbidity and improve maternal and child health^{10,92,97,100}.

Risk factors for perinatal mental illness

Like other forms of psychological disorder, the aetiology of perinatal mental illness is complex, heterogeneous, and contested. This has led to the development of different aetiological models – namely, biological, psychological, sociological, and biopsychosocial^{53,59,101-104}. Although there is a substantial body of work on hormone-related risks and aetiology^{59,66,77,105-108}, the consensus is that risk factors are predominantly psychosocial (see fig 1 overleaf). Some of the key risks for onset of perinatal mental illness are outlined briefly overleaf.

* Also referred to as “maternal depression”

Section 1: Background (continued)

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Figure 1: Predictors of postnatal depression

Powerful predictors

History of psychopathology

Antenatal psychological disturbance – anxiety, depression, or dysphoric mood

Poor marital relationships

Low levels of social support

Stressful life events

Less powerful but significant predictors

Low social status

Personality type and attributional style

Adapted from O'Hara and Swain (1996)

Vulnerability: In their seminal work on depression and motherhood, George Brown and Tirril Harris reported that some women were particularly vulnerable to emotional and psychological problems during and following pregnancy – for example, women who experienced early emotional trauma such as separation from their mothers at an early age or who had developed ambivalent or avoidant attachment styles such as might result from poor mother–infant interaction⁴⁹. Additional vulnerability factors included having a history of depressive disorder (especially a previous episode of postnatal depression) or other mental illness; having a familial history of mental illness, and experiencing psychopathology or developing psychological disturbance during pregnancy^{57,64,109,110}.

Material, social and emotional deprivation: Additional risk factors for onset of perinatal depression in particular include stressors such as social and emotional isolation (especially the absence of a close confidant); marital discord; recent adverse life events and on-going difficulties, and unwanted pregnancy^{64,110-115}. There is a strong correlation between marital status, educational attainment, employment status, poverty, and the likelihood of experiencing psychological illness in the perinatal period^{72,116,117}. Being a single mother also increases the risk of onset. This is not surprising as lone motherhood is associated with lack of emotional support, higher levels of poverty and related negative socioeconomic variables^{4,118,119}. However, according to some researchers, it is lack of affective or emotional support (versus unmet practical or material need) that predisposes women to psychological ill health in the perinatal period. In this context, poor or absent partner support increases vulnerability and being in a positive, stable relationship decreases risk of onset. This might at least partly explain emerging evidence of high levels of morbidity among some BME women who experience high levels of lone parenthood^{76,120}.

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Black and minority ethnic women and perinatal mental illness

Although Britain is an increasingly diverse and multi-cultural nation, the population remains overwhelmingly White. According to the last census, over 92% of the population self-identified as White.¹²¹ Of the 7.9% (4.6 million people) who self-identified as belonging to an ethnic minority group, Asians or British Asians formed the largest majority, accounting for over 50% of all ethnic minorities. Within the Asian group, Indians (22.7%) and Pakistanis (16.1%) formed the largest sub-groups. Almost a quarter (24.8%) of ethnic minorities self-identified as Black, Black British or Black Other. Chinese people accounted for five per cent of the population, as did those who regarded themselves as belonging to an Other ethnic group¹²².

While the collection of data on ethnicity might be an important part of developing appropriately responsive services, categorising people into ethnic/cultural groups can and does obscure important differences within as well as between them¹²³⁻¹²⁵. When considering the perinatal mental health needs of BME women, it is therefore important to recognise that 'BME' is a catch-all term used to encompass a range of heterogeneous sub-groups. For example, the large White sub-group includes Irish, other Europeans, and non-European White people. It also includes recent and settled migrants from a range of countries and ethnicities.

Taken-for-granted assumptions about people's ethnic, cultural and national identities may therefore not hold true – especially where these are based on skin colour or other cultural markers such as dress and religious affiliations. To illustrate, among the non-White groups, more than 80% of Black Caribbeans, Pakistanis, Bangladeshis and people who self-identify as being of Mixed ethnic origin regard themselves as British, as do three quarters (75%) of all Indians. Many adopt ethnic labels such as British-Pakistani to reflect their hyphenated self-identities and the fact that many are British-born third generation descendants of migrants.

Prevalence of perinatal mental health among BME women

The international picture

Perinatal depression affects around 15% of women giving birth to live babies in the UK. One of the intriguing findings from international analyses is that this level of morbidity appears to be consistent across nations and, indeed, continents^{57,64,126,127}. This phenomenon was first reported by Professor John Cox in the early 1980s, in a comparative study of postnatal depression in African and Scottish women¹²⁸ and was endorsed by a large meta-analysis of 59 international studies that concluded that the international prevalence rate of postnatal depression was 13%⁶⁴.

However, a review of the literature suggests that meta-analyses, which aggregate large amounts of data derived predominantly from studies among White women in western, industrialised countries, might obscure important inter-ethnic/cultural differences. For example, very low prevalence rates have been reported among Israeli (5.2%)¹²⁹, Chinese (5.5%)¹³⁰ and Japanese (6%)¹³¹ women. At the other end of the spectrum, high levels of depression (24%) have been reported among Black South African women¹³². A Brazilian study of women of African descent reported prevalence rates of over 40% (42.8%), and a study among Mexican women in the US reported that 53% of the sample had clinically significant depression during the perinatal period¹¹². In another US study, Hobfall and colleagues found that high rates of depression (over 25%) during and after pregnancy among an improvised, inner city sample were independent of ethnicity¹³³.

In summary, despite claims of internationally consistent levels of morbidity, this is not substantiated by emerging evidence that suggests that Black and some other minority ethnic women may be particularly vulnerable to onset of perinatal mental illness.^{13,134-136} However, while some BME women record prevalence rates that are more than twice the expected levels, others record

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significantly lower levels of morbidity. Reasons for such inter-ethnic variation remain unclear and relatively under-researched.

The UK context

There have been relatively few studies into perinatal mental illness among BME women in the UK. However, recent research suggests that, compared with the majority population, some BME women experience significantly higher levels of psychological morbidity in the perinatal period that may become chronic and are often associated with other health problems^{20,137,138}. It appears that chronic, persistent perinatal mental illness might be linked to unmet need, as very few of the women in studies among Pakistani¹³⁹ or Black Caribbean women¹⁴⁰⁻¹⁴² access care and treatment. For example, a north of England study reported that, although more than a quarter of Black Caribbean women recorded Edinburgh Postnatal Depression Scores suggesting clinically significant morbidity (EPDS >12), only around seven percent received any formal care or treatment. Women who did so reported receiving sub-optimal care. Additionally, they were rarely offered talking therapies and were more likely than their White British peers to have been referred to secondary care instead of receiving treatment from their GPs or other statutory community-level services^{27,143}.

Rationale for the study and report

Relatively little is known about whether and to what extent current provision meets the needs of BME women. Indeed, the available information makes it difficult to determine whether the needs of women from the majority population are being met.

The National Perinatal Mental Health Project was established to address this issue. A specific component of the project's remit is to ensure that new strategic developments in perinatal mental healthcare (centred around the implementation of managed care networks) meets the needs of all women – including women from under-served communities and those considered vulnerable or hard to reach.

This report and the work that underpins it focus on the specific needs of women from BME groups. Findings from this scoping exercise will enable national and regional teams to:

- map current and proposed provision for BME women
- identify gaps in provision
- gain a better understanding of what is working well
- identify examples of good practice and share these via the regional managed care networks.

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Methods

A number of strategies were used to collect relevant information.

- 1 A review of the literature was undertaken throughout the period of data collection and report writing (August 2009–June 2010). The purpose of the literature review was to ensure that findings about effective provision of perinatal mental healthcare were placed within the context of what is currently known nationally and internationally about BME women and perinatal mental health.
- 2 A survey was undertaken using a questionnaire developed with input from practitioners and academics with expertise in perinatal mental healthcare (Appendix 1). The questionnaire, which was distributed nationally via existing regional and other networks, was designed to collect data to:
 - facilitate mapping of current and proposed provision for BME women
 - provide insight into how participants' definition of 'BME' relates to service delivery
 - provide information about the extent to which service providers and commissioners believe BME-specific services (where they exist) meet the needs of women for whom they are designed
 - enable practitioners to report on the extent to which services for BME women are integrated into the perinatal and mental health services more generally – both in terms of current provision and planned service development
 - encourage regional and local representatives to share good practice.

Participants were stakeholders in the provision of perinatal mental healthcare, such as members of regional networks and mental health commissioners. Adopting a snowball sampling approach, participants were asked to pass the questionnaire to colleagues and relevant members of their networks. It was anticipated that this strategy would ensure that the questionnaire reached all levels of service provision.

- 3 An electronic data collection sheet was used to survey mother and baby units (MBUs) in England, Scotland and Wales about the ethnic backgrounds of the women using their services a) at the time of the survey and b) in the previous 12 months.

Data analysis

Simple descriptive statistics have been used to report quantitative findings. Qualitative data have been reported using direct quotation from transcripts and questionnaires. They have been used primarily to illuminate quantitative findings. To protect respondents' identity, quotations are reported using the numbers assigned to completed questionnaires.

SECTION 2: FINDINGS

In this section

Survey 1:
A review of current
provision

Survey 2:
Mother and baby units

This section of the report presents findings from the survey on current perinatal mental health provision for BME women. Findings were derived from analyses of the Survey 1 questionnaire (Appendix 1). Responses to the questionnaire were supplemented by information gathered during follow-up telephone conversations and site visits. Preliminary findings from a national survey of MBUs are also presented (Survey 2).

Survey 1 – A review of current provision

A total of 45 questionnaires were returned during the six month period of data collection. As questionnaires were distributed via perinatal mental health networks and at a national stakeholder conference, it is not possible to state accurately how many were distributed or to calculate response rates.

Perinatal mental health services and practitioners

Of the 45 completed questionnaires, 31 (69%) were returned from secondary care and nine (20%) from primary care. One third of all questionnaires (n=15) were returned by consultant psychiatrists. The remainder came from a range of NHS professionals including clinical coordinators (n=9), managers (n=9), and commissioners (n=2). Responses were also received from non-NHS organisations such as local authority (n=1) and voluntary sector agencies (n=2).

Virtually all respondents (n=42) reported that they functioned as part of a wider team. Altogether, 27 different professional groups were identified as being involved in the delivery of perinatal mental healthcare. Perhaps reflecting the predominance of inpatient services among participants, it is noteworthy that, with the exception of specialist health visitors (n=11) and social care staff (n=11), primary care practitioners were rarely mentioned. Specialist nurses

(n=16) and doctors (n=17) – comprising staff grade/specialist registrar level psychiatrists (n=9) and specialist or consultant psychiatrists (n=8*) – were the professionals most frequently cited as additional team members (Table 1).

The length of time for which services had been established varied tremendously – from a newly-established service (operational for less than one month) to one that had been in existence for almost 40 years. The majority of services had been established between two and 10 years.

Table 1. Members of perinatal mental health teams	Frequency
Nurse/Specialist nurse	16
Midwife/Specialist midwife	11
Consultant psychologist	11
Specialist health visitor	11
Staff grade doctor /Specialist registrar	9
Consultant/Specialist psychiatrist	8
Social worker/Social care worker	7
Obstetrician	7
Admin/Support	7

*As the questionnaire asked respondents to list **additional** members of their teams, it is assumed that this number is in addition to the 15 consultants who returned questionnaires – ie. 23 in total.

Section 2: Findings (continued)

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Service provision

Asked about the kind of services they provided for BME women, assessment and treatment (n=28), liaison (n=25), education and training (n=15), support (for women and other health professionals/services) (n=13), and consultancy (n=11) were the most common responses among the 20 main categories of services reported.

More than half the respondents 53% (n=24) stated that they had no services specifically for women from BME backgrounds, although 13% (n=6) were in the process of or had aspirations to develop such services. A number of respondents (n=8) stated that they took an overtly inclusive/universalist approach to service delivery, as typified by these quotes:

'... [our] service model is based on delivering culturally specific and competent services (for example, being aware of issues that affect particular groups such as honour-based crime and witchcraft) ... but the clear focus is on the needs of individual women.' [Respondent #36]

'We feel that BME women integrate well with non-BME women within our service ... Our aim is always to encourage integration not marginalisation and we signpost women to specific services in their local communities when appropriate.' [Respondent #23]

Respondents spoke of the challenges they encountered in trying to meet, with what some regarded as inadequate or inappropriate resources, the range of complex needs with which some BME women presented. For example, a number of respondents referred specifically to the needs of asylum seekers.

In doing so, they highlighted issues and experiences that directly (and usually negatively) impact on pregnancy, childbirth and motherhood such as rape and other forms of sexual violence, forced/traumatic migration, and uncertainty about the welfare of family members who might have been left in women's home countries. Practitioners reported that these are issues for which their training had not prepared them and for which services currently provide little support.

Others spoke about wider inequalities in provision for BME women, including poorer access both to specialist services and to psychological or talking therapies. According to one respondent, government initiatives such as IAPT (Improving Access to Psychological Therapies) had made 'little difference' [Respondent #21] to the lives of BME women in his care.

A number of participants stressed that inadequacies in perinatal mental healthcare were not unique to BME women but applied to all women, irrespective of ethnicity or culture. This respondent articulated the views of a number of others:

'We are not providing specific resources for women from BME communities but then we do not have specific resources for White British women either ... there are no resources in adult mental health [services] for women who are pregnant or have recently delivered.' [Respondent #3]

Section 2: Findings (continued)

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Table 2. Services for BME women	
BME-specific services	Frequency
None	24
Interpreter	1
Education and training, mentoring	8
Translation and information	4
Equality impact assessment	4

Where respondents reported delivering or having access to BME-specific services (Table 2), these were most frequently providing services in interpreting (n=11), education and training (n=8), translation and information (n=4), and performing equality impact assessments (EIAs) (n=4).

In response to questions about how these services were working, participants were able only to share their perceptions; just one reported having been involved in any formal service evaluation.

Definitions of 'BME'

During the initial consultations with mental health professionals to inform development and piloting of the questionnaire, it became apparent that definitions of 'BME' varied widely. An item asking participants to define 'BME' was therefore incorporated into the questionnaire. Forty per cent (n=18) of respondents stated that 'BME' referred to women who belong to 'Black and (other) minority ethnic' groups. A number added that it includes 'other' White minorities, such as Eastern Europeans and Irish people. Other definitions included 'not White British', 'people whose first language is not English', and 'African-Caribbean or South Asian'.

One respondent stated that their service had no formal definition of 'BME'. Instead, practitioners worked to a 'list provided by the wider organisation, which includes many sub-groups' [Respondent #13].

Another suggested that 'BME' refers to individuals who are:

'... visibly ethnically diverse from the majority population and those clients who are from minority communities or whom describe themselves as belonging to a minority culture.' [Respondent #15]

Citing poor ethnic data monitoring and recording, 16% (n=7) of respondents stated that they did not know and were unable even to make a rough estimate of the proportion of BME women using their service (Table 3). Others estimated that the proportion of BME women service users ranged from less than 10% to 100%.

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Range (%)	Frequency
0-10	9
10-20	8
21-30	4
31-50	3
61-70	4
71-80	3
100	1
61-Don't know/low	7

Asians or South Asians (44%, n=20) constituted the largest group of BME women in participating services. Within this group, British Asian (n=6) and Pakistani (n=5) women were the most commonly cited South Asian/Asian sub-group, which also included Bangladeshi, Bengali, Indian and Tamil women. One third of the respondents (31%, n= 14) reported having Eastern Europeans, including Polish women (n=5), among their patient population. Other ethnic groups included African (n=8), Caribbean (n=3) White Irish (n=2), Orthodox Jews (n=2), Portuguese (n=2), Chinese (n=2), Turkish (n=2), and travellers (n=2).

Section 2: Findings (continued)

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Survey 2 – Mother and baby units

In May 2010, a brief questionnaire incorporating a data collection sheet was sent electronically to the 17 NHS mother and baby units (MBUs) in England, Scotland and Wales (Appendix 3). In eight weeks of data collection, 13 questionnaires (response rate 76%) were returned: England n=11, Scotland (n=1) and Wales (n=1).

The participating units provided 91 (76%) of the total number of beds (n=120) available in all MBUs. At the time of the survey, 72 beds and 69 cots were occupied. This represents occupancy rates of 79% and 74% respectively within participating units.

Two thirds of women (66%; n=47) in MBUs at the time of the survey were White British or Irish (Table 4). The next largest ethnic group was Eastern European women (n=6), of whom four were classified by services as recent migrants. Women of Black Caribbean (n=4), Pakistani (n=2), and Indian (n=2) origin were predominantly British-born. The one Pakistani woman not born in the UK was listed as a recent migrant. It is noteworthy that there were no Chinese or Middle Eastern women in MBUs during the survey. According to half the respondents (n=7), this ethnic mix is 'fairly typical' of women accessing their services. Only one four-bedded unit reported that 'ethnic minorities [were] under-represented in this sample', which comprised one Indian and three White British occupants at the time of the survey.

Ethnic category	No. of women
Bangladeshi	1
Black British/Caribbean	4
Black British/African	2
Black Mixed	1
Black Other – please specify Zimbabwean	1
Chinese	0
Eastern European eg. Polish, Romanian	6
European (EU) eg. Spanish, French Swedish	1
Indian	2
Middle Eastern eg. Turkish, Kurdish	0
Middle Eastern – Arab States eg. Iraqi, Egyptian	0
Pakistani	2
White British/Irish	47
Other (Please specify)	3
• French Guyana	1
• Sri Lanka (Tamil)	1
• Mauritius	1
Total	71

Section 2: Findings (continued)

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Asked to reflect on potential barriers that women might face in accessing services, half the respondents (n=5) said there were no ethnically-based barriers to receiving care within their units. Those who reported barriers said they included 'distance from home', 'difficulty accessing home treatment', and inter-professional issues with wider mental health services, such as the [un]availability of crisis teams and 'other services deciding that women are too ill' to be referred to MBUs. It was suggested that this perception might lead to women being admitted to general wards and separated from their babies.

The most commonly reported problems in terms of meeting the specific needs of BME women related to language difficulties, such as difficulty accessing interpreters and unavailability of alternative language formats for patient information. The latter was felt to be especially acute in relation to medication and consent to treatment. Other respondents highlighted the low numbers of BME women who access their service but asserted that 'the few we have had ... we have managed to meet their needs'. Some respondents acknowledged service limitations and highlighted the need to work closely with voluntary organisations in order to 'meet patient needs on an individual basis'.

In response to a question about activity in the previous 12 month period, Table 5 shows that a total of 380 women occupied the available beds in units responding to the survey. This suggests a high turnover – that is, an occupancy rate of four women per bed or an average length of stay of three months. In the 12 months covered by the survey, 75% of MBU occupants were White British. Combining categories meant that South Asians (n=36) and women of African origin (n=20) formed the largest BME groups. The largest BME sub-groups were Pakistani (n=13) and Indian (n=12) women.

*One 3-bedded unit reported figures for the previous month. All other units reported 6–12 months figures.

Ethnic category	No. of women in previous 3-12 months*
Bangladeshi	11
Black British/Caribbean	8
Black British/African	10
Black Mixed	4
Black Other – please specify	7
Nigerian	2
Zimbabwean	1
Somali	2
Black African	2
Chinese	2
Eastern European eg. Polish, Romanian	9
European (EU) eg. Spanish, French	1
Indian	12
Middle Eastern eg. Turkish, Kurdish	0
Middle Eastern – Arab States eg. Iraqi, Egyptian	3
Pakistani	13
White British/Irish	286
Other (Please specify)	10
Brazilian	1
Indonesian	1
Thai	2
Somali	3
Asian/British/Other	3
Declined to comment	2
Total	380

Section 2: Findings (continued)

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As these are preliminary findings from an ongoing study (a qualitative follow-up study is currently in progress), they should be interpreted with caution.

Findings are presented here in part to illustrate some of the challenges inherent in collecting and analysing this kind of information. One of the key issues in this regard is the lack of denominator data. For example, without knowing the number of BME women giving birth, it is difficult to estimate what proportion of these women should be represented in point prevalence studies. Making accurate sample size calculations is therefore problematic.

Accuracy of ethnic monitoring data is a significant issue in the NHS generally but especially for maternity services, where incomplete and inaccurate datasets have been reported for some time¹⁴⁴. While it might be possible to extrapolate to some extent from census data, it must be remembered that the last census was undertaken in 2001. It is unlikely that data recorded at that time could accurately reflect the increasing diversity of the UK's population and changing patterns of migration in the last decade. This is particularly the case for refugees, asylum seekers and recent Eastern European migrants who, according to a senior clinician, are 'most likely to be major sources of admissions for the mother and baby units'. The paucity of good quality ethnic data means that such information cannot be properly evidenced and remains largely anecdotal. These issues have potentially important ramifications for those delivering and commissioning services.

Summary

Inequalities in access to appropriate care and treatment for perinatal mental illness are antithetical to a number of government policies. For example:

- in their ten-year plan to reform the NHS, the government pledged to remove structural inequalities that perpetuate the inverse care law. This is 'law' is

based on observations that those in greatest need, such as marginalised and socio-economically deprived communities (among whom BME groups are over-represented), are least likely to receive the healthcare they need¹⁴⁵

- the National Service Framework (NSF) for Mental Health highlighted the need to improve primary care mental health services, especially for women¹⁴⁶. The Department of Health's plans to bring women's mental health 'Into The Mainstream' advocated improving the mental health of women and their children by increasing access to psychological care and support in the community^{30,147}
- the five-year action plan for Delivering Race Equality (DRE) in mental health care³² set an ambitious target to address the inequalities in access, treatment and outcomes experienced by BME people in mental health services by 2010, thereby enabling the NHS to fulfil its obligation to provide non-discriminatory services^{148,149}. DRE was based on three key 'building blocks':
 - developing more appropriate and responsive services (including alternative therapies, models of care and mechanisms of delivery)
 - promoting greater community engagement (to reduce stigma, fear, and distrust of mental health services among BME communities)
 - providing better data (such as gender, ethnic, and lifespan monitoring) and improved dissemination of information, good practice and health promotion to facilitate delivery of more culturally aware and responsive services³²
- more recently, the government underscored its commitment to Improving Access to Psychological Therapy (IAPT) for all sections of the population¹⁵⁰.

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The responses from practitioners, commissioners and policy makers who participated in these surveys suggest that policy initiatives have not had the anticipated impact on improving access to perinatal mental healthcare in general, nor on increasing the quality and availability of support and treatment for BME and other under-served groups. Indeed, respondents asserted that, despite policy and practice guidance, shortcomings in maternal mental healthcare persist – not only for BME women but for women of all backgrounds.

Findings from these studies raise a number of important issues:

- 1 There was a lack of consensus on definitions of 'BME' among respondents. Some respondents were unable to define the acronym, let alone identify the women to whom it might be ascribed. Others focused on visible or obvious differences such as skin colour, clothing and language. This may be understandable in the absence of agreed definitions and approaches. However, it suggests a somewhat narrow perspective that has potentially important implications for the delivery of culturally appropriate services.
- 2 More than half the respondents stated that they had no specific provision for BME women. Where such services existed, they tended to focus on language and the provision of interpreting and translation services. While the ability to communicate effectively with BME women is a vital component of caring for them, focusing on this aspect of service delivery might obfuscate other relevant issues, such as cultural differences in child-bearing and attitudes to mental illness. These factors might become increasingly important within an ethnically diverse population that includes a greater proportion of settled migrants and their descendants, among whom there may be no obvious language difficulties.
- 3 The absence of good quality ethnic data means that the clinical evidence of the under-representation of BME women in services is largely anecdotal. Research is urgently needed to strengthen this evidence base.
- 4 Only one of the 45 respondents to Survey 1 stated that they had been involved in any form of service evaluation. To build more responsive, accessible and sustainable services, further research is needed about what interventions are effective, how they work, and in what context. This information is crucial if good practice is to be replicated and maintained.
- 5 The majority of questionnaires in Survey 1 were returned by secondary care practitioners. This might reflect perceptions that perinatal mental illness is a secondary care issue. If this is the case, it might increase the likelihood of conditions like postnatal depression being under-diagnosed and treated sub-optimally in primary care.
- 6 The relative under-representation of responses from primary care might also be indicative of fragmentation in service delivery. To illustrate, respondents to Survey 1 were asked to cascade information to colleagues in their wider networks. Given statutory providers' assertions about high levels of liaison and engagement with community-based and third sector providers, it is surprising that they did not appear to share information with them about this study. As communication is integral to multi-disciplinary and cross-sector working, lack of information flow might suggest more significant issues in partnership working between different sectors of the NHS and between statutory and voluntary sector providers. Further work is needed both to understand these issues and to facilitate working across boundaries if joined up care pathways are to be established and maintained.

Section 2: Findings (continued)

In this section

Survey 1:
A review of current
provision

Survey 2:
Mother and baby units

- 7 Altogether, 27 different professional groups were identified as members of perinatal mental health teams. Previously reported inter-professional boundary issues and lack of ownership of perinatal healthcare²⁸ were reflected in respondents' comments, which endorse concerns that the number of professional groups involved in delivering perinatal mental healthcare and reported fragmentation of services might impede rather than enhance delivery of holistic care. In this context, it is suggested that the needs of BME women are more likely to be overlooked or to remain unmet.
- 8 Respondents raised concerns about their ability to manage the range and complexity of some BME women's needs. This was particularly so in respect of refugees and asylum seekers. Practitioners felt that neither their training nor their post-qualification experience had equipped them to deal with the level of diversity and complexity that they regularly encountered in everyday practice. This suggests that greater emphasis on working with diversity is required in undergraduate and postgraduate training and in Continuing Professional Development (CPD) if the needs of an ethnically diverse and multi-cultural population are to be adequately addressed.

Conclusions

In terms of perinatal mental health, the evidence base for BME women in the UK is relatively low. It is therefore difficult to effectively advocate for or implement the kind of services that would best meet the needs of these women. Evaluation of current provision and new research to establish levels of morbidity and unmet need among BME women are urgently required to bridge the evidence gap.

The inherent tension in developing services without a robust evidence base was clearly articulated by respondents. However, services continue to emerge (particularly non-statutory provision) in the face of apparently obvious need and increasing national and international evidence about the deleterious consequences of perinatal mental illness for women's long-term mental health and the close inter-relationship between maternal mental health and child outcomes^{4,29}. This is especially relevant for BME women, among whom social and material deprivation (including high rates of lone parenthood in some groups) renders them particularly vulnerable to onset of perinatal mental illness and increases their children's exposure to its consequences. Available evidence suggests that the intersections of ethnicity, gender, disadvantage and mental illness could result not only in high and apparently undetected levels of morbidity among BME women in the UK^{139,140} but might also contribute to disproportionate levels of perinatal mortality⁸⁶. These findings therefore suggest that urgent action is required to develop/improve care pathways to provide effective care for women experiencing perinatal mental illness.

Section 2: Findings (continued)

In this section

Survey 1:
A review of current
provision

Survey 2:
Mother and baby units

The response rate to the survey of perinatal mental healthcare for BME women (Survey 1) and the sources of those responses might be indicative of structural issues in service provision. Given that the majority of women experiencing perinatal morbidity do not reach the threshold for entering secondary care and should therefore receive care in the community, the virtual absence of primary care respondents is particularly concerning. Low response rates from primary care might suggest that communication with secondary care providers needs to be strengthened and that more work is needed if plans to develop more integrated services are to be realised.

More positively, indications that obstetricians, health visitors and social care staff are part of wider perinatal mental health teams suggests that initiatives to develop more holistic, joined up services are beginning to bear fruit. However, it is vital to monitor, evaluate and share examples of good practice in order to improve provision, delivery, and outcomes.

One of the recurring themes among respondents was that, while acknowledging that BME women often have urgent and specific needs, perinatal mental services were fragmented and patchy at best and poor or virtually absent in some areas. Inadequacies in service delivery adversely affect women from all backgrounds and under-detection and sub-optimal provision in primary care have caused concern for some time^{151,152}. However, there is evidence that the needs of BME groups are more likely than those of other groups to remain unmet – especially where provision is poor²⁰. This is contrary to policy initiatives to improve the mental healthcare of the population in general but especially that of BME and other marginalised groups who are known to have poorer access, experiences and outcomes.

In summary, these findings concur with previous research suggesting that proposals to improve perinatal mental healthcare by developing more responsive care pathways are timely. An important part of this work is facilitating development of holistic models of care that incorporate all levels of service provision so that the full spectrum of perinatal mental health need might be addressed. Strategies to ensure that marginalised and hidden minority women such as travellers, Irish, Jewish and English-speaking non-White women do not continue to fall through the net are also required.

SECTION 3: RECOMMENDATIONS

- 1 According to respondents, initiatives are needed that will improve perinatal mental healthcare for all women. While acknowledging the particular needs of BME women, participants asserted that perinatal mental health services are 'poor', 'patchy' or 'virtually absent' for all women. In light of evidence about the deleterious consequence of perinatal mental illness for women and their children and a number of policies to improve the mental healthcare of women and BME communities more generally, this work remains under-developed and is now urgently needed.
- 2 Proposals to develop Regional Managed Clinical (Care) Networks might be an effective means of addressing poor, absent or inconsistent provision. However, further evidence for the clinical and cost-effectiveness of these networks is required. Additionally, from the example included in this report and anecdotal reports about plans to develop others, it appears that such networks are often built on the passion and energy of key individuals. This clearly has implications for their sustainability.
- 3 A surprising number of professional groups were reportedly involved in delivery of perinatal mental healthcare provision. Inter-professional roles, relationships, and boundaries need to be clarified as there was evidence of the potential for misunderstanding, with potentially negative consequences for women. Addressing these issues is important if effective care pathways that transcend levels and sectors of service are to be developed.
- 4 For truly joined up services to become a reality, these findings also suggest that more needs to be done to improve the links between primary and secondary care and between the statutory and voluntary sectors. In light of evidence that BME women currently favour community-based models, perhaps greater emphasis should be placed on creating care pathways in which non-statutory provision is more formally integrated into mainstream services. Such a strategy might also go some way towards addressing voluntary sector agencies' concerns about their financial viability – especially in financially straitened times.
- 5 Further research is urgently need to:
 - a. improve the evidence base on perinatal mental health in BME women, both for producing accurate denominator data in order to accurately assess prevalence and incidence of morbidity and for developing effective interventions. Without better evidence, it is likely that provision will continue to fail to achieve anticipated benefits and that good practice will remain confined to isolated pockets, rather than being shared across all levels of provision
 - b. improve understanding of the factors that might account for low levels of diagnosis and/or engagement with mental health services among BME groups, as exemplified by the relatively low number of minority women accessing MBUs despite their disproportionate exposure to known psychosocial risks.

SECTION 4: EXAMPLES OF GOOD PRACTICE

EAST MIDLANDS PERINATAL MENTAL HEALTH CLINICAL NETWORK, NOTTINGHAM

Summary of role and function

We are a managed organisation that is accountable to the NHS East Midlands and the nine regional primary care trusts. We have a lead chief executive, a clinical director and network manager and are funded jointly by the nine PCTs. We work closely with the East Midlands Specialised Commissioning Group and the PCT lead mental health commissioners, advising them on service design and function and on quality standards of care.

The aim of the Network is to promote the highest quality of care for all women who experience mental health problems during pregnancy and following childbirth, and their infants. The key principles of the Network are to support the development of a regional specialised perinatal mental health service which is:

- inclusive – for all women living in the East Midlands
- comprehensive – providing medical, nursing, psychological and social care in the setting most appropriate for recovery (inpatient or community-based settings)
- integrated – all components of care including access and discharge are integrated in a seamless fashion
- appropriate and flexible – ensuring that women have speedy access to the right level of care.

At the core of the organisation is a network of lead clinicians that includes medical, nursing and other professionals who are involved in the care of women who have perinatal mental health problems. A Network management board and a number of committees and working groups undertake the work of the Network. This includes an expert patient group, which contributes to all aspects of our work.

The Network has developed a service model and commissioning framework for a regional specialised perinatal mental health service, which includes quality standards, a care pathway,

an education and training programme and information booklets. In the future the Network will develop robust methods for measuring clinical and patient outcomes, an information system to support audit and monitoring and an advice line/ website for patients and clinicians.

The Network brings together the core principles of the Specialised Commissioning Group and Darzi Next Stage Review process, ensuring the continued development and smooth running of the East Midlands Specialised Perinatal Mental Health service.

Perinatal mental health services are an NSR priority for the East Midlands SHA. They have appointed a clinical lead in perinatal psychiatry funded by the nine PCTs and accountable to the Specialised Commissioning Group. We also have a formally constituted managed clinical network for perinatal mental health services. It has a medical director (Dr M Oates), a project manager (Dr Ian Rothera) and a Network co-ordinator (Mrs Sue Tilbury). This managed clinical network has been operating since 2004. It is an integral part of the NSR Implementation Programme.

Section 4: Examples of good practice (continued)

We have a service model and commissioning framework. The intention is to organise the East Midlands Perinatal Mental Health Service on a hub and spoke model. The hubs will be one or more inpatient mother and baby units closely linked with five mental health trust-based specialised perinatal mental health services. These, in their turn, will be closely linked with activities in primary care. We have an East Midlands-wide integrated care pathway to ensure seamless integrated care at all levels of healthcare provision. We have standards that have been consensus designed for inpatient mother and baby units, community perinatal mental health teams, maternity liaison, general adult psychiatry, primary care and IAPT. These are standards for both form and function and both advise providers of perinatal mental health services and inform the commissioning process.

In Nottinghamshire there is a comprehensive and integrated perinatal mental health service, which includes a six-bedded mother and baby unit, a maternity liaison service and a specialised community perinatal service with three bases in Nottingham, Mansfield and Worksop. The service is complete – that is, all women referred to psychiatric services during pregnancy and the postpartum year are seen by the perinatal mental health service. They also manage women already in contact with psychiatric services with pre-existing psychiatric disorder and run an antenatal clinic in conjunction with maternity services for women with a past history of psychiatric disorder.

Lincolnshire at the moment has one specialised community perinatal psychiatric nurse. They have a service level agreement with the mother and baby unit in Nottingham for all inpatients. The commissioners have recently funded a specialised community perinatal service, including a consultant, and these posts will be advertised shortly.

Derbyshire has a four-bedded mother and baby unit. They have a specialised community psychiatric team that also provides a maternity liaison service for South Derbyshire. Plans are proceeding to develop a linked specialised community perinatal team for North Derbyshire.

Leicester has a three-bedded mother and baby unit and a partial community perinatal community psychiatric team. Discussions are taking place between the provider unit and the local commissioners to develop the services further.

Northamptonshire currently has no specialised psychiatric provision, but it does have a well developed system in primary care for mild to moderate conditions. Discussions are taking place to develop a specialised community perinatal team in Northamptonshire.

Section 4: Examples of good practice (continued)

In summary, NSR Implementation is complete in Nottinghamshire, well under way in Lincolnshire, partially completed in Derbyshire and is at the moment at the stage of commissioner implementation working groups in Northamptonshire and Leicestershire.

Expert patient group

Ex-patients have been involved in the managed clinical network from its beginnings in 2004. They have helped us develop standards for mother and baby units and specialised perinatal community mental health teams and given us important information on the care that they received from mental health services, midwives, health visitors and general practitioners. They told us what was good, what could be improved and what was distressing. They have been members of the managed clinical network steering group and at some regional meetings on perinatal mental health.

We aim to expand the size and influence of the expert patient group by setting up local expert patient groups in the five mental health trust areas: Derbyshire, Lincolnshire, Nottinghamshire, Leicestershire and Northamptonshire. The managed

clinical network will reimburse travelling expenses and provide administrative support and the venue.

Initially, these meetings will be led by Dr Ian Rothera, the clinical network manager. However, it is hoped that the local groups will elect their own chair when they have become established.

In addition, the managed clinical network will have a regional standing committee of ex-patients. This will consist of representatives from the five local groups. This regional expert patient group will be asked to consider the work of the perinatal managed clinical network but will in the future have its own agenda as well.

The expert patient groups both regionally and locally will provide a user perspective, views and suggestions through:

- contributing to all the workstreams of the managed clinical network – both short-life task and finish working groups and other standing committees – for example, education and training, standards, research and audit, workforce development and the production of information leaflets
- receiving and commenting on all the products and strategies of the managed clinical network
- commenting on proposed service developments
- providing opinions and views on proposed service changes to outside bodies – for example, primary care trusts, commissioners, the Royal College of Psychiatrists, locally, regionally and nationally.

Contact details

Sue Tilbury, PA to Dr M R Oates and Managed Clinical Network Coordinator
 East Midlands Perinatal Mental Health Clinical Network
 Room K03, First Floor, Duncan Macmillan House
 Porchester Rd, Nottingham NG3 6AA
 Tel: 0115 969 1300 Ext 10199
 Fax: 0115 952 9411

SECTION 4: EXAMPLES OF GOOD PRACTICE

FAMILY ACTION NEWPIN PERINATAL SUPPORT PROJECT, SOUTHWARK

The Family Action Newpin Perinatal Support Project (PSP) received funding for two years from the Parenting Fund in 2006. The project was initially planned to start in June 2006 but, due to a revision of the original proposal, has in effect run from January 2007, when the project co-ordinator was recruited. The statistics in this report relate to the period from April 2007 to December 2008.

The service targets socially excluded women in Southwark identified by partner agencies as being vulnerable during their pregnancy. The project provides intensive support to them throughout their pregnancy and the first year of their child's life and aims to improve the parent's mental health, enabling them to become part of a peer support network and to improve outcomes for their children. It specifically aims to promote a healthy attachment between the baby and mother by supporting the mother.

Target group

The target group includes:

- women who have an existing mental health problem
- women who have been identified as vulnerable to postnatal depression
- teenage mothers with identified risk factors
- refugee and asylum seeker mothers
- fathers, partners and other family members from the above groups.

Description of the project

The project is based at Guy's Hospital, where it shares an office with a community midwife, enabling a strong link with midwifery to develop. The Family Action Newpin Southwark Centre is also available for the project one day a week and the drop-in and the befriender training and supervision take place there.

The project is staffed by one project co-ordinator working 28 hours, eight hours of play staff time and a project manager who is also the manager of Family Action Southwark and devotes three hours a week to the Perinatal Support Project.

The service provision includes:

- assessment of new families at home by the project co-ordinator
- regular home visits by the project co-ordinator and befriender during pregnancy and the first year to offer practical and emotional support
- weekly drop-in peer support group for parents at Family Action Southwark Newpin
- delivery of the Newpin Antenatal Volunteer Befriender training
- regular supervision sessions for befrienders
- a parenting group for young parents developed in partnership with the Young Parents Support Project (Sure Start Plus)
- liaison with hospital staff at St Thomas' Hospital including MAPPIM (peri-natal mental health) and SCBU (Special Care Baby Unit) neonatal parents group facilitator.

Section 4: Examples of good practice (continued)

Young parents group

This is a development of the main project and consists of a group for young parents under the age of 19. The group takes the form of a 12-week parenting skills course 'Understanding Your Child', which is co-facilitated by the project co-ordinator.

Measuring outputs and outcomes

Appropriate systems are in place for recording statistical information relating to service users and this is stored on a database, which was made available for the evaluation.

The statistical information collected during the course of the project has been collated and presented in the report. This includes:

- the number, age, sex, ethnic grouping and mental health of both referrals and users of the project
- breakdown of referrers to the service
- the number, age, sex and ethnic grouping of befrienders trained
- the number of contacts through home visits
- the number of contacts through drop-in groups
- the number and nature of workshops or semi-structured groups.

Project activity is recorded on a monthly basis and submitted quarterly to the project manager. A summary of this is also presented below.

The progress of individual members is reviewed every three months by the project co-ordinator during a home visit to the family. Relevant issues are recorded and targets set for the next three months. The evaluation reviews to what extent the project co-ordinator sees these targets as having been met on a scale from 5 (fully achieved) to 0 (not achieved).

Validated evaluation forms to measure anxiety and depression – The Hospital Anxiety and Depression Scale or HAD (Zigmond & Snaith, 1983) – and social support – the Maternal Social Support Index or MSSSI (Pascoe *et al*, 1988) – were put in place at the start of the project and they have been collated and presented to show initial scores and any changes in mental health and level of social support.

Section 4: Examples of good practice (continued)

Summary of key outcomes

- The project is reaching its target group, including those who have English as a second language and those who have no recourse to public funds. Nearly half have mental health problems as the main reason for referral.
- Service users report that they have received both emotional and physical support and feel more confident as parents.
- 88% of service users who have been followed up show a reduced score for anxiety and 59% show a reduced score for depression on the HAD (Hospital Anxiety and Depression) scale.
- 47% of service users who have been followed up show a higher level of social support on the MSSSI (Maternal Social Support Index) Scale.
- When observed, 45% of service users are seen to have fully achieved their target to develop good communication and a close bond with their baby, and 55% have partly achieved this.
- 75% of service users have achieved their target of joining activities at a Children's Centre.
- Befrienders report that they have gained in confidence from volunteering and one has been offered paid work as a result.
- Partner agencies say there is good communication from the project and have reported a high level of emotional support and continuity of care.

Contact details

Family Action Central Office, 501–505 Kingsland Road, London E8 4AU

Tel: 0207 254 6251

Fax: 0207 249 5443

Email: info@family-action.org.uk

www.family-action.org.uk

SECTION 4: EXAMPLES OF GOOD PRACTICE

MOTHER AND BABY UNIT EAST LONDON

City & Hackney and East London is an area of immense cultural diversity and deprivation. The population includes indigenous people, immigrants and refugees. Within City & Hackney, over 70% of referrals to the outpatient and community service are from the non-white Irish/British population and the numbers within our mother and baby unit reflect even greater diversity. Our work in East London is supported by maternity, community psychiatry and primary care services as well as children's social care, all of whose work is rooted in providing a service to the same diverse community.

The workforce in East London is also diverse, which enables the service to be self-reflective, challenging of stereotypes and able to provide individual, patient-focused care. Perinatal services in East London began in the mid 1990s, when a four-bedded mother and baby annexe within an acute psychiatric ward was opened. There was erratic use of this facility until 2000. The service was not clearly defined and the staffing of the unit was not led by specialists. Since 2000, we have, with the support of our trust, developed a service that we hope is comprehensive and provides equity of access to women in East London through obstetric liaison, community perinatal psychiatry and an inpatient mother and baby unit.

The East London NHS Foundation Trust covers three boroughs: City & Hackney, Tower Hamlets and Newham. In 2000 the dedicated professional time to this service was through nursery nurse staff in the mother and baby unit and three sessions of consultant time. This has grown incrementally over the years.

In Tower Hamlets there is now a 0.5 whole time equivalent consultant psychiatrist, one whole time equivalent staff grade psychiatrist and one clinical nurse specialist, supported by administrative time.

In Newham there is a 0.7 whole time equivalent consultant psychiatrist, one whole time equivalent specialist registrar and one clinical nurse specialist, supported by administrative time.

In City & Hackney our obstetric liaison and community service has got two whole time equivalent clinical nurse specialist posts. There is one whole time equivalent consultant psychiatrist, one whole time equivalent specialist registrar and one whole time equivalent C1-C3 and one whole time equivalent modern matron covering both the mother and baby unit and the obstetric liaison and community service. The mother and baby unit has expanded from four beds to the 10-bedded Margaret Oates mother and baby unit, which opened in January 2010. We have a hub and spoke model where the mother and baby unit provides a service to residents within the borough served by our trust but also aims to provide a regional service to neighbouring North

Section 4: Examples of good practice (continued)

East London boroughs that do not have inpatient facilities. We have been influential in helping develop perinatal services in neighbouring North East London boroughs and work closely with clinicians there to improve access and enhance outcomes for women with mental health problems during pregnancy and in the postnatal period.

We are very proud of our new, state of the art, modern mother and baby unit and aim to meet the wider needs of women admitted to the unit. We therefore have invested in several sessions of non-talking therapy such as dance, art and music, so that women who have difficulty expressing themselves have an outlet to work with other women in a group. We have 24-hour access to translating and interpreting services and also use colour coding of equipment and space within the unit so that women who are unable to read feel confident within the unit.

Working in such a culturally diverse and deprived area has many challenges but having a sympathetic trust and a committed positive workforce helps us in our aim to provide an excellent service for women whatever their background. We aim to support and understand both objective (food, manner of dress etc) and subjective (values, roles etc) determinants of culture.

We acknowledge that many women may be at different stages along the spectrum of acculturation or they may feel alienated both within the wider community and within the community that develops in the unit. Asylum seekers and refugees are not a homogenous group and are different to the settled refugee population. Their health problems are often related to their country of origin and therefore we take particular care to ensure that their physical health needs are attended to.

These women often have many issues with regard to accessing health services and may display unusual help-seeking behaviours, which we seek to understand. There is immense shame and stigma associated with mental health problems within many cultures. We attempt to address this while also taking note of cultural and individual attitudes to professionals and the effects of women's religious beliefs on both their presentation and their acceptance of care.

Within such a diverse population, issues related to trauma and violence are not uncommon. We seek to assess, address and understand women's experience of domestic violence, abuse and neglect in their childhoods, sexual abuse and exposure to community violence, war and civil conflict and natural disasters.

We are aware that many women admitted to acute inpatient units have a history of exposure to trauma and violence and we believe that this risk is increased in those women who come from the refugee and asylum-seeking populations.

Section 4: Examples of good practice (continued)

Confidentiality is extremely important with this group of women because they may be unwilling to divulge their history of trauma to others because of the stigma associated with it. This means that, while we use interpreters and translators, we have to take account of the women's links with these individuals within their communities and ensure that we provide a safe environment for women to disclose traumatic events that may be contributing to their psychopathology and presentation.

Our service has developed close links with local voluntary organisations and advocacy groups, including Derman (a counselling service for Turkish/Kurdish women), the Asian Women's Advisory Service, Chisuk (a mental health charity for Ultra Orthodox Jewish families), the NIA Project (a group that works with individuals exposed to domestic violence) etc.

When assessing and caring for women within our service, we aim to pay close attention to gender issues such as the role and status of the woman within her family, what level of autonomy she has within the household and community and whether, because of her gender, there are any particular issues relating to language and communication, such as being allowed to access English language courses. We feel strongly that gender, social and the individual's own issues may be of equal significance and importance as cultural factors and therefore feel that it is always of the utmost importance to assess each woman as an individual first and foremost.

Contact details

Dr Liz McDonald, Consultant Perinatal Psychiatrist
 Perinatal Mental Health Service at E9, City & Hackney Centre for Mental Health
 East Wing, Homerton Row. London E9 6SR
 Tel: 020 8510 8151
 Fax: 020 8510 8552
 Web: www.eastlondon.nhs.uk

MBU DVD is now live on the microsite:

http://mbu.eastlondon.nhs.uk/for_commissioners/watch_mother_and_baby_unit_dvd.asp

SECTION 4: EXAMPLES OF GOOD PRACTICE

MRANG: MERSEYSIDE REFUGEE AND ASYLUM SEEKERS PRE- AND POST-NATAL SUPPORT GROUP, LIVERPOOL

Background

MRANG caters for refugee and asylum seeking women who are pregnant or have children missing in their country of origin. It is based in Liverpool.

The project was set up because there was a gap in services that specifically catered for raped, traumatised women who became pregnant as a result of the rape. There was nowhere such women could go for support and advice.

Key concerns

The key concerns were around attachment with the babies. For many women, their newly born baby is a constant reminder of the rapist. Many of the women are too far into their pregnancy for a termination to be an option; many assume they have no choice but to keep their babies. When they find out they do have choices, this very often helps them to accept their pregnancy.

Many have never had the opportunity to make decisions about their own life before, so this is very empowering for them.

How the project started

The project was started by the founder member during her Social Work Diploma course. Her final placement was at an asylum support agency and she was working with a pregnant asylum seeker who was destitute, with no recourse to NASS support. It was while working with her that two other pregnant women who were also destitute and pregnant approached her. The founder member then started a group that met every Wednesday afternoon for tea and peer support and this gave the women the opportunity to access a social worker, in a safe place, who was able to advocate on their behalf about housing, health, financial and legal issues. The numbers grew from three to 15 in a couple of weeks. The project now has over 280 members who have accessed support from the group. It regularly has over 35 women attending the Friday group.

How the project is staffed

When it first started, the project had six members on the management committee and three volunteers. The management committee is now made up of three social workers, three teachers, a priest, a barrister, a solicitor, a journalist, four group members and two retired women with a professional background in banking. The project has one full-time member of staff, who is also a qualified social worker. None of the staff is paid.

How the project is funded

The project has accessed local funds from LCVS, Local Network for Children,

Merseyside Disability Federation, Awards 4 All and the Eleanor Rathbone Trust. It has also received donations following high profile local and national press articles and radio coverage.

Section 4: Examples of good practice (continued)

Issues/initiatives that are promoted

The project promotes:

- safe sex and sexual health screening
- good child/mother relationships
- the importance of learning English
- understanding of child protection issues
- the importance of a balanced diet
- information on how to budget
- effective methods of tackling racism and which agencies to notify
- fire safety
- surviving rape.

How issues are promoted

The project has developed links with local HIV services and with Merseyside Fire and Rescue Service, who have delivered talks in other languages and also provided leaflets in other languages. Key personnel working for the project talk with the women about diet. An advocate from the PCT Social Inclusion Team attends the Friday group in order to deal with any wider health issues that may arise.

Links with outside agencies

The project has strong links with:

- women's hospital and community midwives
- Link Clinic (antenatal clinic for speakers of other languages)
- Sure Start, which has provided the project with play workers
- the Postnatal Depression Service (PSS)
- Medical Foundation
- Alder Hey Children's Hospital
- CAMHS team for children affected by trauma
- IOM (International Organisation for Migration)
- RASA (Rape And Sexual Assault)
- Home Office Reporting Centre Liverpool
- Social Inclusion Team
- Asylum Link Merseyside
- local solicitors
- AIT Manchester
- accommodation providers and Liverpool City Council Resettlement Team
- Merseyside Police (work around domestic violence and racist abuse).

People/Groups who benefit from the project

- The local Maternity Hospital. Before the project was initiated they had nowhere to refer these women for support and guidance.
- The women themselves, who previously had nowhere to go and sit and laugh together, cry together, or talk about their experiences.
- Other asylum seeker and refugee organisations – as before, there was nowhere to refer the women with such complex issues.
- Local solicitors have told us that they value working with the project because we are a source of advice and support when they have concerns about clients.
- Local NASS accommodators know their clients are better off psychologically after receiving the services of the group.
- Local community housing groups often call for guidance around issues being faced by their tenants.

Section 4: Examples of good practice (continued)

Where the project currently stands

According to the key project worker:

'We are desperately trying to get funding from grant making trusts to enable us to employ paid staff. We are also hoping to have our own counselling project as there are no specific counselling projects for traumatised refugees and asylum seekers who are over 21 years of age in the Merseyside area. We already have volunteer counsellors who attend the Friday group weekly to see women for counselling but we are very aware that we are only touching the tip of the iceberg. We envisage having counselling taking place three days a week.

'Our recycling project has developed to being very busy and in demand for essential items for both mum and babe. We also have a great demand for the recycled toys, the condition of which we pride ourselves on. We are very particular in what we recycle and will only recycle what we ourselves would accept for our own children.

'We would like to be able to offer ESOL and UK culture and integration classes, which are now integral to those with status who want to progress to UK citizenship. We have developed a very positive link with Blackburn House Women's College in Liverpool, which is willing to facilitate these courses as soon as we are in a position to open five days a week. Again, we cannot do this without core funding for paid staff. However the plans are already in place to take this forward.'

Lessons learned

As the project has evolved into the successful initiative that it is today, lessons have been learned. These include:

- finding comfortable accommodation with low maintenance problems
- not locating the project at a place where men are regular clients as moving location proved very difficult and it made professional relations with the former agency difficult.

Acknowledgement of service provided by MRANG

In June 2006 the service received a number of awards for their work in Merseyside:

- Most Helpful Asylum and Refugee Support Organisation in Merseyside
- Louise Massamba – Volunteer of the Year (not specifically refugee focused)
- Andre Massamba – Male Refugee of the Year for his work with the group
- Julia Wilambuwa and Olive Turinawe – Female Refugee of the Year went to two members of the group for the work they have done supporting other members of the group.

Contact details

MRANG

Louise Massamba, 36 Windsor Street, Toxteth, Liverpool L8 1XE
Mob: 07904 831 620 Email: louisemassamba@btinternet.com

Drop-in Centre

St Patrick's Church Hall, South Chester Street, Toxteth, Liverpool L8 5RA

SECTION 4: EXAMPLES OF GOOD PRACTICE

TAMIL HEALTH ADVOCACY PROJECT, SOUTH LONDON

Brief description of our success story

Tamil Health Advocacy services were started in 2005 (14hrs/week), in partnership with Sutton and Merton PCT at St. George's Hospital as a pilot project. Followed by its success, these services were commissioned directly by St. George's Hospital and Lavender Children's Centre in 2006 (21hrs/wk). Since the project was a big success, in 2008 this project was split into two separate projects:

- to support the Tamil ladies at St. George's Hospital (25hrs/wk), commissioned by St. George's Hospital
- to support Tamil families and help them to access the children's centres in Merton (two workers, one full time and other 30hrs/wk).

This service is commissioned by London Borough of Merton. This project has been nominated for a health award and a paper about the project's success has been published.

Project aims

1 Providing support for Tamil women who opt to have babies at St. George's Hospital via:

- Tamil antenatal classes facilitated by a midwife and interpreted by a health advocate
- interpretation and advocacy along with the midwives:
 - weekly Tamil antenatal clinics
 - during booking appointments at home
 - accompany families to appointments at GP and consultant appointments
 - during scanning sessions at foetal medicine unit

- translation of patient information and screening tests
- help Tamil parents by explaining their rights and choices in maternity healthcare. By this we provide equal access to maternity services and informed choices are made possible
- telephone support:
 - health advice via midwives
 - signposting for requested services
 - postnatal family support health advice via midwives
 - feeding and dietary advice for both mom and the child
 - arranging appointments
 - reassurance

On average, the health advocate receives 15 calls per day.

- postnatal family support services.

Section 4: Examples of good practice (continued)

2. Providing support to Tamil families at Lavender Children's Centre

- ESOL Towards Employment project, where Tamil moms can learn English and take up volunteering opportunity at the LCC.
- Tamil drop in sessions.
- Supporting Kids club, Yummy Mummy and Little Uns group at LCC.
- On demand from the parents, we started icing classes for Tamil moms. This was aimed towards housebound moms, empowering them towards self-employment. Some of the ladies now even supply decorated cakes to supermarkets.
- Working together with other partners, and supporting them by translating and interpreting.
- Signposting the parents to the concerned agencies for help with housing and benefits, schooling and other relevant information about other activities at the Children's Centre.

What has the project achieved?

Through this project, we were able to reach an under privileged and hard-to-reach community. The Tamil families benefited as this service:

- bridges communication gaps between families and midwives:
 - language
 - culture
- families are confident that they get equal access to services
- women now attend Tamil antenatal classes (midwives found it hard to motivate the ladies to attend antenatal classes and hardly any Tamil moms attended these services, which were previously provided in English)
- services are more approachable
- consistent, trusted support from someone who understands needs
- gives mothers a voice:
 - informed consent
 - avoids husbands speaking for them, making decisions

- supports midwives to give families better service:
 - equal access for Tamil families
 - better understanding of cultural, social, religious issues
 - able to pick up on sensitive problems
- avoids using family members for interpreting
- encourages more partnership with the Children's Centre
- greater job satisfaction for midwives
- helped the Tamil families to integrate into the UK culture.

This project has become a role model and has set an example for several other communities. For example, initially for the Lavender Children's Centre it was hard to recruit any Tamil parents to access the services. But now they are one of the major service users at the centre. Followed by its success, this has motivated the Polish community, who were not accessing the services at the centre initially, to come up with similar activities at the centre. Also, the families are becoming more aware of various activities at the centre and try to access them.

By this we are also helping them into integrate into the society.

Section 4: Examples of good practice (continued)

What were the main factors contributed to your success?

- Voluntary sector partnership such as South London Tamil Welfare Group (SLTWG), which has been serving the community for the past 23 years. Working with such groups has:
 - Improved access to Tamil community networks
 - Given us better understanding of the needs of the community
 - Enabled us to recruit appropriate candidates as advocate
 - Helped us to link service users to other community services.
 - Strengthened our reputation as a well trusted organisation
- Advocates have enhanced our service in a number of ways.
 - being fully integrated into team's services, they work closely with and are valued partners for midwives and family support workers
 - facilitating smooth referrals process
 - identifying needs
 - recruiting the families to access the service
 - for many ladies, health advocate has become a first point of contact during labour before accessing the delivery suite.

Contact details

Raji Chandirassegarane, Family Learning Project Manager, South London Tamil Welfare Group Volunteer Centre Croydon, CVA Resource Centre, 82 London Road, West Croydon CR0 2TB

Tel: 020 8542 3285

Mobile: 07814 399 152

Website: www.sltwg.org.uk/contact-us

SECTION 4: EXAMPLES OF GOOD PRACTICE

YAD L'YAD (HAND IN HAND), MANCHESTER

Why we started

In February 2007, we started Yad l'Yad (Hand in Hand), when we realised that there was no appropriate support system for Jewish women suffering from postnatal depression (PND).

Due to cultural and ethnic sensitivities, our women will not access the general services available for women suffering from PND. In addition to this, the service we provide is not offered by statutory services. We receive very positive feedback from local GPs, community midwives and Rabbis, who all feel we provide the community with a much-needed service.

The way we work

When a client calls our confidential helpline, our co-ordinator will have a brief conversation in which she will do a very short assessment with the client. She then puts her in contact with one of our dedicated volunteers. The volunteer will decide with the client how and when they will be

in contact with each other. However, in case of emergency, the volunteer has to be available 24 hours for the client.

We always make it very clear that we are 'befrienders' and not professionals. Our job is to be a non-judgemental listening ear for our clients. We signpost our clients to the various services available for them and, in case of specific need, we will arrange for cleaning help and night nurses, for example. However, it is not our job to do these tasks ourselves but rather support the client to return to normal functioning. When the client wishes, we will accompany her to see doctors or to hospital appointments. Another important part of the task of the volunteer is to 'be there' for husbands, children and other family members who need support or explanation about what is going on.

Our training

The management committee asked various women from within the community whom they regarded as being suitable for this task if they were ready to train as volunteers. Some of our volunteers have trained as professional counsellors and others have had experience in counselling to some extent.

When we had a group of ten volunteers we brought over the head of a sister organisation in Israel to undertake further training with the group. This woman is originally from Manchester, so she could identify with our community. She also had experience of working as a trained volunteer for over 10 years.

After this initial training, we have had subsequent training days with various professionals in the field. We also have our own supervisor with whom we have case discussions and who also gives us training on various subjects. Our volunteers are expected to see the supervisor at regular intervals, so as to ensure that they are providing the clients with the right help and also to ensure that they have support as needed.

Before the volunteers can start to work for us they have a CRB check.

Since our initial training three and a half years ago, we are about to train a new group of volunteers as two of our initial volunteers had to stop providing their services for various reasons but the demand for our help has continued to grow.

Section 4: Examples of good practice (continued)

How do the clients find us?

Since emotional and mental health issues are such a taboo in our community, it is quite difficult to reach potential clients. The main way we reach the women is through advertising in the local advertising magazines. We also give our leaflets to community midwives who pass them on to expectant mothers. We work closely with a local labour support group, who also puts our leaflet in their information pack.

Our funding

We have managed to fund our needs up to now through grants and some private donations. It is quite difficult to obtain grants since often we get the response that our services are statutory provided (which is not true) and grant providers, although they might provide set-up costs, often do not provide funding for ongoing costs.

We need quite significant amount of funds to pay for our advertising costs, since advertising is the main way we can reach our potential clients. This is an ongoing issue and the cost of advertising continues to rise. However, it is difficult to attract funding for advertising.

The future

Slowly but surely Yad l'Yad is becoming more known within the community. We hope that, as more people know about us, women will more easily access us. We have already had calls from outside of Greater Manchester. Also, GPs are gradually starting to refer clients to us, which means we get more established within the area. This also means more accessible and sustainable care pathways are being established to meet the specific needs of Jewish women in the area.

Final words

Although we wish it was not necessary, we are glad that more women are finding us, and that we can provide them with the help they so desperately need. Taking all this into account, we anticipate steady growth in the amount of women contacting us for help.

Contact details

Chava Waldmann
Tel: 0161 792 9690

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Policy and practice

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APPENDIX 1: NMH DU survey questionnaire

The National Equalities Programme, which is part of the National Mental Health Development Unit, is looking to create a picture of the nature and extent of provision of perinatal mental health provision across the regions with a specific emphasis on services for BME women. To assist us, we would be most grateful if you would complete this questionnaire as fully as possible. Please email completed questionnaire to: dawn.edge@manchester.ac.uk

Section 1: About you and your organisation

1.1 Name of Your Organisation

1.2 Please state the role of your organisation in providing perinatal mental health services e.g. commissioner/PCT/secondary care provider

1.3 What is your role in providing perinatal mental health services?

1.4 Are you part of a wider team?

1.5 If yes, who are the other team members (professional roles)?

Appendix 1 (continued)

Section 2: Services that you provide

2.1 Please tell us about the service(s) that you provide

2.2 Please tell us about services designed specifically to meet the needs of BME women or plans to develop these

2.3 How long have these services been in place?

2.4 Please say how you define BME

2.5 Roughly, what percentage of your patient/client group is of BME background?

2.6 What are the BME groups for whom you provide/plan to provide a dedicated service?

2.7 How are services for BME women working out? In your answer, please include observations about interface with/impact on services for non-BME women

Appendix 1 (continued)

Section 3: Tell us more?

3.1 Please provide additional information here (use additional sheet if necessary)

We would also like to talk in more detail to a sample of people who complete this questionnaire. If you are willing to be interviewed, please insert your name and contact details here:

APPENDIX 2: Survey of mother and baby units (MBU)

National Perinatal Mental Health Project, Royal College of Psychiatrists CCQI
Ethnicity & Maternal Mental Health Survey of Mother & Baby Units (MBU)

1) About your MBU

Name of Unit

Location

Number of beds/cots

Number currently occupied

Date of survey

2) About the women in your MBU

Please state how many women and babies currently in your MBU belong to the following groups:

Ethnic category	No. of women	Nationality/Citizenship		
		UK	Recent	Refugee/Asylum Seeker
Bangladeshi				
Black British/Caribbean				
Black British/African				
Black Mixed				
Black Other – please specify				
Chinese				
Eastern European eg. Polish, Romanian				
European (EU) eg. Spanish, French				
Indian				
Middle Eastern eg. Turkish, Kurdish				
Middle Eastern – Arab States eg. Iraqi, Egyptian				
Pakistani				
White British/Irish				
Other (Please specify)				

3) How typical is this of your usual patient/client group?

Appendix 2 (continued)

4) Please use this space to tell us anything else you think we should know.

For example: any barriers to access, any particular problems in meeting the patients needs

5) How many women have been admitted to your service in the past three months (or if you can for six months or one year?)

Ethnic category	No. of women	Time period
For example: Somali	xx	12 months
Bangladeshi		
Black British/Caribbean		
Black British/African		
Black Mixed		
Black Other – please specify		
Chinese		
Eastern European eg. Polish, Romanian		
European (EU) eg. Spanish, French		
Indian		
Middle Eastern eg. Turkish, Kurdish		
Middle Eastern – Arab States eg. Iraqi, Egyptian		
Pakistani		
White British/Irish		
Other (Please specify)		

Date form completed

Thank you for your time.

APPENDIX 3: Perinatal mental health mother and baby units in England, Wales and Scotland

Area	Address	Telephone	Number of beds
Leeds	Mother & Baby Unit, The Mount, 44 Hyde Terrace, Leeds LS2 9LN	0113 305 5505	4
Manchester	Anderson Ward, Laureate House, Wythenshawe Hospital, Southmoor Rd, Wythenshawe M23 9LT	0161 291 6823/6829	10
Newcastle	Beadnell Ward, St George's Park, Morpeth, Northumberland NE61 1NU	01670 501 869	5
York	Mother & Baby Unit, Bootham Park Hospital, Bootham, York YO30 7BY	01904 725 572	4
Stafford	Brockington Mother & Baby Unit, St George's Hospital Foundation NHS Trust, Corporation St, Stafford ST16 3AG	01785 221 5560	6
Welwyn Garden	Thumbswood, Queen Elizabeth II Hospital, Howlands, Welwyn Garden AL7 4HQ	01707 365 416	6
Birmingham	Mother & Baby Unit, Queen Elizabeth Hospital, Mindelsohn Way, Edgbaston B15 2QZ	0121 678 20000	8 and 1 flat
Nottingham	Perinatal Psychiatric Services, Perinatal Inpatient Unit, A Floor South Block, Queens Medical Centre, Clifton Boulevard, Nottingham NG7 2UH	0115 924 9924 Ext. 64479	6
Bristol	New Horizon Mother & Baby Centre, Southmead Hospital, Westbury-on-Tryme, Bristol BS10 5NB	0117 950 5050 Ext 2266 or 2317	4
Basingstoke	Fairways House, Parklands Hospital, Aldermaston Rd, Basingstoke RG24 9RH	01256 376 492	8
Beckenham	Mother & Baby Unit, Bethlem Royal Hospital, Monks Orchard Rd, Beckenham, Kent BR3 3BX	020 3228 4255	12
North Middlesex	Coombe Wood Perinatal Mental Health Unit, Coombe Wood Annexe, Park Royal Centre for Mental Health, Centra Way, Acton Lane, London NW10 7NS	020 8955 4495	10
Hackney	Mother & Baby Unit, Mermaid Ward, City & Hackney Centre for Mental Health, Homerton Hospital, Homerton Row, London E9 6SR	020 8510 8420	4
Derby	Mother & Baby Psychiatric Unit, Derby City General, Uttoxeter Rd, Derby DE22 3NE	01332 625 591	4
Tooting	Mother & Baby Unit, Springfield Hospital, 61 Glenburnie Rd, London SW17 7DJ	020 8682 6000	4
Cardiff	Mother & Baby Unit, Monmouth House, University Hospital, Heath Park, Cardiff CF14 4XW	02920 747747	3
Leicester	Mother and Baby Unit, Brandon Unit, Leicester General Hospital, Coleman Road, Leicester LE5 4PN	0116 225 6174	3
Glasgow	Perinatal Mental Health Service, Department of Psychiatry, Southern General Hospital, 1345 Govan Road, Glasgow G51 4TF	0141 232 7635	6
Kent (Independent Sector Unit)	Mother and Baby Unit, Godden Green Clinic, Godden Green, Sevenoaks, Kent TN15 0JR	01732 763 491	12