



Prevention in mind

All Babies Count: Spotlight on Perinatal Mental Health

Sally Hogg

NSPCC 
Cruelty to children must stop. **FULL STOP.**

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All the mothers who took part in the Bounty 'Word of Mum™' Research Panel.

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This report is one of a series of Spotlight reports that will be published as part of the NSPCC's **All Babies Count** campaign. **All Babies Count** aims to raise awareness of the importance of pregnancy and the first year of life to a child's development. The NSPCC is calling for better early support for parents during this period to ensure all babies are safe and able to thrive. Our Spotlight reports focus on particularly important issues that affect families during this time.

EXECUTIVE SUMMARY

- During pregnancy and in the year after birth women can be affected by a range of mental health problems, including anxiety, depression and postnatal psychotic disorders. These are collectively called perinatal mental illnesses.
- Perinatal mental illnesses affect at least 10% of women and, if untreated, can have a devastating impact on them and their families. When mothers suffer from these illnesses it increases the likelihood that children will experience behavioural, social or learning difficulties and fail to fulfil their potential.
- The onset and escalation of perinatal mental illnesses can often be prevented through early identification and expert management of a woman's condition, and prompt and informed choices about treatment. Even if the illness itself is not preventable, it is possible to prevent many of the negative effects of perinatal mental illness on families.
- Effective prevention, detection and treatment of perinatal mental illnesses could have a positive impact on the lives of tens of thousands of families in England, and improve the wellbeing, health and achievement of children across the country.
- Universal services – particularly midwives, GPs and health visitors – have an important role in identifying mothers who are at risk of, or suffering from, perinatal mental illness, and ensuring that these women get the support they need at the earliest opportunity.
- If we are to significantly reduce the harm caused by perinatal mental illnesses in England, a significant change is needed in our universal services so that health professionals are confident in detecting, discussing and dealing with mental illnesses. Mental health needs to be given parity of esteem with physical health in the work of primary care services.
- A range of services must be in place in every local area to ensure that women who are at risk of, or suffering from, perinatal mental illnesses are given appropriate support at the earliest opportunity. To achieve this there should be strategic commissioning of perinatal mental health care pathways in every area, based on accurate data or evidence-based calculations on levels of need.
- Specialist midwives can act as champions for women with mental illness in their area; provide women with specialist support; help to develop local care pathways, and provide training and advice for other maternity staff.
- In every area, women with perinatal mental illness should be able to promptly access psychological support if they need it, including both individual or group therapeutic services. Pregnant women and those with a baby should be a priority for psychological therapy (IAPT) services.
- Women with perinatal mental illnesses and their babies have specific needs, and it is important that they are given expert specialist care. Therefore every area should have a specialist community perinatal mental health team with expertise in this area.
- Expert early identification and management of perinatal mental illness should prevent women reaching the point where they need inpatient care. However, if women with severe perinatal mental illness do need to be admitted for 24 hour care, it is important that they can access a specialist Mother and Baby Unit. Without access to a specialist unit, women can go without the intensive expert care that they need, and are separated from their babies, which is traumatic and can disrupt vital early bonding.
- If untreated, perinatal mental illness can inhibit a mother's ability to provide her baby with the sensitive, responsive care that he or she needs. To reduce the impact of perinatal mental illness on babies, mothers must get timely support from services which explicitly address

their interactions with their babies; supporting mothers to give babies the physical and emotional care that they need to thrive. Without this support, maternal mental illness can have a negative impact on infant mental health.

- Partners and other family members can provide important support to a woman who has a perinatal mental illness, and also reduce the impact of her illness on their baby and other children. Therefore it is important that services for women with perinatal mental illness engage, support and work with partners and other key family members.
- There is a wealth of evidence and expert consensus about what works in tackling perinatal mental illnesses, and some excellent services do exist. However, as the infographic on the next page shows, there are currently huge gaps in the services to support families affected by perinatal mental illnesses in England. These gaps mean that we are failing to prevent the harms caused by perinatal mental illness, jeopardising the current safety and wellbeing of women and children, and their future life chances.
This document is a call to action for key decision makers at a national and local level to work together to close these gaps, to improve the lives of families, and to prevent unnecessary suffering.

Falling through the cracks

At least one in ten women will suffer from a perinatal mental illness. Mothers who experience perinatal mental illness need high quality, expert care. But the evidence shows that they do not get the care and support they need.

700,000

women in England give birth each year

There is a shortage of

5,000

midwives in England



73%

of maternity services do not have a specialist mental health midwife



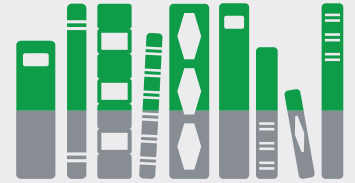
of PCTs did not have a perinatal mental health strategy



of mental health trusts do not have a perinatal mental health service with a specialist psychiatrist

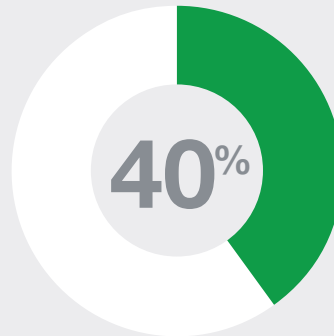
29%

of midwives said they had received no content on mental health in their pre-registration training

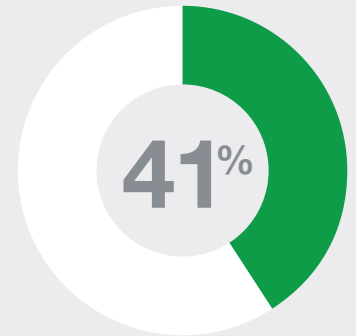


42% of GPs said they lacked knowledge about specialist services for people with severe mental illnesses

Nearly all women see a midwife during pregnancy but...



say they saw a different midwife at every appointment



say their health visitor or midwife never asked about depression

“ There is NO specialist training on perinatal mental health for Improving Access to Psychological Therapies providers ”

There is a shortage of

50

beds in Mother and Baby Units

INTRODUCTION

Mental illnesses affect more than 1 in 10 women during pregnancy and the first year after childbirth, and can have a devastating impact on them and their families.^{1,2} Effective and timely action by public services can prevent much of the harm done by perinatal mental illnesses. This report shines a spotlight on these illnesses: it discusses their nature, prevalence, and effects on families; the care that women and their families need, and the gaps in services that currently exist in England.

Perinatal mental illnesses are diverse and complex. A range of services are required in order to prevent these illnesses where possible, identify and treat them when they do occur, and mitigate their effects on families. This report reveals that at the moment a 'postcode lottery' determines whether families get the right help. In some local areas there are good services in place, but in others there are gaps and families cannot access the help they need. Public services are failing to tackle perinatal mental illnesses effectively, and in doing so are jeopardising the wellbeing of women and children, and their future life chances. The neglect of these preventable or manageable conditions by public services is a national scandal.

The action needed to tackle perinatal mental illness is twofold. Immediate action is needed to plug the gaps in services and ensure that women with perinatal mental illnesses get the timely expert support that they need. In addition, we need a step-change towards better prevention of perinatal mental illnesses, and early intervention when they do occur. Perinatal mental illnesses are a major public health issue. With the right action from midwives, GPs, health visitors, specialist mental health services and others, much of the harm done by perinatal mental illness can be prevented. The whole system needs to be better at preventing the onset of illness in women who are known to be at risk, and acting quickly and appropriately when illness does occur.

This report consolidates the latest evidence about perinatal mental illness and makes recommendations for policy makers,

commissioners and providers. The actions called for in this document are consistent with Government policy, the Healthy Child Programme, and with the recommendations made by many experts in the sector, including the Royal College of Psychiatrists. Many of the services described here are also included in NICE guidance. Much has been written on this topic in the last decade. However, despite the repeated evidence of problems, consensus from experts on what needs to be done, and a helpful policy environment, families are still not receiving the support they need. We have published this document as a call to action for key decision makers at a national and local level to work together to close gaps in services, to improve the lives of families, and to prevent unnecessary suffering.

The action required to tackle perinatal mental illnesses is clear, the additional spending required is relatively small, and the potential gains are enormous. The shortage of beds in Mother and Baby Units is a clear example of this. As a result of this shortage, babies are separated from their mothers at a critical period in their development, and women are admitted to general psychiatric wards where they do not get the specialist care they need. Less than £6 million additional funding per year would be sufficient to provide a Mother and Baby Unit bed for every woman in England who needs one. This amount would be lower if effective prevention reduced the number of women needing this care. An investment in Mother and Baby Units should generate long-term savings for public services through improved outcomes for mothers and babies.

The Coalition Government has shown wisdom in pledging to improve both maternity and mental health services, and we were pleased to see a commitment to diagnosis and support for women experiencing postnatal depression in the Mid-Term Review.³ Many of the recommendations in this document echo the principles of the Government's 'No Health without Mental Health' Strategy which calls for early intervention, equality of

access, and a 'whole-family' approach.⁴ The Government's pledges to increase the number of health visitors and midwives, and to extend the Family Nurse Partnership are also very positive. This report reveals, however, that the Government's commitments are still far from a reality for many expectant and new parents and their families. More can and must be done.

National and local governments, health commissioners and providers need to focus their attention and take action now. Government must lead these efforts to turn its vision into reality.

The scope of this report

This report focuses specifically on the services and support needed by women who experience perinatal mental illnesses. It does not cover the wider work that can, and should be done to improve the emotional wellbeing and mental health of pregnant women, and indeed the wider population. This work is also very important and we are pleased that Public Health England has a focus on public mental health in their work. If successful, this could reduce the need for some of the services in this report in the future.

We have not included any detail on the work that needs to be done to tackle the issues of stigma, and poor awareness and understanding of mental illness more generally. These too are important and we support programmes like Time to Change that are doing excellent work in this space.

This report focuses on the mental illnesses experienced by women in the perinatal period. It acknowledges the prevalence of depression amongst fathers and the need to support men who are affected by their partner's mental illness. However, it does not go into detail about the evidence about paternal mental illnesses and the support that fathers need. Readers who are interested in this could read the useful review of the evidence on the Fatherhood Institute's website.⁵

This report focuses specifically on provision in England, although the problems faced by women and the care and support that they and their families need are similar in all jurisdictions of the UK.

THE ISSUE

What are Perinatal Mental Illnesses?

Perinatal mental illnesses are a range of conditions, which affect at least 10% of new mothers

During pregnancy and after birth, women can be affected by a range of mental health problems, including anxiety disorders, depression and postnatal psychotic disorders. Sometimes the term ‘postnatal depression’ is wrongly used to refer to all mental illnesses experienced by women in the perinatal period, when actually it is just one of a number of conditions. In this report we use the term ‘perinatal mental illnesses’ to capture all of these conditions.

Some women who experience mental illness in the perinatal period may have no history of mental illness and experience it for the first time in relation to their pregnancy or childbirth. Other women may have a pre-existing mental illness which persists, deteriorates or recurs during the perinatal period as the result of the intense social, psychological and physical changes occurring at this time, because of a change in medication, or as a result of the events of childbirth.

The incidence of many mental health disorders does not change in the perinatal period: pregnant women and new mothers have the same level of risk as other adults, although the effects of these illnesses are likely to be more significant at this critical period in their lives. However for certain serious mental illnesses – postpartum psychosis, severe depressive illness, schizophrenia and bipolar illness – the risk of developing or experiencing a recurrence of the illness does increase after childbirth.⁶

Depression is the most prevalent mental illness in the perinatal period, with research suggesting that around 10 to 14% of mothers

are affected during pregnancy or after the birth of a baby.^{7,8} Many cases of depression are mild, but a significant proportion of mothers suffer from a severe depressive illness.⁹ The key symptoms of depression include persistent sadness, fatigue and a loss of interest and enjoyment in activities. Evidence also shows that symptoms of anxiety and depression often co-occur.¹⁰ Whilst we often associate depression with the postnatal period, symptoms of anxiety and depression are actually more likely to occur in late pregnancy than after birth.¹¹ A number of studies have shown that many women who have postnatal depression have symptoms of depression in pregnancy, and therefore can be identified antenatally.¹² Better antenatal detection of depression therefore offers an opportunity for earlier intervention to address the illness and reduce the risk that it will cause longer term problems for the mother or her baby.

“I always wanted to be a Mum. When my first son was born, I was fine. I looked forward to the birth of my second baby, another little boy, he stopped breathing when he was 6 hours old, he’s fine now, but I wasn’t. By the time he was 3 months old I had started planning his funeral, even picking out the clothes he would wear. I know it sounds awful but I was so convinced he was going to die, when I tried to sleep I would dream of graves, digging graves, so I stopped sleeping. I convinced myself that if I stayed awake he wouldn’t die and I had this unshakeable belief that if I told anyone of my plans, even my husband, my son would die. When I thought of depression and anxiety disorder before this I always pictured somebody not able to get out of bed, to laugh, but I could. I got really good at pretending.”

Quote from a mother on the Bounty ‘Word of Mum™’ Research Panel.

Perinatal obsessive compulsive disorder (OCD) causes women to experience severe

anxiety, obsessions and compulsive behaviours. OCD can occur at any time, but the onset of OCD or worsening of symptoms has been associated with pregnancy and childbirth.¹³ This is thought to be a result of hormonal changes, and the psychological stress of pregnancy and infant care. The evidence on the prevalence of perinatal OCD is not definitive, but some studies have suggested that it is experienced by around 3% of new mothers.¹⁴ The symptoms of OCD vary widely from individual to individual. Perinatal OCD is similar to other forms of OCD, but the focus of a woman's obsessions and compulsions are more likely to focus on the baby. For example, women might experience extreme fears of harming their baby, which lead to excessive checking on the baby and seeking reassurance.¹⁵ These thoughts and the behaviours that follow from them can interfere significantly with women's wellbeing and their experiences of pregnancy and parenting. Many women with perinatal OCD also experience depression.¹⁶ Their depression is more likely to be detected because there is better professional awareness of, and screening for, depression in the perinatal period, but the symptoms of OCD often go undiagnosed.

Postpartum psychosis (also known as puerperal psychosis) is a severe mental illness that affects around 2 in 1000 new mothers¹⁷ and causes symptoms such as confusion, delusions, paranoia, hallucinations (usually hearing voices), and mood symptoms of mania and depression. Unlike milder forms of depression and anxiety, this severe mental illness is more likely to occur after childbirth. Most cases occur during the first few weeks of a child's life.¹⁸ Women are 20 times more likely to be admitted to a psychiatric hospital in the two weeks after delivery, than at any other time in the two years before or afterwards.¹⁹

Post-traumatic stress disorder (PTSD), and mental health problems which result from childhood trauma, such as emotionally unstable personality disorder, can recur or worsen both during pregnancy and after childbirth. Research suggests that rates of PTSD are higher in pregnant women than in adult female population as a whole.²⁰ It is thought that the experience of being pregnant triggers the symptoms of these disorders,

particularly for women who have experienced childhood abuse or sexual abuse and who may experience complex feelings as a result of becoming a parent, and the physical care experienced in pregnancy.²¹

Post-traumatic stress disorder can also be triggered by childbirth, and is estimated to occur in approximately 3% of women after birth. Women are particularly at risk if they have an emergency caesarean, are admitted to high dependency or intensive care units, or if their baby dies.²²

Whilst this document focuses primarily on *maternal* mental illness, it is important to note that many fathers also suffer from mental health problems in the perinatal period, and between a quarter and half of new fathers with depressed partners are depressed themselves.²³ Paternal depression in the perinatal period has been shown to affect couple relationships and the developing infant.^{24,25}

Some women are at higher risk of maternal mental illness

Some women are at increased risk of experiencing mental illness in the perinatal period, particularly those who have a history of mental illness. Women who have suffered from a severe perinatal mental illness such as postpartum psychosis or severe depression in the past have around a 50% chance of it recurring in a subsequent pregnancy.²⁶ Women who have had a previous episode of bipolar disorder (which may or may not have been related to the birth of a child), are also at an increased risk of having a severe episode in the perinatal period, even if they have been well during pregnancy and for many years previously.²⁷ Having a first-degree relative affected by mental illness is also an added risk factor for perinatal mental illness.²⁸

Experiences and socio-economic factors can also increase the risk of mental illness or exacerbate its effects. Rates of perinatal depression are higher amongst women experiencing disadvantages such as poverty or social exclusion.²⁹ The risk of depression is also twice as high amongst teenage mothers.³⁰ In addition the stress caused by issues such as poor housing, domestic violence and poverty can exacerbate symptoms of anxiety and depression.

The box below summarises some of the factors that are known to increase a woman's risk of illness. However it is important to note that the causes of perinatal mental illness are complex and heterogeneous, and these are risk factors rather than determinants of illness.

Factors associated with increased risk of perinatal mental illnesses³¹

- history of mental illness
- family history of mental illness
- psychological disturbance during pregnancy (eg. anxiety or depression)
- lone parent or poor couple relationship
- low levels of social support
- recent adverse or stressful life events
- socio-economic disadvantage
- teenage parenthood
- early emotional trauma/childhood abuse
- unwanted pregnancy

Despite the increased risk of mental illness amongst some disadvantaged groups, we must not forget that women from all parts of society can be affected by mental illness: over half of the women who committed suicide during pregnancy or shortly after birth in the UK between 2006 and 2008 were white, married, employed, living in comfortable circumstances and aged 30 years or older.³² Universal services who work with women during the perinatal period must be alert to the risks of perinatal mental illness in all the women they work with.

The onset and escalation of symptoms of mental illness can often be prevented through proper management of a woman's condition, avoidance of environmental risk factors and triggers such as stress or sleeplessness, and making prompt and informed choices about medication. This is why it is critically important to identify women who are at risk and ensure they get timely and appropriate support.

Maternal suicides

Mental illness is one of the leading causes of maternal deaths in the UK. Between 2006 and 2008, 29 women were known to have committed suicide during pregnancy, or in the 6 months after delivery. The number of new mothers committing suicide has not fallen over the past decade. Psychiatric disorder is also associated with maternal deaths from other causes, and in the same period a total of 67 deaths were recorded as being the result of, or associated with, a psychiatric disorder. Many of these deaths could have been prevented with prompt referrals to specialist services, and in particular specialist inpatient Mother and Baby Units.³³

Estimated numbers of women affected by perinatal mental illnesses in England each year



1,380



Postpartum psychosis

Postpartum psychosis is a severe mental illness that typically affects women in the weeks after giving birth, and causes symptoms such as confusion, delusions, paranoia and hallucinations.

Rate: 2/1000 maternities

1,380



Chronic serious mental illness

Chronic serious mental illnesses are longstanding mental illnesses, such as schizophrenia or bipolar disorder, which may be more likely to develop, recur or deteriorate in the perinatal period.

Rate: 2/1000 maternities

20,640



Severe depressive illness

Severe depressive illness is the most serious form of depression, where symptoms are severe and persistent, and significantly impair a woman's ability to function normally.

Rate: 30/1000 maternities

20,640



Post traumatic stress disorder (PTSD)

PTSD is an anxiety disorder caused by very stressful, frightening or distressing events, which may be relived through intrusive, recurrent recollections, flashbacks and nightmares.

Rate: 30/1000 maternities

86,020



Mild to moderate depressive illness and anxiety states

Mild-moderate depressive illness includes symptoms such as persistent sadness, fatigue and a loss of interest and enjoyment in activities. It often co-occurs with anxiety, which may be experienced as distress, uncontrollable worries, panic or obsessive thoughts.

Rate: 100-150/1000 maternities

154,830



Adjustment disorders and distress

Adjustment disorders and distress occur when a woman is unable to adjust or cope with an event such as pregnancy, birth or becoming a parent. A woman with these conditions will exhibit a distress reaction that lasts longer, or is more excessive than would normally be expected, but does not significantly impair normal function.

Rate: 150-300/1000 maternities

* There may be some women who experience more than one of these conditions.

Source: Estimated using prevalence figures in guidance produced by the Joint Commissioning Panel for Mental Health in 2012 and ONS data on live births in England in 2011.

How can perinatal mental illnesses affect children?

Perinatal mental illnesses can have a lasting effect on some children

It is not only women and their partners who are affected by perinatal mental illnesses; their children can be too. It is estimated that approximately one quarter of adults using mental health services in the UK have dependent children.³⁴ The NSPCC's All Babies Count report showed that in England approximately 122,000 babies under one are living with a parent who has a mental health problem.³⁵ Whilst the majority of adults with mental illnesses are good parents, and others can manage if appropriate support is provided, there is a risk that without the right support perinatal mental illnesses can have a lasting effect on their children.

If not managed effectively, maternal mental illnesses in pregnancy and the early years of a child's life can have adverse effects on a child's brain development and long-term outcomes.³⁶ It is important to note that, whilst perinatal mental illness increases the risk of children experiencing poor outcomes, it does not determine that they will. Many children whose mothers have perinatal mental illness go on to achieve their full potential, particularly if their mothers receive effective support.

Children of mothers experiencing perinatal mental illness are at increased risk of prematurity and low birth weight, irritability and sleep problems in infancy, and behavioural problems and academic difficulties when they get to school.^{37,38,39,40,41} The risks of children experiencing these poor outcomes are greatest when their mother's mental health problems begin in pregnancy or the first year of life, are long lasting and/or severe, although other children are also at risk.⁴²

The South London Child Development Study showed that children of mothers who were anxious or depressed in the perinatal period:

- had lower IQs at 11 and 16 years of age (20 points lower for boys);
- were 12 times more likely to have a statement of special needs in primary school;
- had an elevated risk of violence at 11 and 16 years of age, and
- were more likely to have a diagnosis of depression themselves at age 16.^{43,44}

It is clear that a 'life course' approach, as advocated by the Government's Mental Health⁴⁵ and Public Health Strategies,⁴⁶ requires that we take perinatal mental illness seriously. When we consider that at least 1 in 10 children will have a mother suffering from perinatal mental illness at the start of their lives, the need for action in this area is clear. Addressing perinatal mental illness could have a substantial positive impact on the wellbeing, health and achievement of children in England.

There are many ways that perinatal mental illness can affect children, beginning before birth

Maternal mental illness can affect children both directly and indirectly, and the causal pathways that lead to poor outcomes for children are neither clear nor simple.

A mother's mental health can affect her baby even before he or she is born. Studies have shown that a range of mental illnesses including depression, anxiety, PTSD and schizophrenia all increase the risk of both early delivery and low birth weight.^{47,48,49} Whilst many babies who are born early and have low birth weight will go on to be healthy and develop normally, these things increase the risk of infant mortality, suboptimal growth, illnesses, neurodevelopmental problems and long-term cognitive outcomes.^{50,51}

A mother's mental health can also affect the way in which her baby's neurological and hormonal systems develop. It is believed that the stress chemicals produced by women experiencing depression and anxiety during pregnancy pass through the placenta into the womb and affect fetal development. Exposure to stress hormones in the womb is thought to affect the child's developing stress response systems which will change how he or she behaves and responds to stimuli and stress when she is born. One study found that depression and anxiety during the third trimester of pregnancy predicted between a quarter and a fifth of infants' observed behavioural reactivity at four months.⁵² Other research has shown that anxiety and depression in pregnancy can have clinically significant effects that continue as a child gets older, even when controlling for factors such as the mothers' postnatal mood. One study has shown that if a mother was in the 15% of the population with the worst anxiety and depression during pregnancy, this doubled the risk of her child having a mental disorder at 13 years of age. However it is important to note that the risk doubled from 6% to 13% – the majority of children whose mothers were ill did not go on to develop a mental disorder in their teens.⁵³

Children whose mothers experience mental illnesses can also be affected indirectly. Mental illnesses often co-occur with, and in some cases cause, other forms of disadvantage. For example, mothers with mental illnesses are at greater risk of unemployment and marital conflict, which are associated with worse outcomes for children.⁵⁴

The effects of perinatal mental illness on mother-infant interactions are particularly important

After birth, mental illness can affect a mother's ability to care for her baby, her parenting style and her developing relationship with her baby.

Interaction with caregivers is the most important element of a child's early experience, and lays the foundations for his or her social and emotional development. It

is through these early interactions that babies learn how to recognise and regulate their own emotions, and build the foundations for later relationships.⁵⁵

During the first year of life, children should develop their first attachment relationship – a significant and stable emotional connection with their primary care giver. The nature of this early attachment sets the template for later relationships, and can predict a number of physical, social, emotional and cognitive outcomes.⁵⁶

Researchers distinguish between four different types of attachment. *Secure attachment* enables the child to feel safe, secure and protected, and is likely to result in them developing social competence and resilience which helps them to cope in later life. *Insecure attachment* falls into three categories – ambivalent, avoidant or disorganised. Children with these types of attachment relationships may have experienced inconsistent or insensitive care and therefore are not able to rely upon their relationship with their primary caregiver. Insecure attachment has been found to be higher in children whose mothers suffer from mental illnesses such as depression or schizophrenia.^{57,58}

In order to develop secure attachment relationships, babies need their primary caregiver to be able to recognise and understand their behaviour and feelings, and respond appropriately.⁵⁹ This capacity is known as parental reflective function,⁶⁰ and can be impaired in women who have a mental illness.⁶¹ Even relatively mild mental illnesses, if untreated, can inhibit mothers' abilities to provide babies with the sensitive, responsive care that they need. In some cases it can lead to mothers being distant and detached, and in cases at the other extreme, it can lead to mothers interacting with their babies in an intrusive or aggressive way.⁶² Either of these extremes means that babies do not receive the warm, consistent, sensitive care that they need to thrive.⁶³ **Of course, not all women with a mental illness will lack reflective capacity, and with the right support many are able to become more attuned and responsive to their babies' needs.**⁶⁴

“My second child was unplanned, and she came along at a really stressful time in my life ... I didn’t feel happy and was ashamed that I wasn’t bonding with her the way I had with my first child, who I had wanted very much. I felt like a horrible person and an inadequate mother. I had no family close by, and I spent my days sitting on the couch crying. It was horrible ... It wasn’t until after my daughter turned one that I began to feel a connection to her.”

Quote from a mother on the Bounty ‘Word of Mum™’ Research Panel.

In more serious cases, parental mental illness increases the risk that children will be abused or neglected. Children are particularly at risk if parents experience psychotic beliefs about the child; if mental health problems result in parental conflict or isolation; or if mental health problems significantly impair parents’ ability to function.⁶⁵ Sadly, in very rare cases, babies have been killed by mothers suffering from postnatal psychotic illnesses that have not been effectively and expertly treated. The abuse, neglect and death of children whose mothers have perinatal mental illness should be preventable if services detect a mother’s illness early, take prompt action to treat it, and assess and manage the risks to her family.

While all of this evidence paints a worrying picture, the good news is that we can prevent much of the negative impact that perinatal mental illness has on mothers’ and children’s lives. Emerging evidence suggests that the quality of parents’ interactions with their babies, and the quality of attachment relationships can be improved through effective interventions. This is yet another reason why it is important that maternal mental illness is detected early and swift action taken to support mothers and their families.

THE WAY FORWARD

A range of services are required to prevent perinatal mental illnesses, treat them when they occur, and mitigate their effects on families. The remainder of this report explains the core support that should exist in every local area. It begins by describing a vision for universal services which will support all women, and ensure that those who have additional needs get timely access to appropriate services. It then moves through to describe the targeted and specialist services needed by those families affected by moderate and serious illnesses.

To bring each section to life, we have included quotes from women who responded to an original survey by *Bounty – the parenting club* about their experiences in the perinatal period, together with examples of good practice and composite case studies that show what gaps in services really mean for women and their families.

Some of the recommendations in this report have been championed by practitioners, academics and other charities over a number of years. The NICE guidance on antenatal and postnatal mental health^{66,i} recommends that health trusts put in place many of the services and interventions detailed here. Sadly however, despite the large consensus about the support that families need, large gaps in provision still exist. **This report is a call to action for managers, commissioners and policy makers to work together to close these gaps in order to improve the lives of children and families, and prevent unnecessary suffering.**

i The NICE guidance on antenatal and postnatal mental health is currently under review and due to be published in 2014. This will provide a good opportunity to remind health commissioners and providers of their role in tackling perinatal mental illness.

What Success Looks Like

Our vision is that women who are at risk of, or suffering from mental illness are identified at the earliest possible opportunity and given appropriate and timely expert care which prevents their illness from occurring or escalating, and minimises the harm suffered by them and their families.

In order to achieve this we believe that:

Universal Services must be able to identify issues early and ensure that all women get the support they need.

- All women should receive continuity and consistency of care from sensitive and supportive midwives and health visitors.
- Perinatal mental illness should be incorporated into pre-registration training for all midwives, health visitors and GPs, and they should be encouraged to attend refresher training once qualified.
- Midwives should tell mothers and fathers about perinatal mental illnesses.
- Midwives should feel comfortable and confident asking women about their mental health, and use evidence-based tools to help them to detect problems antenatally and postnatally.
- Information about risks or symptoms of mental illness must be shared appropriately between professionals.
- Professionals must actively manage cases where a risk of mental illness has been identified.
- Every maternity service should have a Specialist Mental Health Midwife to champion the needs of women with perinatal mental illnesses.

Timely psychological support must be available to all expectant and new mothers with mild or moderate mental illnesses.

- Medication should be prescribed cautiously to women with mild or moderate mental illnesses, and women who are given medication should also be offered additional support.
- There should be evidence-based individual and group therapeutic services in every area.
- Expectant parents and those with young children should be a priority for IAPT services.
- Parents should be able to access therapeutic support within one month of identification.
- Women with perinatal mental illness should have access to sources of social support, including the opportunity to share experiences and support one another.

Women should be able to access specialist perinatal mental health teams and inpatient units when necessary.

- Every area must have a Specialist Perinatal Mental Health Service.
- Every new mother who needs inpatient psychiatric care must be able to access a nationally accredited Mother and Baby Unit.

Services must address the impact of perinatal mental illnesses on babies and other family members.

- Services must help mothers to provide sensitive and responsive care, and develop healthy relationships with their babies.
- Services must involve and support fathers.
- In the worst cases, where a baby is removed or a mother dies, professionals must ensure that ongoing support is available for the family.

There must be strategic commissioning of perinatal mental health care based on need.

- Every local area must develop and deliver a perinatal mental health strategy.
- There must be local clinical leadership in each area to champion the needs of women with perinatal mental illnesses.
- There must be accurate data about women's needs to inform local commissioning and planning.
- Commissioning and funding arrangements for specialist perinatal mental health services must support preventative work.

PART 1: UNIVERSAL SERVICES

Universal Services must be able to identify issues early and ensure that all women get the support they need

Universal services – particularly midwives, GPs and health visitors – have contact with nearly all families during pregnancy and the postnatal period. This provides a great opportunity, and means that they can play an important role in identifying mothers who are at risk of, or suffering from, perinatal mental illnesses and take action to ensure that these women get the support they need at the earliest opportunity. This section details the things that universal services need to know and to do in order to achieve our vision.

All women should receive continuity and consistency of care from sensitive and supportive midwives and health visitors

All new mothers and their partners would benefit from sensitive and supportive care from consistent professionals during the perinatal period. This sort of care increases the likelihood that professionals will identify, or be told about, mental health problems when they arise. If a woman sees the same midwife at all her appointments, and feels able to talk openly and honestly to that midwife, then she is more likely to be able to disclose concerns about her mental health, and the midwife is more likely to be able to identify changes in her behaviour or mental state which may give cause for concern.

Sadly many families in England do not currently receive this sort of care. In a survey of new mothers by *Bounty – the parenting club* for the Royal College of Midwives (RCM) in summer 2012, 40% of women reported that they had seen a different midwife at every contact during their most recent pregnancy.⁶⁷ In a survey for the NSPCC, only around half of pregnant women or new mothers reported that they felt able to tell their midwife or health visitor about mental health issues. Many reported that this was because they didn't feel comfortable with their midwife or health visitor, and saw a different person at every appointment.

"I feel that I've struggled most with anxiety and stress, having two children under 2 years old was hard. I only saw my midwife three times following my youngest child's birth and then a health visitor came to the house twice. I never really got a rapport with either of the health professionals (they were nice but I never saw them enough). Therefore I felt that I couldn't talk to them about my feelings."

Quote from a mother on the Bounty 'Word of Mum™' Research Panel.

In recent years, midwifery teams have struggled to introduce the caseload systems required to deliver continuity of care, largely because of staff shortages: The RCM estimates that there is a shortage of 5,000 FTE midwives in England.⁶⁸ However things are getting better. The Government has pledged that every woman should have a consistent midwife throughout her pregnancy and the immediate postnatal period, and has invested in 5,000 midwives, who are currently in training.⁶⁹ The RCM recently reported that the shortage in midwives is coming down.⁷⁰ Similarly the Government's pledge to create an additional 4,200 health visitors, and to expand the Family Nurse Partnership should also ensure that more women receive the professional support they need in pregnancy and the first years of their child's life.

Government must deliver on its commitment to secure continuity of care during the perinatal period: ensuring there is sufficient funding in the system to recruit the midwives required, and holding commissioners and providers to account for delivering on this promise.

Continuity of care is only part of the answer. Midwives and health visitors also need to develop strong and supportive relationships with women. Many would, of course, see this as core to their role. However enquiries

into maternal deaths have found that some midwives can focus too much on collecting information about a woman's medical history in a "task-orientated" way, rather than spending time in conversation, exploring the woman's situation.⁷¹ The Healthy Child Programme recommends that health visitors and midwives use techniques like motivational or promotional interviewing which enable them to communicate more effectively with parents and help them to explore their situation and make informed decisions about their, and their families', needs. There are excellent examples of this approach being widely used, but it is still far from consistent. In the recent survey by *Bounty – the parenting club*, for the NSPCC, many women reported that their interactions with health visitors and midwives felt rushed and impersonal.

All local midwife and health visitor managers must work to improve the quality of interactions between women and professionals, including:

- ensuring midwives and health visitors are trained in the use of techniques like motivational interviewing, and
- ensuring appointment times are long enough to enable good quality discussions with women about their experiences and needs.

Perinatal mental illness should be incorporated into pre-registration training for all midwives, health visitors and GPs, and they should be encouraged to attend refresher training once qualified

Because midwives, health visitors and GPs can play such an important role in the early detection and escalation of concerns about perinatal mental illness, they should all receive training so that they know how to identify the signs and symptoms of mental illness, what advice and support to give women, and how to refer women for additional support in their local area. There

are many outstanding professionals across the country who do excellent work, but sadly we also hear stories of some who do not have the skills or knowledge required to deal with these problems.

"Doctors diagnosed me with postnatal depression and told me to get a nanny or give up breastfeeding and take anti-depressants. Left me feeling like no one understood and nearly resulted in me taking my life."

Quote from a mother on the Bounty 'Word of Mum™' Research Panel.

There is no mandatory requirement for perinatal mental illness to be covered in either midwife or health visitor pre-registration training. We think that this is shocking. In reality the topic is covered in most programmes, but the quality and quantity of this training is currently very patchy and must be improved. Research has shown that 29% of midwives said that they had received no content on mental health in their pre-registration training. Of those that had, only 17.6% said that it was sufficient.⁷²

Government should introduce a requirement for perinatal mental illnesses to be covered in pre-registration training for midwives and health visitors. Mental health must be given parity of esteem with physical health.

The providers of this training should ensure that midwives and health visitors gain the knowledge, skills and confidence to deal with perinatal mental illness.

The Royal College of GPs (RCGP) has raised concerns that the current three year training programme for general practice provides GPs with only limited opportunities to receive specialist-led training in mental health. They estimate that only 50% of doctors in training for General Practice currently have the opportunity to undertake specialist-led mental health training placements. RCGP propose that specialist-led mental health training should become a mandatory part of an extended, four-year core training

programme for all new GPs. Health Education England has accepted the 'educational case' for this extended GP training and is working with partners to agree how this can be implemented.⁷³ The Department of Health is simultaneously looking into the economic case and affordability of the extension. We strongly support extension of GP training, and believe that perinatal mental illness needs to be embedded in the 'core curriculum' for GPs, and that GPs should have specific opportunities to train in perinatal mental illness.

Government should agree to the proposed extension to the GP core training, and ensure that this results in all GPs having improved training in perinatal mental health.

Even if the quality of pre-qualification training improves, professionals in universal health services will still need regular training to refresh their knowledge and skills. We are pleased to see that the Government is creating a new training programme in perinatal mental health which will be available to health visitors from summer 2013.

Research has shown that whilst there is training in maternal mental health available, it is not widely accessed, partly because staff are very stretched, attendance at training is not mandatory and there are competing demands for study time.⁷⁴ Therefore it is important that staff are encouraged and enabled to attend this training.

The NSPCC issued a Freedom of Information (Fol) request to all health trusts in England that provide maternity services to find out what training their midwives have done relating to perinatal mental illness. 123 (84%) of the trusts responded. Of these, more than 10% reported that not a single midwife from their trust had done any training in perinatal mental illness in the last year.

100 trusts reported that their midwives were required to do some training in perinatal mental illness, and of these, 74 said that midwives were required to do mandatory annual training. However in many cases, this training consisted of a PowerPoint presentation during a study day, which was

often less than an hour long, and which sometimes also sought to cover other important issues such as safeguarding or domestic abuse in the same session. We do not believe that this is sufficient.

Providers of maternity and health visiting services should ensure that midwives and health visitors have good quality refresher training in perinatal mental illness at least every two years. Training must be delivered by an expert who has had particular training and experience in working with women with perinatal mental illness. It should cover a range of issues, including the identification and management of the full range of perinatal mental illnesses; risk factors; safeguarding concerns; medication; local care pathways, and how to make a referral. It should not only consist of taught content, but also some interactive activities that give professionals the opportunity to build their confidence and skills, such as the opportunity to discuss case studies or role play conversations with clients.

It is important that professionals are supported to understand the care pathways and protocols in their local area. Local multiagency training can be useful in helping professionals to learn how they can work together to best support women and families in their area and to develop a shared approach. This can be an important part of a local perinatal mental health strategy.

Health service commissioners and providers should encourage all midwives, health visitors and GPs to undertake regular refresher training in perinatal mental health. This should part of the local perinatal mental health strategy.

An Educational Resource

The **Breakdown or Breakthrough** films are a resource for professionals working with parents affected by mental illnesses in the perinatal period. The films were created by the NSPCC in partnership with Dr Amanda Jones, Head of North East London NHS Foundation Trust's Perinatal Parent Infant Mental Health Service.

There are five short films, which can be viewed online for free at www.nspcc.org.uk/breakthrough, or can be bought on a DVD from the NSPCC. There is also a set of guidance notes which give an overview of each film and a set of questions for discussion.

The films include personal stories of perinatal mental illness, discussions of the challenges of working with vulnerable families, and summaries of the latest research on the impact of perinatal illness on babies' brains.

Midwives should tell mothers and fathers about perinatal mental illnesses

Many people do not know about the risk and prevalence of perinatal mental illnesses. This means that women may not recognise when they are becoming ill, and may be reticent to discuss this. We believe all midwives should talk to both mothers and fathers about perinatal mental illness in antenatal appointments, so that they are aware of and alert to the symptoms and know what to do if they are affected. We want parents to feel confident seeking support, and not fearful that they will be judged.

Midwives should talk to all mothers and fathers antenatally about the prevalence and symptoms of mental illness and what to do if they are affected.

Midwives should feel comfortable and confident asking women about their mental health, and use evidence-based tools to help them to detect problems antenatally and postnatally

It is not always easy to identify women at risk of, or suffering from a mental illness. A lack of awareness of perinatal mental illness, and the stigma attached to these problems mean that women are often reluctant to raise issues with midwives. These are important issues that need to be tackled. In the meantime, midwives must take proactive action to try and detect women who are at risk of, or suffering from mental illness. This includes both identifying women with a history of mental illness who are currently well, and those who are experiencing symptoms for the first time.

"I developed serious anxiety issues along with depression, I went to my health visitor for help, reluctantly, as I thought she would think I could no longer care for my babies and would take them away ..."

"My ex-husband told me not to tell anyone about my feelings because of what they might do. I suffered in silence for a few months before I told my health visitor ... I often find it hard to tell people how I am feeling for fear of being judged or not believed."

Quote from a mother on the Bounty 'Word of Mum™' Research Panel.

NICE guidance states that at a woman's first contact in the antenatal and perinatal periods, healthcare professionals should ask about her, and her family history of mental illness.⁷⁵ It is important that this is done effectively, and the results recorded and acted upon. The latest enquiry into maternal deaths reported that over half of the women who died from suicide in the perinatal period had a previous history of serious mental illnesses such as bipolar disorder and schizophrenia, and if this history had been known about, and the correct action taken, their suicides may have been prevented.⁷⁶

Midwives should be comfortable in discussing mental health with all women in their antenatal and postnatal appointments, and should encourage women to raise any concerns they may have. They should also be sensitive to any indicators that a woman's mental health may be deteriorating. It is important that their training equips midwives not only with knowledge about perinatal mental illness, but also with the skills and confidence to talk to women about their feelings and explore issues about their mental health.

A number of tools have been developed to help professionals to assess whether they should be concerned about a woman's mental health. The NICE guidance recommends the use of the 'Whooley' questions.⁷⁷ There are also other more detailed tools that can be useful, such as the Edinburgh Postnatal Depression Scale (EPDS). Both the Whooley questions and the EPDS will only identify symptoms of depression and not other symptoms of mental illness, therefore it is important that professionals are alert to the signs of other mental illnesses.

The Whooley Questions

- During the past month have you been bothered by feeling down, depressed or hopeless?
- During the past month have you been bothered by having little interest or pleasure in things?
- If YES is this something you feel you need or want help with?

Although there has been an increase in the use of assessment tools such as the Whooley questions and Edinburgh Postnatal Depression Scales in recent years, they are still not used consistently or comprehensively, particularly not after babies are born.^{78,79,80} It is encouraging that many local health trusts have a policy that midwives should ask women about their mental health.⁸¹ However, a high-level commitment to use the questions does not guarantee that midwives always ask all women the questions, or that they do so in a meaningful way. In a survey for *Bounty*

and the NSPCC, 41% of new mothers said that their health visitor or midwife had never asked them about depression in their most recent pregnancy.⁸²

Researchers have found 'positive resistance' from midwives to asking the Whooley questions because they are afraid that they could uncover issues which would be difficult to resolve, and would create additional work when they are already very stretched.⁸³ This is why it is so important that there are local pathways for women with mental illnesses, and that midwives are informed about these pathways. This will enable midwives to feel confident in asking about women's mental health because they know that support is available if required. It will also ensure that when the risk or onset of mental illness is identified, midwives know what to do with this information to ensure that women get the care they need.

Midwife managers must take concerted action to ensure that questions about mental health are regularly asked of all women, antenatally and postnatally, and that the answers are recorded and acted upon following a locally agreed care pathway.

Information about risks or symptoms of mental illnesses must be shared appropriately between professionals

In each local area, there should be locally agreed care pathways that set out the support that women with perinatal mental illness should receive. These should include processes for sharing information between services in order to ensure that women get the care they need.

It is important that midwives record and share information about a mother's mental health and her risks of developing mental illness with other professionals who are working with her family, and, if necessary, with specialist mental health teams who can offer her additional support. In the most serious cases, where professionals judge that a pregnant woman or new mother has a mental illness that may result in her baby not receiving the

care that he or she needs, the local children's social services team should also be alerted so that they can assess what additional support the family might need.

Research shows that midwives do not consistently record or act when they find that a woman is at risk or experiencing symptoms of mental illness.⁸⁴ This is reflective of wider issues around recording and information sharing during the perinatal period. Work by the NSPCC and others has shown that communications systems between midwives, health visitors and other services are not always robust and consistent, particularly when services are not coterminous, or when women access health services outside their home area.^{85,86}

Many midwives and health visitors now work in community teams, often based in children's centres. This has many advantages. However, in some cases it means that health visitors and midwives have weaker links with GPs than they may have done in the past, and this can make information sharing more difficult. It is therefore important that GPs, midwives and health visitors have clear information sharing protocols and alert one another if they know that a woman has, or is at risk of, mental illness.

It would be ideal if women's records were kept on a central system where they could be accessed by any midwife or health visitor working with her. This is far from being a reality, but should be an ambition for the future.

A women's handheld maternity records, and a child's 'red book' are important tools in ensuring that information about her pregnancy, and about her babies' development is shared with professionals. We therefore support NICE's 2012 recommendation to create standardised hand held maternity notes in England. A standardised hand held record already exists in Scotland, which means that information about a woman's mental health is recorded in a consistent way. We welcome the work that is being done to create an electronic red book, which we hope will improve the way that information about a mother and baby is recorded and shared.

Local maternity services, GPs and health visitors must develop robust local systems and protocols for sharing information about a woman's mental health and risk of mental illness.

The Department of Health, the Royal College of Midwives and the Royal College of Obstetrics and Gynaecology should work together to create standardised maternity notes for England, which capture information about a woman's history and risk of mental illness and her current mental health.

Professionals must work together to actively manage cases where a risk of mental illness has been identified

If women are identified to have, or be at risk of, mental illness, it is important that health professionals proactively manage their case, monitoring and supporting them regularly, and ensuring they receive any additional help that they need. Identification and management of risk is currently very patchy. Research into women who have died as a result of maternal mental illness found that 19 (66%) of the women who committed suicide had a psychiatric history, yet there was evidence of a plan to manage the risk of postpartum recurrence in only 4 cases.⁸⁷

"I suffered puerperal psychosis after giving birth prematurely to twin girls. It took until I got in a pretty bad way before the midwives noticed. I didn't get a visit from the health visitor as the babies were in special care ... I only got help by ringing the Crisis team who helped with my psychosis, if it wasn't for me knowing about them, I really don't know where I would be now as I was having thoughts of suicide ..."

Quote from a mother on the Bounty 'Word of Mum™' Research Panel.

All women at risk of, or suffering from, mental illness should have a written care plan that includes the actions that should be

taken by different agencies to support her. This should include the GP, midwife, health visitor, children's services and any specialist services. Those women who have a history of severe mental illness should be referred to a mental health team during their pregnancy, and this team should play a lead role in developing their care plan.

It is particularly important that professionals ensure that women who are at risk are well supported by all, and that their mental health and functioning are closely monitored in the immediate postnatal period, when serious illness is most likely to emerge. There should also be clear arrangements in place to ensure that babies receive the physical and emotional care and sensitive social interaction that they need if mothers do become ill.

Midwives, Health Visitors, GPs and specialist mental health services must ensure there is a plan in place to monitor and support every woman who is identified as being at risk of perinatal mental illness.

Every area should have a Specialist Mental Health midwife to champion the needs of women with perinatal mental illnesses

Specialist midwives can act as champions for women with mental illness in their area, and can:

- provide women suffering with mental illness with information, specialist support and expert advice;
- be a point of liaison with other midwives and offer them advice on their cases;
- be a key point of contact for social services, health visitors, obstetricians, GPs and mental health services;
- provide training, information and advice for midwives and other professionals in how to deal with mothers experiencing mental illness, and

- work with other local specialists to develop care pathways in the local area.

Specialist midwives should work closely with their local perinatal mental health team to ensure women with severe mental illnesses receive high quality coordinated support. They can also offer specialist support to women with milder mental illnesses which may mean that these women do not have to access specialist services, thus reducing the burdens on specialist services. Professionals working in areas that have a Specialist Mental Health Midwife have observed that some women with mild illnesses prefer to receive the support they need from a midwife rather than a specialist mental health professional.⁸⁸ However it is important that Specialist Midwives supplement rather than replace specialist mental health professionals.

To carry out their role effectively, Specialist Mental Health Midwives should all have additional high quality, in-depth training in perinatal mental illness, and the chance to refresh this training regularly.

In our Freedom of Information requests to maternity services, the NSPCC asked how many trusts had a specialist midwife for women with perinatal mental illness. Only 27% of the 123 trusts that responded had a Specialist Mental Health Midwife. A further 27 (22%) told us that they included mental health within the remit of another specialist midwife, however this was usually alongside other challenging responsibilities such as domestic violence, learning difficulties, substance misuse or safeguarding. Therefore it is unlikely that these midwives would have had sufficient capacity to carry out all aspects of the Specialist Mental Health Midwife role.

All health trusts that provide maternity services should appoint a Specialist Mental Health Midwife.

Case Study

Specialist Mental Health Midwife in Kent

For the last three years, Kent has had a Specialist Mental Health Midwife. This position is funded by the maternity services at Medway NHS Foundation Trust.

Women who are experiencing mental health problems during pregnancy or after birth are referred to the Specialist Midwife who will meet them to discuss their mental health needs, talk to them about how best to manage their psychological difficulties advise them on the support available locally, and make referrals to specialist services if needed.

All women who are referred to the Specialist Midwife are offered a one hour appointment, and encouraged to bring their partner along since they play an important role in supporting the mother and baby. Referrals come from other midwives, as well as GPs, obstetricians, social workers and health visitors.

Since the development of this position, women and their families have experienced much more coordinated support to help them to improve their mental health. The Specialist Midwife provides an all-inclusive service where women are triaged and supported in their personal pathway,

meaning that all women are offered the opportunity to talk to a specialist about their mental health and wellbeing, even if they do not meet the thresholds for other services. Before this position existed, women were often 'bounced' from one service to another because they did not meet the threshold for particular services, or because they had not been referred in the most appropriate way. Now the Specialist Midwife can ensure that when women do need additional support, they are referred to the appropriate services and the quality of the referral is high. This means women get more timely support and also saves time for other midwives, GPs and obstetricians.

The Specialist Midwife is able to develop strong working relationships with other services. In addition to her work with individual women, she also:

- provides mental health training to midwives and other maternity staff;
- is a key member of the perinatal mental health clinical network, which brings together all services for women with perinatal mental illness, and
- sits on a subgroup of the Children's Trust to ensure that children's services consider the needs of families affected by perinatal mental illness.

PART 2: TIER 1 AND 2 SERVICES

Timely psychological support must be available to all expectant and new mothers with mild or moderate mental illnesses

Mothers with mild or moderate depression and anxiety can benefit from a number of different interventions, and it is important that they can access the treatment or support that is most appropriate for them, when they need it. Many women will benefit from evidence-based psychological support, including self-help, counselling and/or individual or group therapeutic services.⁸⁹ Drugs should be prescribed cautiously for women with mild or moderate mental illnesses, but for some women drugs will be appropriate to help them manage their conditions. It is important that all mothers who are given drugs or psychological support are also offered support to help them to develop their relationships with their babies, as explained in part 4 of this report. Women with perinatal mental illness can also benefit from services which increase their social support, such as support groups or befriending services. These are very unlikely to be sufficient on their own, can provide welcome source of support that aide recovery. Whilst psychological and social support will not be sufficient for women with more serious mental illness, they can also provide an important part of the package of care that they receive.

Medication should be prescribed cautiously to women with mild or moderate mental illness, and women who are given medication should also be offered additional support

It is important that doctors are cautious in prescribing medication for women who develop mild or moderate mental illnesses during the perinatal period, and that they do so in line with the NICE guidance. Whilst medication is necessary for some women, it is not appropriate or effective for other women with mild mental illness. Social or psychological support is likely to be more

effective for these women, and therefore GPs should make them aware of this support and help them to access it rather than prescribing medication.

A survey for 4Children suggested that 70% of women with postnatal depression were given medication.⁹⁰ It is highly likely that some of these women would have benefited from alternative treatments. Therefore it is important that there are a range of alternative services available in every local area, and that GPs understand the different care pathways available.

Some medications can potentially harm a baby if used during pregnancy or when breastfeeding. When giving any woman medication to deal with a perinatal mental illness, professionals – in partnership with parents – must carefully balance the risks posed to a baby by a mother’s mental illness, against any possible risk to the baby that might result from using medication. Women should be able to make an informed choice about whether to use medication to treat their symptoms, and be offered alternative treatment wherever possible. In many cases, there are alternative medications that women can take to manage their conditions, and it is important that mental health teams, GPs and midwives know about these and are able to talk women through their options.

Medication can be useful in treating the symptoms of some mental illnesses. However if a mother’s mental illness has affected her interactions with her baby, this relationship may not automatically improve as a result of treating her illness with medication. In addition, if there are underlying psychosocial causes of the illness, these also need be addressed. Therefore when medications are prescribed, women should also be offered additional support to address the causes of their illness and to care for their babies.

All women of child-bearing age who are on medication to manage a mental illness

should be advised about the implications of becoming pregnant. This is a key part of any perinatal mental illness prevention strategy. Women and their partners should be able to access specialist pre-conception counselling and expert advice through pregnancy and the postnatal period about how best to manage their condition and minimise the risks to their baby. Similarly, when it is necessary to start prescribing medication during the perinatal period, it is important that women are given advice about the effectiveness of drugs; any possible risks to their baby; whether the drugs are compatible with breastfeeding, and when and how they should stop the drugs when they need to.

GPs must be cautious in prescribing medication for mild or moderate mental illnesses. They should always investigate alternative or additional treatments.

GPs and psychiatrists should ensure that women who are considering or taking medication to treat a mental illness are fully informed about the benefits and risks of taking medication, and of not taking medication, before conception, during their pregnancy, and after birth.

There should be evidence-based individual and group therapeutic services in every area

Individual and group therapeutic services can address both mothers' mental illness and support their relationships with their infants. These services might be provided by voluntary sector organisations; by midwives or health visitors; as part of children's centres, or by community mental health services. It is important that they are offered in accessible venues that women feel comfortable to attend, such as children's centres. An example of such services is shown in the box opposite. Similar services should exist in all local areas to support women with mild or moderate anxiety and depression.

Clinical Commissioning Groups should work with other partners to ensure that there are sufficient, accessible therapeutic services in their area.

Case Study

OXPIP – Oxford Parent Infant Project

OXPIP is a charity that helps parents and their babies to form strong and loving relationships. Specialist therapists offer high quality one-to-one support to parents and their babies up to the age of two. This therapeutic work focuses on helping parents to recognise and respond to their babies' feelings and needs.

The charity also runs group sessions, including baby massage and baby chatting groups for babies aged 3-9 months and their mothers. These groups help mothers to meet other parents, whilst also promoting activities that foster positive mother-infant interaction.

An evaluation of OXPIP's services in 2010/11 showed that 72% of mothers and fathers were at least 'moderately depressed' on the Patient Health Questionnaire when they started work, and only 23% when they finished. Similar results were also seen on measures on anxiety. At the same time, parent-infant relationships had also improved.⁹¹

Expectant parents and those with young children should be a priority for IAPT services

In 2007, the Government announced a large scale initiative for improving access to psychological therapies (IAPT) for anxiety and depression disorders in England. Between 2008 and 2011, 3,600 new psychological therapists were trained, and a further 2,400 are being trained between 2011 and 2014. This investment means that there will be sufficient capacity to offer treatment to at least 15% of people with anxiety and depression in the community.⁹²

IAPT support can be very useful for women suffering from anxiety and depression in the perinatal period, and many do access it. An IAPT pathfinder site estimated that 27% of clients were pregnant and postpartum women.⁹³ However IAPT services are not set up to cater explicitly for the specific needs of these women.

Specific guidance was published by the Department of Health in 2009, but there is no coverage of perinatal mental illnesses in the core training for IAPT professionals.⁹⁴

IAPT guidance recognises the importance of supporting women in the perinatal period and makes recommendations for ensuring services are accessible for them. However the Department for Health has not explicitly indicated that mothers in the perinatal period should be a priority when decisions are made about the roll out of the programme. Parents in the perinatal period should be a priority group for commissioners of IAPT services, and providers should find ways to promote the service to these parents, and ensure that they can access support quickly when required. This will prevent problems from escalating and reduce the risks to their children.

IAPT services can help to treat anxiety or depression, but don't support parents with their parenting role to reduce the impact of their depression on their interactions with their babies. Therefore we believe that all parents who access IAPT services who are expecting or have young children should also be offered evidence-based parenting support.

Government should make expectant parents and those with of young children a focus for IAPT services, including:

- **ensuring that there is specific training in perinatal mental illness for IAPT practitioners, and**
- **giving clear directions that these parents should be 'fast tracked' for support.**

Parents should be able to access therapeutic support within one month of identification

Early action to address perinatal mental illnesses can prevent problems from escalating and reduces their negative effects on a family. Fast responses to mental illnesses are important whenever they occur, but this issue is particularly pertinent in the perinatal period because of the potential impact on the baby. Babies develop rapidly during pregnancy and in the first year of life, and even short-term problems in this critical period can have long-term effects. It is therefore important that women who need therapeutic support to deal with perinatal mental illness should be able to access this quickly.

The NICE guidance says that women requiring psychological treatment should be seen for treatment within 1 month of initial assessment.⁹⁵ In an FoI by 4Children, 81% of English health trusts who responded said that they provided psychological treatment within six weeks. However, five Trusts reported waiting times of more than three months, some as many as six months.⁹⁶ These delays can have devastating consequences for women and their babies.

Commissioners and providers of services for women with perinatal mental illness must ensure that all women receive appropriate psychological treatment within one month of being identified.

Local Healthwatches should monitor whether women can access the services they need at the right time, and hold commissioners and providers to account.

Women with perinatal mental illness should have access to sources of social support, including the opportunity to share experiences and support one another

Social support can lower the risk of mental illness, reduce symptoms, and improve the quality of life of people affected.⁹⁷ Improving social support will only be sufficient to address a woman's perinatal mental illness in a small proportion of cases of mild depression or anxiety. However it can be beneficial for most women with a perinatal mental illness, and, in conjunction with specialist services, can help to aid recovery.

A number of studies with women who have severe mental illness have identified a need for peer support groups. Studies found that mothers with postpartum psychosis felt isolated and would welcome the opportunity to share their experiences and gain guidance from other mothers with similar experiences.⁹⁸

Maintaining a social support network can be difficult for women with mental illness and a new baby, and therefore services can play an important role in facilitating and fostering social support networks. This might be through organising peer support groups or befriending services. Mental health services, maternity services, and children's centres could all play a role in establishing these services. Many voluntary sector organisations, such as Family Action and PANDAs, provide good peer support services for women and their families.

It is not just women themselves who can benefit from increased social support. Such support is also useful for partners, carers and other family members.

Clinical Commissioning Groups, Local Authorities and the voluntary sector should work together to ensure that there is social support available in their area for families affected by perinatal mental illness and social isolation.

Composite Case Studies

The composite case studies in this report are not real cases, but instead incorporate experiences from a range of real women and their babies. They are intended to illustrate the huge difference it makes to women and families when the right services and support are, or not in place.

A Bad Experience

In the latter stages of her pregnancy, Kate started to feel very low. She lacked energy and felt constantly down. This continued after Kate's baby was born. It felt like a vicious cycle – Kate felt awful for not being happy about her baby arriving, and this made her even more depressed.

Kate's midwife and health visitor were very nice, but their visits after her baby was born focused on how her baby was doing and some issues that Kate was having with breastfeeding. Kate didn't get a chance to talk about how she was feeling.

Kate's husband was very supportive, but he didn't seem to notice how low she was feeling and attributed her behaviour to being tired because of the new baby.

After a few weeks when things didn't improve Kate talked to her husband about how she was feeling. She told him that she felt ambivalent about their baby and was struggling to bond with her. Kate's husband was concerned, but encouraged her not to mention this to the GP because he might think she wasn't capable of looking after the baby.

Gradually, with time, Kate began to feel better, but the first four months of her daughter's life had been overshadowed by her depression. As she grew, Kate's daughter became withdrawn and anxious, which was likely to be a result of her early experiences.

A Good Experience

Kate had the same midwife, Claire, throughout her pregnancy. Claire encouraged Kate to bring her husband to appointments so that he also learned about the pregnancy. At one of these appointments, Claire told the couple about depression, and the signs to look out for.

In the latter stages of her pregnancy, Kate started to feel very low. She lacked energy and felt constantly down. Her husband recognised some of the symptoms that their midwife had described and suggested to Kate that she might want to get some extra support.

At her next appointment, Kate raised her concerns with her midwife, who was very supportive and told Kate about some of the different services and support that she could access in her area. Kate decided not to get extra help at that point, but even just talking about the depression with her midwife had helped a lot.

After Kate's baby was born, her midwife visited her at home and they spent some time talking about how Kate was feeling. The midwife told Kate and her husband about a support group at their local children's centre. With encouragement from her husband, Kate went along to the group. Here she got help to manage her depression and bond with her baby. She also got some useful information and advice to share with her husband to enable him to understand her illness. The group helped a lot, and Kate also made friends who she could continue to meet regularly throughout her maternity leave.

PART 3: TIER 3 AND 4 SERVICES

Women should be able to access specialist perinatal mental health teams and inpatient units when necessary

NICE guidance recommends that women with perinatal mental illness should be able to access specialist perinatal mental health services.⁹⁹ Whether they have mild, moderate or severe mental illness, women should be able to receive information, advice and care from a specialist professional who understands the specific needs of pregnant women and those with a young baby.

Every area must have a Specialist perinatal mental health service

In addition to general adults and children's mental health services, every local area should also have a specialist community perinatal mental health service, with a multi-disciplinary team of nurses, psychologists and psychiatrists, including a specialist perinatal consultant psychiatrist. This team should be embedded within the local area, with clear referral pathways from universal health services, and other mental health teams.

Pregnant women and new mothers have specific needs, which general adult mental health services may not be able to meet. For example, professionals working with women during this time need:

- a specialist knowledge of the nature and risks of illnesses which occur at this time;
- a specialist knowledge of the risks and benefits of medication in pregnancy and when breastfeeding;
- an understanding of how to help women meet the emotional and physical needs of their babies, and to promote healthy parent-infant interaction;
- an understanding of the emotional and physical changes associated with pregnancy and birth;
- an ability to respond to the accelerated timescales of pregnancy (both in terms of the baby's development and the rapid

onset and deterioration in postpartum disorders), and

- strong relationships with maternity services.

Unless professionals have experience of regularly working with new mothers, they are unlikely to have these specialist skills, understanding, and the contacts they need. For example, postpartum psychosis is relatively uncommon, so may be unfamiliar to professionals who are not specialists in this area.¹⁰⁰ Studies have found general psychiatric nurses can feel very uneasy and scared working with women with postpartum psychosis and their babies, and want specialist training to do this.¹⁰¹

Specialist perinatal mental health services can provide women with up-to-date, correct advice about managing their illness during pregnancy, birth and the postnatal period – for example in the appropriateness, risks and benefits of medication in pregnancy and whilst breastfeeding. They can also develop strong links with maternity and children's services, as well as other adult health services, and can attend to the parent-infant relationship, and the needs of infants as well as parents. The existence of specialist perinatal mental health teams also has wider benefits: they can share expertise with other universal and targeted services, and drive the development of local care pathways.

Case Study

Southern Health Mental Health Service

Southern Health's Mother and Baby Mental Health Service in Hampshire helps mothers experiencing severe mental illness through treatment and support in the community, and a specialist Mother and Baby Inpatient Unit.

The team is multi-disciplinary and comprises of a Specialist Perinatal Consultant, associate specialist doctor, ward doctor, psychologist, social worker, occupational therapist, inpatient and community specialist perinatal mental health nurses and nursery nurses, and health care support workers. A paediatrician and health visitor are also linked to the team.

The service works with women pre-conception, during pregnancy and up to a baby's first birthday. The support offered to women in the community includes:

- advice and support over the telephone;
- outpatient consultations in clinics, GP surgeries or at home;
- support and guidance for families;
- medication (if appropriate);
- psychological ('talking') therapies, and
- group and individual therapy sessions.

This team effectively prevent the escalation of mental illness, thereby reducing suffering by women and avoidable admissions to inpatient care. Evidence suggests that the rates of inpatient bed use in Hampshire were as much as 50% lower than in a neighbouring area which did not have a specialist community team.¹⁰²

The importance of specialist perinatal mental health services has been widely recognised and was underpinned by the last three enquiries into maternal deaths, which showed that, with few exceptions, the women who died as a result of psychiatric disorders had been cared for by non-specialised psychiatric teams unfamiliar with these conditions.¹⁰³

The report also highlights that mothers with severe mental illnesses can be terrified of losing the care of their babies, and this fear can influence their cooperation with mental health services and treatments. Specialist community perinatal teams can be more sensitive to these issues and confident in addressing them appropriately.¹⁰⁴

Despite the clear case for specialist services, they do not exist everywhere. It is estimated that fewer than half of all mental health trusts in Great Britain provide a specialist perinatal mental health team that is staffed by at least a consultant perinatal psychiatrist and specialist community perinatal mental health nurses.¹⁰⁵ A survey of NHS Trusts in 2007, found that less than a quarter of those who responded had access to a specialist perinatal psychiatrist.¹⁰⁶

To understand more about specialist perinatal mental health services in England, the NSPCC sent a Freedom of Information request to the 52 mental health trusts in England, asking them about whether they had a specialist service, the number of staff employed and their roles, and how many women had benefited from the service in the last year. 46 mental health trusts (88.5%) responded to our request, but the information given was incomplete or unclear in many cases. For example, it was often unclear whether professionals were full time or not.

26 of the 46 mental health trusts that responded to our request said they provided a Perinatal Mental Health Service (57%). Three more said that they provided an integrated parent and infant mental health service, which included perinatal mental health care for mothers. Two other trusts said they had a specialist nurses, or a weekly clinic for women with perinatal mental illness. 33% of the mental health trusts told us that they have no specialist perinatal provision at all.

The number of staff employed as part of perinatal mental health services varied greatly. Answers indicated that teams included between one and 24 FTE staff. Obviously staffing numbers were higher if the service included an inpatient unit. A few teams were staffed solely by nurses, and some were led by psychologists. Only a very small proportion were truly multi-disciplinary.

21 of the teams included consultant psychiatrists, but these were not all specialist perinatal mental health psychiatrists, and some only worked for one day a week with the service. Therefore our findings are consistent with the estimate of the Joint Commissioning Panel for Mental Health and suggest that less than half of all mental health trusts in England provide a specialist perinatal mental health team that includes at least a specialist perinatal psychiatrist.

NHS England must work with Clinical Commissioning Groups to ensure that a specialist perinatal community mental health team exists in every local area, and has sufficient capacity to meet local need.

Every new mother who needs inpatient psychiatric care must be able to access a nationally accredited Mother and Baby Unit

Inpatient Mother and Baby Units are hospital psychiatric wards that are specially equipped for mentally ill women and their babies. These units enable seriously ill women to receive the dedicated care that they need, whilst also maintaining and strengthening their bonds with their babies. NICE guidance, and previous enquiries into maternal deaths have all recommended that women who need inpatient care within 12 months of birth should be admitted to a specialist Mother and Baby unit.^{107,108}

Separating mothers and babies when a mother has to enter hospital can have a detrimental effect on mothers and babies, and on mothers' confidence and capability as a future carer, whereas Mother and Baby Units can ensure mothers receive support to meet her babies' social and emotional needs whilst closely monitoring the safety of the child.

Although there is no trial based evidence to demonstrate the relative benefits of Mother and Baby Units compared to other types of care, there is evidence to suggest that women with serious perinatal mental illness have better outcomes and better relationships with their babies if they are cared for in Mother and Baby Units.¹⁰⁹

Case Study – Bethlem Royal Hospital

The Channi Kumar Mother and Baby Unit at the Bethlem Royal Hospital has 13 beds for women who develop or have a relapse of serious mental illness during pregnancy or following the birth of their baby. The Unit offers a holistic treatment programme, which involves fathers and families, and promotes the parent-infant relationship, alongside treating the mothers' illness. Alongside the psychiatric support, Interventions on offer include:

- medication (if needed);
- psychological therapies, including psychotherapy, cognitive behavioural therapy (CBT), cognitive analytic therapy (CAT), family therapy and couple therapy;
- mother-infant relationships support, including baby massage and video feedback;
- occupational therapies including life skills, health skills and leisure activities, and
- art psychotherapy and dance therapy.

Evidence shows that the Unit's work leads to:

- significant improvements in mental state in around three quarters of women;
- significant improvements in the sensitivity of mothers with schizophrenia and postpartum psychosis when interacting with their babies, and
- significant improvements in infant-cooperativeness in the babies of mothers with schizophrenia, psychosis and depression.¹¹⁰

Ideally, alongside psychiatric care, Mother and Baby Units should provide psychological therapy, recreational activities, interventions to improve parent-infant interaction, and support for partners. However there is currently substantial variation in what is provided. The most recent national survey of alternatives to standard acute inpatient care in England in 2005 found that, out of 12 inpatient Mother and Baby units:

- five units did not provide any individual psychological treatments or psychotherapy;
- three units provided only cognitive-behavioural therapy, and four offered cognitive-behavioural therapy and one or more other therapies;
- all units that offered some form of individual psychological therapy also offered family therapy or couple therapy;
- all units had access to occupational therapy or organised recreational activities;
- three units offered alternative therapies, including aromatherapy and body massage;
- three units offered baby massage;
- nine units had advocacy services available, and the same proportion had a welfare rights or benefits advisor, and
- most units provided facilities for caregivers. 10 provided them with education about mental illnesses, and five had support groups for caregivers.¹¹¹

A national accreditation scheme is in place to assure quality of Mother and Baby Units. Most units in England belong to this scheme, which assesses the care they provide to mothers, babies and the mother-infant relationship on an annual basis. All women in England who require inpatient care in late pregnancy or in the first year of their baby's life should have access to an accredited unit.

Staff on Mother and Baby Units can make an expert assessment of the mother's ability to be a parent. Sadly, on rare occasions, babies don't always return home with mothers from Mother and Baby Units. However, the ability of staff to make an expert assessment in the Unit ensures that decisions about babies' futures are timely and informed by the best evidence about the mother-baby relationship; mother's functioning; baby's development, and their mother's capacity to change.

Because of the relative rarity of serious perinatal mental illness, there does not need to be a Mother and Baby Unit in each local area, but ideally, there should be Mother and Baby Units in all regions of the UK with clear links with specialised community perinatal mental health teams in each local area.

Unfortunately Mother and Baby Units are still not available to women in many parts of the

UK.¹¹² The Joint Commissioning Panel for Mental Health estimates that there are 168 mother and baby beds in England, and that this is a shortfall of approximately 50 beds.¹¹³ Without access to a specialist unit, women must either go without the intensive care that they need, or be separated from their babies, which can disrupt early bonding.

In 2007, NICE estimated that beds in MBUs cost £271 extra per day compared to those in a non-specialist Unit.¹¹⁴ Based on inflation, this would now be £318 per bed per day, and so the costs of 50 extra beds in England each year would be around £5.8 million per year in addition to what is already spent.¹¹⁵ However, this should be offset against the important long-term benefits and savings associated with providing this care. In addition, if we can be successful in the early detection, prevention and effective management of perinatal mental illness, then fewer women should need inpatient care in the future.

The location of Mother and Baby Units has not been strategically planned to secure equality of access from women across the UK. Instead they have emerged and thrived in areas where local clinicians have championed their development and managers or commissioners understand the importance of perinatal mental health and are driven to do something about it. The map opposite (using information from Action on Postpartum Psychosis) shows the distribution of Mother and Baby Units in England, and demonstrates the large gaps that exist in some parts of the country – particularly the Midlands, East of England, and South West. Women in these areas can struggle to get a place in a Unit, or if they do, they have to travel long distances to find one.

Whilst health trusts can procure beds in Mother and Baby Units outside their area, evidence shows that whether or not women can access MBUs depends significantly on where they live. An FoI request conducted by the Patient's Association showed huge differences in the number of women accessing Mother and Baby Units between trusts.¹¹⁶

NHS England must ensure that there are sufficient beds and equitable access to Mother and Baby Units for all eligible women in England.

Mother and Baby Units in England



Composite Case Studies

Maria has a history of bipolar disorder, but she had been taking lithium and had been healthy for a long time when she became pregnant. Maria's pregnancy was not planned, and she was not in a relationship with the baby's father.

A Bad Experience

Maria's first appointment with her midwife felt rushed, and Maria felt very overwhelmed. Maria's history of bipolar disorder was not discussed.

A few months into her pregnancy, Maria read that lithium could be damaging to her unborn baby, so stopped taking her medication. She did not discuss this with anyone.

Maria's birth was not problematic, and she was discharged from hospital within 24 hours. At that time she started to experience the signs of postpartum psychosis.

Maria managed to hide her problems from the midwife during her home visit, but over the next few days, these symptoms got worse, and Maria experienced rapid changes in mood, confusion and paranoia. When her health visitor called, she realised that Maria was unwell and organised for her to see an emergency psychiatric team.

The psychiatrist decided that Maria should be admitted to an inpatient ward straight away, and an emergency foster placement for her baby was arranged by social service. Maria was distraught about having to be separated from her baby, and at first refused to go to the hospital. The whole experience was very traumatic.

Because her psychosis had escalated before it had been treated – and may have been exacerbated by the trauma of her admission to hospital – it took more than two months before Maria felt better and could be discharged.

Her baby remained in foster care for a few more weeks after Maria was discharged, so that social services and the community psychiatric team could support Maria and assess whether she was ready to look after her baby.

A Better Experience

Maria's midwife asked her about her history of mental illness and discovered about her bipolar disorder. She explained to Maria that she would probably need to change her drug regime during the pregnancy and referred her to a general psychiatric team: there was no specialist perinatal team in the area.

The psychiatrist recommended that Maria should stop taking lithium during the pregnancy if she wanted to breastfeed, so Maria gradually came off the drug.

Maria's birth was not problematic, but she was kept in hospital for two days and closely monitored. During this time Maria was on a busy and noisy ward, which made sleep difficult.

A few hours before she was supposed to be discharged, Maria started to experience some of the symptoms of postpartum psychosis, particularly confusion and paranoia. Maria's midwife spotted this and called the psychiatrist, who felt that Maria should be transferred to a psychiatric ward.

There was no Mother and Baby Unit in the local area, but Maria's midwife and psychiatrist arranged for Maria to get a bed in a unit three hours' drive away.

The Mother and Baby Unit was a lovely space, where Maria instantly felt more relaxed. The staff there gave her more drugs to manage her symptoms, and helped her to look after her baby.

The MBU staff did a parenting assessment for Maria and liaised closely with her local social services team. When Maria was ready to be discharged, they agreed that her baby should come home with her. Maria received ongoing support from a community psychiatry team and her local children's services.

A Good Experience

Maria's midwife asked her about her history of mental illness and found out about her bipolar disorder. She explained to Maria that she would probably need to change her drug regime during the pregnancy and referred her to a specialist perinatal psychiatrist.

The specialist psychiatrist talked to Maria about the risks associated with using lithium in pregnancy and when breastfeeding, and about her other options. They decided that Maria would gradually stop using lithium, but start again soon after her baby was born, and that she would bottle-feed her baby.

The psychiatrist advised Maria's midwife on how to care for Maria to reduce the risks of postpartum psychosis, and they agreed a joint plan for monitoring and supporting Maria.

Maria's midwife worked with her to reduce her stress and anxiety during her pregnancy and birth. After her baby was born, Maria was given a side room in the hospital where she could get some sleep. The midwives in the hospital supported Maria to restart her lithium and bottle-feed her baby. She also had regular check-ups from the perinatal psychiatry team.

Maria was kept in hospital for three days, and then discharged. Because she knew about the importance of looking after herself and getting sleep, she arranged for a friend to stay and help her care for her baby.

Maria's midwife contacted her regularly in the following weeks. She also encouraged Maria to start attending a local children's centre group.

PART 4: THE WHOLE-FAMILY APPROACH

Services must address the impact of perinatal mental illnesses on babies and other family members

As explained earlier in this document, perinatal mental illnesses can have a significant impact on the families of women who are affected. Family members are also important sources of support for the mother, and can mitigate the effect of her illness on the baby. Therefore it is important that mental health services ‘think family’.

Services must help mothers to provide sensitive and responsive care, and develop healthy relationships with their babies

Maternal mental illness can have pervasive long-term impacts on babies. Evidence shows that therapeutic interventions which only focus on the mother can produce reductions in maternal depression, but do not necessarily impact on child outcomes.¹¹⁷ In order to mitigate the effects of perinatal mental illness on babies, services at every stage of the pathway must explicitly attend to mothers’ capacity for reflective functioning, the quality of their interactions with their babies, and their relationships with the babies.

Specialist perinatal mental health services can support the mother-infant relationship, something that general adult mental health services may not have the time, resources or expertise to do, which is a key reason why these specialist services are so important. Interestingly, while improving maternal mental health will not necessarily improve mother-infant interactions, there is evidence that the reverse can be true: improving mother-infant interactions can reduce a mother’s symptoms of mental illness. A review for the Department for Education found that *“There is some evidence ... that dyadic interventions which involve depressed mothers, and which are designed to improve mother-infant interactions, can alleviate or prevent depressive symptoms even if the intervention was not designed specifically to target this.”*¹¹⁸

Local Authorities and Clinical Commissioning Groups should ensure that women who have a perinatal mental illness get support to help them to care for their babies, either as part of, or in addition to their mental health treatment.

Examples of Good Practice

There are a range of programmes that have been shown to be successful in improving mothers’ reflective functioning, which can be used alongside or as part of therapeutic services. One example of a programme that appears to be successful in this area is the Minding the Baby programme, developed by experts at Yale University, in which social workers and nurses work with new mothers to enhance attachment relationships by developing reflective functioning capacities and supporting positive parent behaviours.¹¹⁹ Other intensive interventions focused specifically on mother-child interactions – including toddler parent psychotherapy and parent-child interaction therapy – have also been shown to have positive results.¹²⁰

Services must involve and support fathers

Fathers and other partners play a critically important role in the lives of women affected by perinatal mental illness. They can provide important support to a mother, and also buffer the effects of her mental illness on their baby and other children. However, as section 1 noted, fathers can often need support themselves: between a quarter and half of fathers with depressed partners are depressed themselves.¹²¹ NICE guidance states that “health professionals should assess, and if appropriate address the needs of the partner, family members and carers of a woman with mental illness.”

Some perinatal mental health services are excellent at working with fathers. One Mother and Baby unit in the UK has space for fathers to stay with their partners, and five provide support groups for partners. However, on the whole, stretched maternity and mental health services do not provide fathers with information and support, despite the wider benefits that this would have for families. In a survey by *Bounty – the parenting club* for 4Children in 2011, 42% of women who thought that they had experienced postnatal depression said that their partners needed more information about the condition.¹²² Sadly stories of fathers who feel excluded from their partners' care are all too common.

All services working with mothers affected by perinatal mental illness must ensure that they engage, support and work with their partners and other key family members.

These services must also have processes in place to identify fathers who are suffering from mental illness themselves and ensure they have access to additional support.

Case Study

The Parkside Parental Mental Health Service

The NSPCC works with NHS mental health services in North West London to help families where a parent has a mental health problem. This joint working enables professionals to consider the needs of the whole family: thinking about patients as parents, and working to improve their children's lives.

NSPCC social workers work alongside mental health professionals to provide a range of multidisciplinary services that build adults' parenting skills and knowledge, and ensure that children get the right support. They also help other local agencies, such as children's social care, to make informed decisions about how to work with families. This service benefits children of all ages.

Case Study

Mellow Parenting and NSPCC's Development Project

The NSPCC and Mellow Parenting are working together to develop a new service for parents affected by mental illness in the perinatal period. This service will:

- build on the latest evidence about effective practice in tackling perinatal mental illness;
- begin work with parents in the antenatal period;
- work with both mothers and fathers, and
- include work to build parent reflective function and promote sensitive and responsive caregiving.

The new service is being designed and piloted over the next two years. Current development work includes reviews of the latest evidence in this area, consultation with commissioners and practitioners, and co-design work with parents to ensure that the service meets their needs.

In the worst cases, where a baby is removed or a mother dies, professionals must ensure that ongoing support is available for the family

Every year there are women who commit suicide during the perinatal period. With the right expert care, at the right time, most, if not all, of these deaths may have been prevented. However, if a woman does die, it is important that her family are supported to cope with their bereavement. GPs in particular should be aware of the family's issues, and be able to signpost them to local bereavement support services. Good provision for bereaved families includes:

- information about how to cope with bereavement and what services are there;
- the opportunity to discuss issues with a primary care professional, such as a GP;

- the opportunity to discuss issues with obstetric, midwifery services and psychiatric services, as appropriate;
- the chance to access 1:1 support or group support for those that need it, and
- outreach and specialist support for those who are particularly vulnerable or traumatised.

Clinical Commissioning Groups should ensure that there are services available for bereaved families in their area, and that GPs feel confident discussing these issues with families and signposting them for support where necessary.

It is very rare for babies to be removed from mothers with perinatal illness. This will only happen if it is judged that, even with support, a woman and her family are unable to provide their baby with the on-going care that he or she needs, and protect him or her from harm. Families where a baby is removed will usually be facing multiple adversities in addition to the mothers' mental illness.

In the rare cases where babies are removed, it is vitally important that mothers get the additional support that they need to deal with this process. Symptoms of mental illness are likely to be exacerbated by the loss of a child, and similarly a mothers' ability to cope with the loss may be compromised by her difficulties. The 2002 Adoption and Children Act gives birth relatives a right to support after a child is adopted. Mapping of the support services available for birth families in 2007 found that, whilst all Local Authorities provided some support, most provided support to help families navigate the adoption process, and therapeutic support was less likely to be provided.¹²³ Other research has found that the take up of these services is often low, perhaps because families distrust services, or because their complex needs make it harder for them to be reached.¹²⁴ It is important that post adoption support, including therapeutic support, is available for mothers whose babies are removed and their family members, and that they are supported to make use of this support. This should not only help them to deal with the loss of their baby, but also to think through how they might

reduce the risks of similar events happening in the future if they want to have other children.

If a child is adopted, children's services and mental health services must work together to ensure that mothers with perinatal mental illness and their families get the support they need during and after the adoption process.

PART 5: COMMISSIONING

There must be strategic commissioning of perinatal mental health care based on need

Every local area must develop and deliver a perinatal mental health strategy

As this report demonstrates, identifying and addressing maternal mental illnesses requires there to be a range of high quality services in place in every area. Tackling perinatal mental illnesses and mitigating their effects requires joint working between mental health services, psychiatry, midwifery, primary care, children's services, obstetrics, paediatrics, adult services and the voluntary sector. Therefore it is important that there are local strategies to secure sufficient, high quality, joined up services and clear care pathways in each place. All commissioners and providers of care for women with perinatal mental health illnesses must participate in the development of these strategies.

Each local strategy should set out clear pathways of care for women with mild, moderate and severe mental illnesses and their families. These will need to include specialist perinatal services, which may be commissioned by NHS England, rather than local partners. Local strategies should also set out plans for developing the knowledge, skills and resources necessary for the detection and prompt and effective treatment of perinatal mental illnesses across the local area.

These strategies do not currently exist in many areas. Research in 2011 suggests that 64% of PCTs did not have a strategy for commissioning perinatal mental health services.¹²⁵ Changes to local commissioning arrangements provide an opportunity for local partners to come together and create or refresh their local strategies.

Every Health and Wellbeing Board must ensure that there is a local perinatal mental health strategy in the area, and that it is properly resourced and delivered.

Commissioning of Perinatal Mental Health Services

In April 2013 the responsibilities for commissioning health services changed. From now on:

Clinical Commissioning Groups will commission midwifery and tier 1-3 mental health services.

NHS England will commission specialist tier 4 mental health services, GPs, Family Nurse Partnership and Health Visitors (although Health Visitors will move to Local Authorities in 2015).

A concerted effort will need to be made by all partners in order to coordinate support for women.

There must be local clinical leadership in each area to champion the needs of women with perinatal mental illnesses

Specialist perinatal mental health professionals not only provide a high quality specialised service to women, but can also bring wider benefits to their local area. They can champion the needs of women with perinatal mental illness, and use their expertise and passion to drive up the quality of local services. These professionals should include, as a minimum, a specialist mental health midwife and a consultant perinatal psychiatrist. They can work to share their knowledge and expertise with other local professionals, and inform and drive the local perinatal mental health strategy.

In 2011, 67% of health trusts who responded to a freedom of information request by the Patient's Association in 2011 had a lead clinician for perinatal health services. The grade and profession of these people varied. In some areas the lead was a consultant psychiatrist, but in others it was a GP, nurse or NHS manager.

Key people from all services working with women affected by perinatal mental illness in a local area should form a clinical network, which can work to ensure successful implementation of the local perinatal mental health strategy.

Clinical leads with sufficient expertise in perinatal mental illness should be identified in each local area.

A Clinical Network should be created in each area, bringing together key services who are working with women with perinatal mental illness.

In addition to clinical leaders, it is also important to ensure that local commissioners have the expertise that they require to commission perinatal mental health services. A survey of 500 GPs in 2010 showed that more than four in ten (42%) said they lacked knowledge about specialist services for people with severe mental illnesses such as schizophrenia and bipolar disorder.¹²⁶ It is important that commissioners draw on the expertise of local clinical leads, and ensure that commissioning decisions are based on evidence and informed by expert opinion.

Commissioners should have training to help them to understand perinatal mental illness, and should draw on experts when developing their local perinatal mental health strategy.

There must be accurate data about women's needs to inform local commissioning and service planning

In order to ensure that there are sufficient services in the right areas to meet the needs of women with perinatal mental illnesses, commissioners need accurate information about levels of need. Without this information, it is also not possible to tell whether women with mental illness are being identified and helped, and whether there are sufficient services in place. Data can also help providers to assess local need, plan care and improve the quality of services.

Commissioners can use research about the prevalence of perinatal mental illness to estimate the number of women affected in their local area. However it would be preferable to find ways to collect up-to-date data about local levels of need.

A report about joint working between adult and children's services published by Ofsted in 2013, described the differences in recording between drug and alcohol services, and mental health services. Drug and alcohol services have to collect information on the number of service users who live in households with children, or who are pregnant women, and report this to local commissioners and to the National Treatment Agency (now part of Public Health England). Systems have been established to achieve this. No similar requirements or systems currently exist for adults with mental illness.¹²⁷

Data on the incidence of perinatal mental illnesses is not currently routinely collated. Freedom of Information requests for the Patient's Association in 2011 revealed that only 22% of PCTs who responded knew the number of women who had used postnatal depression services in their area (which clearly is not the same as the number who might have needed these services, but is an important start). A similar request by 4Children the same year showed that only 9% of 150 PCTs and other health trusts in England could provide information regarding the number of women diagnosed and/or treated with postnatal depression within the trust boundary.¹²⁸ The low response rate was also accompanied by 'wildly divergent' figures which suggested that trusts were not holding accurate information.

It is very positive that the Government has said it is investigating the feasibility and appropriateness of adopting a measure of maternal mental health into the Public Health Outcomes Framework, as recommended by the Children and Young People's Mental Health Forum.¹²⁹

There are a number of things that might be done to improve data collection around perinatal mental illnesses. For example:

- Routine information about mental health collected by midwives and health visitors could be recorded in a way that provides

standardised information to a central source.

- ICD codes could be amended to include specific codes for perinatal depression and postpartum psychosis.
- Adult mental health services, including IAPT, could routinely collect data on whether patients are pregnant or parents, and the ages of their children.

Government should bring together experts in this area – including Royal Colleges, Public Health England and provider representatives – to find ways to improve data on perinatal mental illnesses.

Commissioning and funding arrangements for specialist perinatal mental health services must support preventative work

There are a small group of women who are known to be at significant risk of developing severe perinatal mental illness. Women who have suffered from postpartum psychosis before, for example, have a 50% chance of developing the illness in a subsequent pregnancy, compared to a risk of 0.1% in all women.¹³⁰ With the proper care from expert services, further episodes of mental illness in these women can be prevented. To do this work, specialist mental health services must be able to work with women who are currently well and would not normally meet the thresholds for care. There are concerns in the sector that the introduction of payment by results could make it more difficult to provide effective preventative care for women at high risk of perinatal mental illness. It is important that arrangements for commissioning and funding mental health services enable this longer term preventative work.

When commissioning and funding mental health services, NHS England and Clinical Commissioning Groups must have prevention in mind.

CONCLUSION

This report shows that we can, and we must, do more to prevent the harm caused by perinatal mental illness in England today. It has shown the changes that are needed across the system to ensure that women with perinatal mental illnesses and their families get the right care, and it has shone a spotlight on the current gaps in services in England. It has included clear data on these gaps in services, but has also tried to bring to life what these problems actually mean for women themselves, and their lifelong impact on families.

The Coalition Government's NHS reforms and localism agenda mean that many of the decisions about the services women receive are for local leaders and commissioners and NHS England. However, Government still has a role in encouraging, enabling and incentivising local decision makers to prioritise this issue.

We welcome the Government's commitment to improve access to mental health services, and the diagnosis and support for women experiencing postnatal depression,¹³¹ and call on all parties to echo this commitment to improving the perinatal mental health of women in their manifestos for the next election. Government now needs to provide focussed and determined leadership to ensure that its commitments translate into reality for all families across the country.

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