The Regulation and Quality Improvement Authority

Review of Perinatal Mental Health Services in Northern Ireland

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Assurance, Challenge and Improvement in Health and Social Care

The Regulation and Quality Improvement Authority (RQIA**)** is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland. RQIA's reviews aim to identify best practice, highlight gaps or shortfalls in services requiring improvement and protect the public interest. Our reviews are carried out by teams of independent assessors, who are either experienced practitioners or experts by experience. We provide our reports to the Minister for Health, Social Services and Public Safety, and make reports available on our website at www.rqia.org.uk.

RQIA is committed to conducting inspections and reviews and reporting on four key stakeholder outcomes:

1. Is care safe?
2. Is care effective?
3. Is care compassionate?
4. Is the service well-led?

These stakeholder outcomes are aligned with Quality 2020[1], and define how RQIA intends to demonstrate its effectiveness and impact as a regulator.

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[1] Quality 2020 - A 10-Year Strategy to Protect and Improve Quality in Health and Social Care in Northern Ireland - http://www.dhsspsni.gov.uk/quality2020.pdf

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Executive Summary

As part of its 2015-18 review programme, RQIA conducted an independent review of services for women who experience mental ill health during or after pregnancy in Northern Ireland (perinatal mental health). The review examined the implementation and effectiveness of the Integrated Perinatal Mental Health Care Pathway which was developed by the Public Health Agency (PHA) in December 2012. RQIA also interviewed a number of service users with mild, moderate and severe perinatal mental health illnesses about their care experience.

RQIA found that all HSC trusts had implemented and adapted the Regional Integrated Perinatal Mental Health Care Pathway and provided guidance to their staff regarding local arrangements for responding to women with mental health needs associated with pregnancy or the postnatal period. The review team found that in all trusts, women will generally be seen and managed within a stepped care model, as recommended by the National Institute for Health and Care Excellence (NICE).

The Belfast Health and Social Care Trust (Belfast Trust) is the only trust in Northern Ireland which provides small scale specialist perinatal mental health services. There is no regional Mother and Baby Unit (MBU) inpatient provision in Northern Ireland or on the island of Ireland.

HSC organisations and service users throughout Northern Ireland acknowledged the lack of specialist perinatal mental health services and the challenges this presents for women and children. HSC providers and commissioners also accept the need for specialist perinatal mental health services, to ensure service users, families and carers receive expert care in appropriate environments.

RQIA recommends that specialist perinatal mental health services should be developed in each HSC trust. Throughout the review, we were told about the lack of psychology input throughout the service in Northern Ireland. This also needs to be addressed within specialist teams and in maternity units.

RQIA wishes to emphasise the importance of reviewing good evidence based practice, to ensure any specialist service is developed effectively and efficiently to meet the gaps in service provision.

RQIA recommends that a single regional Mother and Baby Unit (MBU) be established in Northern Ireland. A number of factors need to be considered as part of such a service development. During the review, the main challenges that emerged in relation to development of an MBU were the potential detrimental effect on the rest of the family in terms of travel/cost and also having to deal with other children, in the absence of an established wider family unit.

Consideration should therefore be given to the development of sufficient infrastructure to deal with the requirements of family travel/costs and the impact on other children, of separation from their mother.
Consideration should also be given to the linkage required between an MBU, specialist teams**,** universal health visiting service and family nurse partnerships in trusts, in order to ensure effective transition back to specialist perinatal mental health teams/trust community teams, on discharge from an MBU.

RQIA also recommends that key decision makers visit both specialist teams and an MBU elsewhere, to gain a better understanding of their structures and services, before deciding on the future provision of perinatal mental health services in Northern Ireland.

RQIA expects this review will support key decision makers in the future development of specialist perinatal mental health services in Northern Ireland.

The report makes 11 recommendations to support the continual improvement of standards in relation to perinatal mental health in Northern Ireland.

The recommendations have been prioritised in relation to the timescales in which they should be implemented:

- Priority 1 – to be completed within 6 months of publication of report
- Priority 2 – to be completed within 12 months of publication of report
- Priority 3 – to be completed within 18 months of publication of report

Chapter 1: Introduction and Context

1.1 Introduction

During pregnancy and in the year after birth women can be affected by a number of mental health problems. These can range from mild to moderate conditions such as anxiety, depression and adjustment reactions, to more severe conditions such as bipolar affective disorder (BPAD), schizophrenia and puerperal psychosis. These conditions often develop suddenly and require different kinds of care or treatment. These problems are collectively called perinatal mental illnesses.

Some women who experience mental ill health 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. This is because of the intense social, psychological and physical changes occurring at this time and in addition in many cases, the impact of change in medication or 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, such as puerperal psychosis, severe depressive illness, schizophrenia and bipolar illness, the risk of developing or experiencing a recurrence of the illness does increase after childbirth[2].

The majority of women will have mild to moderate disorders and can be treated within a primary care setting. They will most commonly not require medication and will respond to psychological and social interventions. Another cohort of women with more significant problems may still be treated within primary care, provided access to specialist advice is available.

Communication between and coordination of the roles of the GP, midwife, health visitor and family nurse partnership nurse are crucial in the early recognition of perinatal mental health problems and ensuring access to initial steps of treatment. Pregnancy and the postnatal period may have a modifying effect on mental illness and so thresholds for access to treatment need to be altered to take this into account. For women who develop more severe disorders, specialist care provided by mental health services is necessary.

The Confidential Enquiries into Maternal Deaths and Morbidity 2009-13[3] highlighted that almost a quarter of women who died between six weeks and one year after pregnancy died from mental-health related causes.

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[2] Joint Commissioning Panel for Mental Health. (2012). Guidance for commissioners of perinatal mental health services.

[3] https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202015.pdf

The National Confidential Enquiry into Suicide and Homicide by People with Mental Illness[4] highlights that perinatal mental health has become a public health concern. The Joint Commissioning Panel for Mental Health[5] states that when mothers suffer from these illnesses, it increases the likelihood that their children will experience behavioural, social or learning difficulties and fail to fulfil their potential.

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[6][7]. Many cases of depression are mild, but a significant proportion of mothers suffer from a severe depressive illness[8]. 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[9]. 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[10]. 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[11].

Depression is the most common condition; however a number of other conditions may occur or recur during pregnancy:

Postpartum psychosis[12]

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 pregnancies.

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 pregnancies.

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[4] http://research.bmh.manchester.ac.uk/cmhs/research/centreforsuicideprevention/nci/reports/2016-report.pdf

[5] Joint Commissioning Panel for Mental Health. (2012). Guidance for commissioners of perinatal mental health services.

[6] Oates, M. (2001). Perinatal maternal mental health services. Recommendations for provision of services for childbearing women. London: Royal College of Psychiatrists.

[7] O'Hara, M. W. & Swain, A. M. (1996). Rates and risk of postpartum depression – a meta-analysis. Int Rev Psychiatry 8:37-54.

[8] Oates, M., & Cantwell, R. (2011). Deaths from psychiatric causes in 2011 Centre for Maternal and Child Enquiries (CMACE), BJOG 118 (Suppl. 1): 132-203.

[9] Teixeira, C., Figueiredo, B., Conde, A., Pacheco, A., & Costa, R. (2009). Anxiety and depression during pregnancy in women and men. Journal of affective disorders, 119(1), 142-148.

[10] Heron, J., et al. (2004). The course of anxiety and depression through pregnancy and the postpartum in a community sample. Journal of affective disorders, 80: 65-73.

[11] Josefsson, A., et al. (2001). Prevalence of depressive symptoms in late pregnancy and postpartum. Acta obstetricia et gynecologica Scandinavica, 80.3: 251-255.

[12] https://www.nspcc.org.uk/globalassets/documents/research-reports/getting-it-right.pdf

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 pregnancies.

Post-traumatic stress disorder

PTSD is an anxiety disorder caused by very stressful, frightening or distressing events, which may be relived through intrusive, recurrent collections, flashbacks and nightmares. Rate: 30/1000 pregnancies.

Mild to moderate depressive illness and anxiety states

Mild-moderate depressive illness includes symptoms such as persistent sadness, fatigue and 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 pregnancies.

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 pregnancies.

Better antenatal detection of actual or potential mental ill health therefore offers an opportunity for earlier intervention, to address the illness and to reduce the risk that it will cause longer term problems for a mother or her baby.

1.2 Context for the Review

For the majority of women in Northern Ireland who develop perinatal mental health difficulties, access to and availability of services is reported by them to be limited. Without appropriate support, these women may struggle with many becoming isolated. Some women will go on to develop more marked symptoms and may require more specialist support. The lived experience of women, supported by clear research evidence demonstrates the need for a range of specialist perinatal mental health services[13].

The epidemiology of perinatal mental illness is well established and suggests that postpartum depression or baby blues affects 30-80% of women after birth, with perinatal disorders occurring in up to 15% of all pregnancies. Given circa 25,000 births per year in Northern Ireland, this could imply that 3,750 women could develop perinatal mental illness per year[14].

There are clear clinical guidelines and policies available for professionals as set out in Appendix 2. These policies and guidelines make consistent recommendations about aspects of care that pregnant women in the postpartum phase should receive, in terms of specialised care for perinatal psychiatric disorder, should it be necessary.

Northern Ireland has committed to implementing the NICE Guidelines on Antenatal and Postnatal Mental Health[15]. In December 2012 the PHA produced an Integrated Perinatal Mental Health Care Pathway[16]. The pathway aims to provide an effective multidisciplinary guide, both for the prediction, detection and treatment of maternal mental health problems through the antenatal and postnatal periods. Its key themes included:

- co-ordination of service delivery
- competencies of the multidisciplinary team
- promotion, protection and detection
- effective communication
- appropriate use of medication

Northern Ireland has also published a number of policies, strategies and frameworks including:

- DHSSPS (2009) 'Families Matter: Supporting Families in Northern Ireland
- DHSSPS (2009) **'**Think Child, Think Parent, Think family' Guide
- DHSSPS (2010) Healthy Child: Healthy Future
- DHSSPS (2012) policy document; 'Child and Adolescent Mental Health Services: A Service Model
- DHSSPS (2012) Strategy for Maternity Care in Northern Ireland (2012-2018)

[13] http://www.rcpsych.ac.uk/pdf/perinatal_web.pdf
[14] https://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml
[15] https://www.nice.org.uk/guidance/cg192
[16] http://www.publichealth.hscni.net/sites/default/files/FINAL%20PERINATAL%20MENTAL%20HEALTH%20CARE%20PATHWAY_20DEC2012.pdf

- DHSSPS (2014) Making Life Better: a Whole System Strategic Framework for Public Health
- DHSSPS (2016) Co-operating to Safeguard Children and Young People in Northern Ireland
- PHA (2016) Infant Mental Health Framework for Northern Ireland

The Belfast Trust is currently the only trust in Northern Ireland which provides small scale specialist community perinatal mental health services. There is no MBU inpatient provision in Northern Ireland.

A 32 week prospective study[17] of 75 pregnant women undertaken in 2013 by a specialist perinatal mental health consultant in Northern Ireland, found that 32 cases required home treatment, and 43 required actual admission to an acute psychiatric ward. Of the 43 admissions to hospital, local assessment procedures determined that community services, including intensive home treatment approaches, were no longer appropriate to treat the patient. In accordance with NICE guidance, it could be assumed that the majority of these cases required care within a dedicated MBU facility if it had been available.

Evidence from this study suggests that women and their families still face an unacceptable situation of great variation in the provision and effectiveness of perinatal mental health services in Northern Ireland.

The Department of Health is also developing a new *Protect Life: Positive Mental Health and Suicide Prevention Strategy* in 2016. A collaborative approach to early intervention funding is being taken forward through the recently established Early Intervention Transformation Programme (EITP). This strategy seeks to build on the Child Health Promotion Programme and the Northern Ireland Maternity Strategy, to equip parents with the skills needed to give their child the best start in life.

This Review of Perinatal Mental Health services provides an assessment of the current arrangements and processes in place to deliver safe, effective and compassionate care to women and their families, who experience mental health illnesses during or after pregnancy. We hope our findings will provide a useful focus to inform the future development of perinatal mental health service provision in Northern Ireland.

[17] GAIN Audit Lynch et al, 2013

1.3 Terms of Reference

The terms of reference for this review:

1. To assess the implementation and effectiveness of the 2012 *"Integrated Perinatal Mental Health Care Pathway"* across HSC Services for the following three stages from antenatal to post-natal provision:

    - Primary Care Provision (GP, community midwife/health visiting family nurse partnership nurse)
    - Community-Secondary Care Inputs, including (i) general community mental health services and (ii) specialist perinatal team (Belfast Trust)
    - In-Patient Care, in the absence of a dedicated Mother and Baby Unit

2. To assess and evaluate service user experiences of perinatal mental health services within Northern Ireland.

3. To report on the findings, identify areas of good practice and, where appropriate, make recommendations for improvements in perinatal mental health service provision in Northern Ireland.

1.4 Methodology

The methodology was designed to gather information about the current provision of services available to women who develop perinatal mental health problems, and to assess if services delivered in Northern Ireland are safe, effective, compassionate and well-led.

The following methodology was used:

- literature search to determine relevant areas in relation to the provision of Perinatal Mental Health Services within Northern Ireland
- discussions with Department of Health Policy Leads & Public Health Agency
- self-assessment questionnaire completed by each HSC Trust
- focus groups and interviews with service users
- focus groups with general practitioners
- focus groups with front line staff from each HSC trust
- meetings with senior management from each HSC trust to discuss findings and the current provision of Perinatal Mental Health Services
- visits to General Adult Psychiatric Mental Health Inpatient Units
- a regional summit event was held involving all relevant stakeholders, to present findings and discuss draft recommendations
- publication of an overview report of the findings of the review

Chapter 2: Findings

2.1 Structure of and Access to Perinatal Mental Health Services in Northern Ireland

The review team found that the structure of perinatal mental health services varied across each of the five HSC trusts. The Belfast Trust is the only trust within Northern Ireland that provides specialist perinatal mental health services. Other trusts identified psychiatrists with an interest in perinatal mental health, but only the Belfast Trust has a limited specialist multidisciplinary team, comprised of part time psychiatry, social work and a community psychiatric nurse (CPN). No specific funding was provided for this specialist service; however, the Belfast Trust having identified the need established it at risk and without additional funding. Part of this service provides a Perinatal Mood Disorder service which has been established to identify and treat women in the antenatal period, at risk of developing serious mood disorder associated with pregnancy. The trust has also established a Perinatal Psychology service, which responds to women booked to deliver babies with the Belfast Trust maternity services, who have or develop psychological problems in relation to pregnancy.

Although each HSC trust has implemented the 2012 pathway, there was however insufficient evidence to suggest that a structured and supervised perinatal mental health service was in place in all trusts. RQIA however acknowledges that HSC trusts continue to develop and implement a number of initiatives to improve the provision of mental health services, such as alcohol and drug initiatives, complex social needs clinics, and close working with addiction teams, inpatient teams and crisis response teams.

RQIA found that perinatal mental health services were delivered in a reactive way by all HSC trusts, except the Belfast Trust. The other four HSC trusts relied heavily on good-will from a small number of professionals with an interest in perinatal mental health. However, if women are unknown to services, they and their babies face greater variation in what they receive. The review team found that women known to services or those with a severe condition are identified and treated appropriately; however there are deficiencies in how the service engages with women presenting for the first time with mild to moderate mental health disorders.

Due to the lack of specialist services across all HSC trusts, RQIA has concerns in relation to the leadership at senior level in terms of driving forward service improvements, and ensuring integrated working both within mental health services and across maternity services.

The review team was told of a lack of dedicated resources to provide input from psychiatry, clinical psychology and a lack of integrated working between maternity services, health visitors and mental health services. They reported difficulties in accessing timely mental health care for women, as referrals could only be made to those teams by GPs. Midwives stated that they encounter difficulties in accessing mental health care for women with mild to

moderate difficulties, for whom they have concerns, who are not already known to services. There are limited specialist psychology services and mental health staff, midwives/health visitors/teams to provide continuity of care for women and their families throughout the pregnancy and post-partum periods.

The review team was informed that this was less of an issue in the Belfast Trust because they have a dedicated clinical psychology service within the maternity hospital. This service takes direct referrals of women who are pregnant or in the early postnatal period from maternity staff, including midwives, obstetricians and neonatologists. Feedback from service users and professionals working with mothers with at risk pregnancies and fetal complications indicated that having an on-site specialist clinical psychology service is invaluable.

Many of these women may have lost one or more pregnancies through miscarriage, ectopic pregnancy or stillbirth, or have taken such a long time to get pregnant that they may find pregnancy a time of huge anxiety. The review team was informed that some women may not be seen in maternity services following recurrent miscarriage as they may be followed up by gynaecology services in the trust. The Imperial College of London report[18] indicates that women should routinely be screened for post-traumatic stress disorder, and receive specific psychological support following pregnancy loss[19]. The Maternity Strategy Implementation group in their 2016/17 action plan has agreed to review the referral and clinical pathways for women who have had recurrent miscarriages.

Pregnant women may also present with fear of childbirth and other anxiety and adjustment difficulties. Women who are vulnerable to postnatal depression may present with depression during their pregnancy and early detection is vitally important.

Babies born prematurely or with medical complications are usually transferred to the Neonatal Intensive Care Unit (NICU). The Belfast Trust highlighted that sadly one baby dies as often as once per week in their NICU. RQIA found that there is no dedicated funding to provide clinical psychology services for these parents and their babies regionally, although the Northern Health and Social Care Trust stated they have recently funded such a post for its neonatal unit. Although HSC trusts have bereavement care teams, the review team considered that they cannot fully fulfil the role of properly trained counsellors and clinical psychologists. Parents and indeed the staff involved undergo very stressful experiences in the normal day to day running of neonatal units.

[18] http://www3.imperial.ac.uk/newsandeventspggrp/imperialcollege/newssummary/news_7-3-2016-17-16-1

Recommendation 1	Priority 2
The HSC Board must ensure that each HSC trust provides a perinatal clinical psychology service for their maternity hospitals and neonatal intensive care units.	

HSC trusts indicated that women with more severe or chronic mental health conditions, who are known to mental health services, generally continue to be managed by their local team, most of which had no specialist expertise in perinatal mental health.

In keeping with professional and good practice guidelines, women who experience severe mental health problems during pregnancy and in the postpartum should be managed by specialist perinatal mental health services.

There is no regional MBU or dedicated beds available within Northern Ireland or on the island of Ireland, to provide inpatient psychiatric care for women who require this service. The review team visited a number of general adult mental health inpatient units across Northern Ireland to get a better understanding of the environment into which women would be admitted during their perinatal mental health period. The review team found that general adult inpatient units are not appropriate environments for the admission of a mother with her baby. However the review team acknowledged that HSC trusts do not admit babies and are not resourced to deliver perinatal mental health services in these units.

Each trust has put arrangements in place to cater for visiting, such as family side units. There are no facilities available to allow for therapeutic work to be undertaken with the mother and baby. Many units do not provide age appropriate toys, changing mats, play gyms or facilitates for feeding such as microwaves or highchairs. Whilst breastfeeding is accommodated where possible, clinical demands often mean that the baby visit must fit in with the ward daily routine, as opposed to properly meeting the needs of the baby and mother. In the interim and pending a further decision about the development of perinatal mental health services by the Department of Health (DoH), every HSC trust should review their equipment and facilities provided for babies and children during visits.

Recommendation 2	Priority 1
In the absence of a mother and baby unit, HSC trusts should provide appropriate equipment and facilities within all relevant general adult psychiatric inpatient units to meet the needs of a mother and her baby and older children during visits.	

Screening Tools

RQIA found that all HSC trusts have Mental Health Assessment Centres which act as a single point of contact for all mental health referrals. Patients referred by their GP or other professionals to mental health services, are initially assessed by the primary mental health care team within the assessment centre and are then prioritised as urgent, emergency or routine.

The review team was also informed that each mental health assessment is carried out using Regional Promoting Quality Care documentation. In addition, to ensure inter-directorate and inter-professional information sharing, a Pregnancy and Early Postnatal Care Plan is completed by the mental health team for women with more severe and enduring mental illness. The review team was informed that assessment tools can now take up to three hours to complete. Professionals have questioned the effectiveness of these tools, and the impact on a mother, who may have to undergo a number of assessments before accessing the right service. A number of women also advised the review team that they often had to repeat their experience on several occasions to different staff.

Statistical Data

Currently, there is no mechanism or coding system in place to capture or report statistical information for perinatal mental health. As a result, it was impossible to determine how many women were admitted to maternity units who subsequently required admission to an acute adult psychiatric ward. RQIA recommends that the PHA should work with HSC trusts to develop a coding system, to capture and report this information to inform the future requirements and planning for perinatal mental health services.

Recommendation 3	**Priority 3**
The HSC Board should work with HSC trusts to develop a coding system to capture and report on statistical information to inform the future requirements for perinatal mental health services.	

Lack of a Regional Clinical Network

The review team was informed that there is no regional clinical network for perinatal mental health in Northern Ireland. In the absence of this, the review team considers that the PHA should work with the DoH to establish a regional group to examine and develop perinatal mental health services. This should be managed and monitored at a senior level by the PHA Maternity Strategy Implementation Group.

The terms of reference for this group should include the following:

- Establish standards for the provision of advice and guidance to maternity and primary care services on the use of psychotropic medication in pregnancy and breast feeding.

- Establish competencies and training resources for health professionals caring for pregnant or postnatal women with, or at risk of, mental illness, at levels appropriate to their need.
- Review the equality of access to advice and care for all pregnant and postnatal women with or at risk of mental illness.
- Review the pathways for referral and management of women with, or at risk of, mental illness in pregnancy and the postnatal period.
- Establish standards for the provision of community specialised perinatal teams with each HSC trust, and a regional inpatient specialised mother and baby unit.

Recommendation 4	**Priority 1**
The Department of Health should request the Public Health Agency to establish a regional group to examine and develop perinatal mental health services with agreed terms of reference and timelines. The delivery and implementation of a work plan by this group should be monitored by the Public Health Agency Maternity Strategy Implementation Group, and the Department of Health.	

Regional Perinatal Mental Health Forum

A Regional Perinatal Mental Health Forum has been established by a voluntary organisation (AWARE NI[20]), to improve the provision of perinatal mental health in Northern Ireland. The review team engaged with this forum to discuss perinatal mental health and to gain an understanding of their current work.

Many women experience perinatal emotional health difficulties that do not require specialist clinical services. Without appropriate support, these women may struggle, with many becoming isolated. Some women will go on to develop more moderate to severe symptoms and may then require specialist support. As part of a comprehensive approach to mental health wellbeing, it is important to plan and develop services for women, who have never reached the threshold for specialist intervention.

The review team considered that continued support should be given to the promotion of emotional wellbeing, for all pregnant women and new mothers. This component is also included in the Infant Mental Health Strategy framework[21] and some work on this has already begun by AWARE NI. For example, the Parent and Baby programme is currently being rolled out with support from PHA.

The forum highlighted a new model, developed in England, to support women experiencing perinatal emotional difficulties. The model is designed to train local facilitators and volunteers to deliver one-to-one and group peer support within community settings such as Sure Start (where available), Parent &

[20] https://www.aware-ni.org/
[21] http://www.publichealth.hscni.net/sites/default/files/IMH%20Plan%20April%202016_0.pdf

Toddler groups and Bumps and Babies groups. It also provides volunteer peer supporters for women during pregnancy and after birth with the aim of improving wellbeing and reducing perinatal mental illness.

The model, which includes evaluation of the services for effectiveness, impact and sustainability, aims to achieve improvements in the mental wellbeing of women who use the service, as well as a reduction in isolation. It aims to support women to engage with specialist services earlier (and thus reduce those reaching crisis point), as well as supporting women with mild symptoms for whom community support might suffice.

The model ensures that peer support is offered to women and that systems are in place that emphasise safety for both the woman and the volunteer peer supporter. RQIA supports the development of a similar model in Northern Ireland, through a collaborative, community based approach involving National Childbirth Trust, Sure Start, AWARE NI and others.

The review team found evidence of a lack of knowledge of available community and voluntary support demonstrated by GPs and other professionals in primary and secondary care settings. The majority of professionals are only aware of statutory services such as Sure Start Programmes, Home Start, and Family Support Hubs. However, many of these services are only offered to women who live within the most 25% deprived areas.

The review team was advised of new initiatives to ensure equity across Northern Ireland. The Department of Health has launched the new EITP.[22] The aim of this Programme is to improve outcomes for children and young people across Northern Ireland through embedding early intervention approaches.

Recommendation 5	**Priority 2**
The HSC Board should ensure that community based peer support services are developed within an overall plan for specialist perinatal mental health services in Northern Ireland in collaboration with relevant voluntary organisations and Sure Start.	

[22] https://www.health-ni.gov.uk/articles/early-intervention-transformation-programme

2.2 Implementation and Effectiveness of the 2012 Integrated Perinatal Mental Health Care Pathway

Implementation of the Integrated Perinatal Mental Health Care Pathway

Following recommendations contained in the NICE guidelines on antenatal and postnatal mental health (2007), a Regional Perinatal Mental Health Implementation Group was established and led by the PHA. The aim of this group was to develop a regional pathway for guidance in relation to perinatal mental health for all health and social care professionals who come into contact with pregnant women.

The pathway was to be developed around the following five areas:

1. Co-ordination of service delivery.
2. The competencies of the multidisciplinary team.
3. Promotion, prediction and detection.
4. Effective communication.
5. Appropriate use of medication.

The pathway also took account of the Stepped Care Framework referenced within the Bamford Report (2007), recommendations contained in the Maternity Strategy for Northern Ireland (2012) and recommendations set out in Transforming Your Care (2011). The aim of the pathway was to support the provision of an effective multidisciplinary service for the prediction, detection and treatment of maternal mental health through the antenatal and postnatal periods for all women in Northern Ireland.

In December 2012, the PHA published the *Integrated Perinatal Mental Health Care* pathway which stated that a stepped care approach needs to be adopted by providers when managing women with mental ill health during pregnancy and the postnatal period.

RQIA found that all HSC trusts had arrangements and processes in place for implementation of the Integrated Perinatal Mental Health Care Pathway and subsequently had developed their own pathway and provided guidance to their staff on local arrangements for women who had mental health needs associated with pregnancy or the postnatal period. The review team found that in all HSC trusts women will generally be seen and managed within an adapted stepped care model focusing on primary, secondary and emergency care.

Communication

The review team was informed that the 2012 care pathway was intended to promote effective communication between professionals and establish effective ways of accessing information and treatment for pregnant women, presenting with a previous history of and/or early signs of mental ill health.

The Regional Communication Pathways (PHA 2015) for Midwives, Health Visitors and Family Nurse Partnership Nurses, require health visitors to share

information with midwifery services if they have concerns or hold relevant information in relation to expectant parents.

However, RQIA found when women cross trust boundaries, no formal pathway for communication or transfer of information between teams or between trusts is in place. For example, if a mother from the Northern locality delivers her baby within the Belfast locality and is discharged back to the Northern Health and Social Care Trust (Northern Trust); staff reported that there is no formal communication pathway agreed to ensure continuity of care when a woman returns to their original trust.

A recent Mental Welfare Commission for Scotland Report on the *Investigation into the care and treatment of Ms OP by NHS Board C*, September 2016[23], highlighted that one of the main failings was very limited communication between the different agencies involved in the care and treatment in this case.

Recommendation 6	**Priority 1**
Each HSC trust should review the communication protocols in place between primary and secondary care to ensure effective communication and information sharing.	

Substance Abuse/Addiction in Pregnancy

The recent Confidential Enquiry into Maternal Deaths[24] highlighted that in the United Kingdom (2009-14), 111 women died by suicide and 58 women died as a consequence of substance misuse, either during pregnancy or up to one year after the end of pregnancy. A number of professionals in Northern Ireland highlighted to the review team a gap in the pathway, as it did not consider all mental health conditions such as women with substance misuse. The review team would advise that any future review of the Integrated Perinatal Mental Health Care Pathway must include a section on dealing with substance/addiction abuse in pregnancy.

The review team was informed by the PHA that they are in the process of revising the 2012 pathway. This is currently out for consultation with key stakeholders. RQIA welcomes this revised consultation, which should ensure better awareness amongst all professionals about specific referral and management arrangements, to help assure service users that they will receive safe, effective and well-led perinatal mental health services within Northern Ireland.

[23] http://www.mwcscot.org.uk/media/340869/Ms%20OP%20investigation%20report.pdf
[24] https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202016%20-%20website.pdf

Effectiveness of the Pathway

General Practitioners

In 2015, the Centre for Mental Health published a report "*Falling through the gaps: perinatal mental health and general practice*"[25]. This report analysed GP surveys and the experiences of women with perinatal mental illness in general practice. The report suggested a number of barriers to identifying perinatal illness. These included 'insufficient training and confidence among GPs in dealing with mental health problems and specifically in the management of perinatal mental health care.'

Just under half of those GPs surveyed said they had received no specific training in perinatal mental illness. In the report, women described mixed experiences when they did disclose mental health concerns to their GP.

The author noted "It is clear from this study that voluntary disclosure of distress should be regarded as a "red flag" moment for GPs, requiring further active and compassionate investigation." To help to address this issue the Royal College of General Practitioners and the Maternal Mental Health Alliance, developed a short, ten point document to aid GPs in this area[26].

For the majority of women in Northern Ireland, GPs are the first point of contact when they become pregnant. GPs have a vital role to play in prevention and early detection of perinatal mental health problems during both the antenatal and postnatal periods. However, feedback from GPs and service users in Northern Ireland highlighted variances between GP practices in relation to perinatal mental health experience, training, confidence, skills, interventions and signposting to community/voluntary services.

During the antenatal period, GPs will assess a woman and refer them for their first booking appointment and document all relevant information. If the woman has a history of mental health problems, the GP will refer to the relevant mental health professional/team or to the trust mental health assessment centre. However, RQIA found that many GPs are not aware of the 2012 pathway.

A recent audit was undertaken by the South Eastern Health and Social Care Trust (South Eastern Trust) which highlighted:

- 80% of GPs were not aware of the 2012 pathway
- 60% were not aware of the perinatal clinic run by their trust
- 100% not aware of the two Whooley questions asked by midwives and health visitors
- There was uncertainty about the services available, and where to get advice regarding medications In focus groups with GPs it was evident that

[25] http://www.rcgp.org.uk/clinical-and-research/toolkits/~/media/0DF1836E7D6B46788519F79E0ACF6EB2.ashx
[26] http://www.rcgp.org.uk/clinical-and-research/toolkits/~/media/92F73D8AA0014DEAB37B55CDF7F2CE2B.ashx

a number were not aware of the pathway and also not clear as to the development of a single point of referral in each trust. The review team considered that this was a potential cause of delay which might lead to exacerbation of an initially moderate condition. There was also no mechanism for midwives or health visitors to check if a subsequent referral had been made.

If the woman has no history of mental health, the GP relies heavily on acute midwifery services for prevention and early detection. At the first booking appointment, the midwife will ask the two Whooley questions and trigger questions from Northern Ireland Maternity system (NIMATS). If the midwife detects any concerns, they will refer the woman back to their GP as set out in the pathway for a further assessment and onward referral if required.

During the postnatal period, the review team found that GPs have a good relationship with their attached midwives and health visitors. However, feedback from service users highlighted that some GPs rely heavily on anti-depressants, with limited interventions available such as cognitive behavioural therapy. RQIA also found that many GPs are not aware of what services are available within both the acute and community sectors.

Variance in practice was also noted across General Practices and in HSC trusts in relation to availability and access to specialist services. For example:

- specialist psychiatry, psychology and CPN services
- trained midwives/health visitors within perinatal mental health
- liaison Services such as alcohol, drugs, addictions
- talking and listening services

Recommendation 7	**Priority 1**
The Public Health Agency should work collaboratively with the HSC Board to ensure that all General Practitioners are made fully aware of the revised Integrated Perinatal Mental Health Care Pathway and of the voluntary and community organisations who can offer support to woman experiencing perinatal mental health in their locality.	

Obstetric and Midwifery Care

At the first booking appointment (10-13 weeks), women are triaged by a midwife using the following tools to screen and identify for psychology distress or health concerns:

- two Whooley questions (introduced by NICE 2007, are contained in the screening tool which is designed to try and identify two symptoms that may be present in depression)
- trigger questions on the NIMATS

Patients who have a history of mental health problems or answer positively to the two whooley questions or show signs of having a mental health problem, are referred in line with the Integrated Perinatal Mental Health Care Pathway Universal flow Chart 1 and 2, using the regional agreed referral letters[27]. For the majority of women, this involves the midwife referring the woman back to her GP for a further assessment. The GP refers the woman to the Mental Health Assessment centre or single point of access and the referral is triaged by the Primary Mental Health Care Team initially and prioritised as either:

- urgent (2 hours)
- emergency (5 days)
- or routine (9 weeks)

Midwives told the review team that this can delay the process in relation to timely access to services and information. Midwives highlighted the workload involved with preparation of referral letters and follow-up with GPs in relation to exchange of information. Midwives stated they would welcome a more direct referral process into specialist services or mental health services. This was also stated by health visitors who identify women during the antenatal and postnatal period. Midwives within the Belfast Trust valued the direct access to the clinical psychologist in the Royal Jubilee Maternity service.

The review team was told that the South Eastern Trust has supported three midwives to attend specific perinatal mental health learning opportunities, and now run a talking and listening outpatient clinic. Mental Health services within the trust take direct referrals from the consultant obstetrician and other disciplines via the mental health assessment centre. The clinical co-ordinators attend monthly meetings and staff discuss patients that have attended the clinic and who are due to deliver in the next four weeks. If known to services there is liaison with the keyworker. If unknown, midwives will update the coordinators. Feedback from service users who attended these clinics has been very positive, with excellent outcomes demonstrated for both mother and baby.

During fieldwork, midwives highlighted the need for specialist training in perinatal mental health as they consider that they are not trained to deal with mental health issues. Midwives would also welcome better communication and greater integrated working with mental health services to share information about their patients.

Midwifery teams are fully engaged with social services, and consultant obstetricians will make a written referral to mental health services if appropriate. In cases where there is evidence or suspicion of drug/alcohol or child protection issues a Understanding the Needs of Children in Northern Ireland (UNOCINI) referral is made, and staff attend regular maternal meetings. The Southern Health and Social Care Trust (Southern Trust) has appointed an alcohol liaison nurse, who works closely with maternity services

[27] http://www.publichealth.hscni.net/sites/default/files/FINAL%20PERINATAL%20MENTAL%20HEALTH%20CARE%20PATHWAY_20DEC2012.pdf

for all new bookings, to ensure screening for hazardous or dependant type misuse of alcohol and substance misuse. Funding was secured from the Big Lottery to fund this development.

The review team was informed that the Ulster of University School of Nursing at Jordanstown will be providing a Post-Registration stand-alone module on perinatal mental health care, commencing in 2017.

Role of the Health Visitor

The role of the health visitor is to identify women that may be at risk of developing mental ill health and to assess women who are currently suffering from mental ill health, during the antenatal and postnatal periods. Health visitors also consider if the woman has a learning disability or an acquired cognitive impairment during the assessment period, as the woman may then require access to more specialist services.

The health visitor will initiate a Family Health Assessment (FHA) in the antenatal period for all women (usually at 28 weeks). The FHA includes discussion of maternal mental health and will include mental health prediction and detection questions. Health visitors ask the prediction and detection questions once in the antenatal period and on two occasions in the postnatal period prior to 16 weeks. If the health visitor is concerned about the woman's mental health, they will offer up to four listening visits in the first instance, if assessed as appropriate. They will seek consent from the woman to share this information with their GP.

Health visitors stated that they speak directly to the woman's partner if available about their own health and how they can support their partner if the woman is experiencing mental health difficulties. Health visitors are aware of the potential impact of mental ill health on parenting and will initiate guided conversations on attachment and explore any factors which impact on parents' ability to nurture or respond sensitively to infant cues. Health visitors can refer women to a range of support services, which include Sure Start, Home Start, and Family Support Hubs. Health visitors can refer women to the trust infant, child and adolescent Mental Health Service following consultation, when they are experiencing significant difficulties with attachment.

The health visitor liaises with the woman's GP and other relevant health professionals regarding appropriate intervention and continues to assess the woman's emotional health and agree appropriate future actions with the woman and her GP.

RQIA found variances across the five HSC trusts in relation to a range of assessment tools used by health visitors. Health visitors may use the following tools:

- Two Whooley Questions
- Edinburgh Postnatal Depression Scale
- Hospital Anxiety and Depression Scale

RQIA found that health visitors work closely with their aligned GP practices, the Midwifery Service, with Mental Health Services and with Sure Start Projects, to support women experiencing poorer mental health, in the antenatal and postnatal period, in line with the PHA (2012) Integrated Perinatal Mental Health Care Pathway, and trust procedures.

Health visitors highlighted that sharing information between teams can be slow due to the lack of staffing capacity and lack of integrated working and multidisciplinary team meetings. Health visitors reported having an average caseload of 300 which was considered by the review team to be very high and is impacting on their ability to provide a comprehensive service. Many trusts reported that a number of posts are vacant. RQIA was informed by the trusts that they have received funding to recruit new health visitors and they are working hard to fill these posts currently.

Like some midwives, health visitors are Solihull trained[28]. During focus groups, health visitors highlighted that they require specific training in prevention and early detection of perinatal mental health. Health visitors told the review team that assessments are point-in-time and they rely on the woman to be open and honest in identifying any concerns.

RQIA found that health visitors (similar to midwives) have limited or no direct referral process to community mental health services. If they detect concerns, they always have to refer back to the patient's GP for further assessment and onward referral.

Emergency Care

RQIA found that when maternity staff have serious concerns related to an woman with mental health issues, the on-call psychiatrist or crisis response team is contacted immediately, to ensure an assessment is undertaken urgently within two hours. As part of this assessment, consideration is given to managing the patient within her own home under the care of the trust Home Treatment Team.

In an emergency, where a woman cannot be managed in the community, admission can only be made to general psychiatric inpatient facilities. Babies cannot be admitted to such facilities; however, all units have family/child friendly rooms available to facilitate visits if prescribed.

Each HSC trust provides a Crisis Response and Home Treatment service on a 24/7 basis which covers all acute hospital sites including maternity inpatient services. The review team was informed that each trust is moving towards seven day working of their Crisis Response and Home Treatment service.

Following assessment by the Crisis Response and Home Treatment Team, home treatment is usually the first option; however, if the risk is significant and unable to be contained at home the woman will be admitted to a general adult

[28] http://solihullapproachparenting.com/

mental health unit in the trust. Treatment will be provided, with ongoing assessment of the patient's mental state and risk factors. Treatment is collaborative with the client and family under the multi-disciplinary team model.

In discussions with staff the review team was concerned in relation to provision of training for staff in restraining pregnant women if necessary, as this is not covered in the curriculum of MAPA **(**Managing Aggression Potential Aggression) training offered by trusts.

RQIA found that HSC trusts, in the absence of a MBU, try to reduce their number of admissions by prioritising home treatment and provision of high intensity community care for patients with significant mental disorder in their home, or as close to their home as possible. However, there is evidence[29] that these teams may not have the necessary understanding of the distinctive features of severe perinatal mental illness, including the rapidity of change in mental state. The particular circumstances of early postnatal mental illness, where minimising risk and preventing alienation from the baby, through early consideration of joint admission, are better understood by specialist services. Crisis response and home treatment teams need additional training if they are to be involved in the management of women at this time.

Recommendation 8	**Priority 1**
In the absence currently of a specialist perinatal mental health service, each HSC trust must ensure appropriate staff receive additional training in understanding the distinctive features and risks of perinatal mental illness.	

RQIA also found that care for the baby can be provided on postnatal wards, but only for a very limited period of time following discussion with social services and family. HSC trusts have ward based social workers, who can closely link in with family and child care services if there are any concerns in this area. Following this, care of the baby will be provided by either the family or designated carers. The trusts work closely with other professionals and the family to ensure that the interests of the child are paramount and safeguarded.

Safeguarding

RQIA found that each HSC trust has similar governance arrangements in place in relation to any safeguarding concerns. Midwifery, mental health, medical, health visiting and nursing staff follow Regional Child Protection Policy and Procedures, UNOCINI guidance and the PHA Integrated Perinatal Mental Health Care Pathway.

[29] https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202015.pdf

Additionally, there is a range of other supporting guidance within each individual trust, such as:

- Safeguarding Children Operational Guidance for nurses and Midwives- this includes detailed sections on recognition, response, referral, report writing, court processes
- Pre-Birth Risk assessment
- Escalating Professional Safeguarding Children Concerns Protocol
- Responding to the Needs of Children Whose Parent has a Mental Health or Substance Misuse Issue
- Domestic Abuse Policy
- Substance Misuse in Pregnancy

All women booking for maternity care are screened for safeguarding issues and referral to social services as required. All women with mental health issues will have social work involvement and birth planning multi-disciplinary team meetings will also be undertaken.

All members of staff in mental health teams are aware of the needs of children including those of the unborn child. Mental health staff liaise regularly with staff from Family & Child Care services, and where appropriate attend meetings and case discussions. The 'Think Family Project'[30] is pertinent to the work of mental health staff and is used by professionals to improve their practice.

Where any concerns are noted regarding pre-pregnancy, these are addressed by an appropriate referral via the UNOCINI, or if known to Family and Child Care services contact made with the team. If there are concerns when the woman becomes pregnant, then liaison with family and child care services starts as soon as possible as there is a need to be aware of the needs of the unborn child.

If there are any concerns post-pregnancy regarding the new born baby or other children, these are addressed via the UNOCINI referral process.

Health Visitors follow trust and regional policies and procedures in relation to any safeguarding/child protection concerns, and issues are also dealt with through a number of other forums:

- strategy meetings
- pre-birth case conferences
- case conferences
- looked after children meetings
- safeguarding supervision procedure for Health visiting (Safeguarding Children Supervision for Nurses)

[30] http://www.cypsp.org/wp-content/uploads/2014/08/Think_Family_NI_article-for-Barnardos-journal_28.07.14.pdf

The review team was informed that all staff within maternity and mental health teams undertake training for care of the vulnerable child and adult, as part of HSC trusts mandatory training requirements. This is monitored and addressed in a number of ways:

- through one to one supervision and appraisal
- discussions with psychiatrists
- maternity training database
- supervision of midwifery practice

The review team found that each HSC trust has social workers aligned to maternity services. Service users informed RQIA that the perceived stigma associated with having a mental health problem continues to prevent women from seeking help.

Service users highlighted a reluctance to be open and honest because they are fearful that their baby will be taken away. During focus groups, social workers highlighted that more needs to be done to remove the stigma associated with mental health problems and to assure service users that social services work in the interest of their family and will always work towards keeping their family together.

RQIA was advised that the PHA, in partnership with the DoH and the Northern Ireland Association for Mental Health (NIAMH) have developed and launched a major mental health anti-stigma campaign 'Change Your Mind'.

Management of Medication

The governance departments within each HSC trust are responsible for issuing new guidance on medicine optimisation to the relevant directorates who disseminate it within and across their teams.

Ideally, information on the administration of psychiatric medications during pregnancy should be given verbally and in written form by the GP or psychiatrist. However, mental health problems cover a wide spectrum of difficulties and it is expected that lower level medication issues are managed within primary care in line with stepped care approach.

Psychiatrists working in both hospital and community settings are available to provide telephone advice regarding medications to GP colleagues if this is required.

Some psychiatrists print information from the UK Teratology Information Service (UKTIS) and/or copy GP letters to the patients. Community mental health staff observe for effect/side-effects and ask about concordance. The keyworker can answer any questions the woman may have and liaise with the prescriber where there are concerns. The woman will be encouraged to be proactive and discuss any concerns. However, there is no formal process in place to ensure this happens for all patients. Leaflets on medication have not been prepared to date because of the rapidly changing advice on medication in pregnancy.

The review team was told that any psychiatrist prescribing medication for a pregnant woman or one who is breastfeeding will refer to the NICE Guideline CG192-*Antental and Postnatal Mental Health: clinical management and service guidance*[31] *and Maudsley guidelines*[32]*.* Consultant psychiatrists are also aware of up to date evidence on UKTIS, which provides a national service on all aspects of the toxicity of drugs and chemicals in pregnancy. Information is also available on the Royal College of Psychiatrists and Choice & Medication websites, including leaflets on mental health in pregnancy.

As stated earlier, not every HSC trust has a consultant with a specialist interest in perinatal mental health. This has resulted in consultant psychiatrists frequently discussing medication issues in complex cases informally with fellow consultants with a particular interest in perinatal mental health, and within consultant medical staff groups. Advice about medication should be a core responsibility of a specialist perinatal mental health team. RQIA found that maternity services, primary care and health visitors do not have a sufficient understanding in this complex area and make arbitrary decisions on medication.

During focus groups, GPs and psychiatrists highlighted challenges in the management of prescribing of medication during the antenatal and postnatal period. RQIA found that GPs and psychiatrists lacked awareness and knowledge of how pregnancy can affect a woman's existing health condition. However, GPs did highlight that they can contact psychiatrists within secondary care for advice if required, and obstetricians do not alter psychotropic medication without the guidance of the psychiatrist.

RQIA found that some HSC trusts offer a preconception service for women wishing to become pregnant, who are already on psychotropic medication. These clinics are staffed by a consultant psychiatrist and senior pharmacist. Information on medication issues is provided for pregnant women by the prescriber.

The review team found that there is no dedicated pharmacist within trusts within antenatal or postnatal wards. However, advice contained in the Northern Ireland and British National Formulary is easily accessed and provides guidance for staff in conjunction with psychiatric professionals.

RQIA was also advised that the HSC Board is currently developing a new initiative to place a pharmacist within a number of GP practices throughout Northern Ireland. Northern Ireland is also piloting a number of GP federations and a pharmacist will be included within each federation. RQIA welcomes these new initiatives which will provide expertise and advice for GPs.

Both GPs and psychiatrists would welcome a specialist multi-disciplinary team, core team or liaison nurses/champions to assist with prescribing and management of medication during the antenatal and postnatal period.

[31] https://www.nice.org.uk/guidance/cg192
[32] http://fac.ksu.edu.sa/sites/default/files/Prescribing_Guidelines11.pdf

RQIA supports that any model for the development of specialist perinatal mental health teams in each HSC trust should provide expert advice on medicine optimisation as part of their core role.

Chapter 3: Experiences of Service Users

3.1 Views of Mothers

As part of the review methodology, the review team engaged with service users who have experienced mild-moderate and severe mental ill health during or after their pregnancy. Seeking life experiences of mothers who have suffered from perinatal mental health problems was critical to RQIA in examining the effectiveness of the PHA Integrated Perinatal Mental Health Care Pathway.

Service users identified a number of other gaps and common themes as follows

- A perceived lack of training, knowledge and experience of some GPs in relation to prevention and early detection.
- A perceived lack of compassion, advice, information and sign-posting from some GPs,
- GPs are unaware of which services to refer to,
- GPs prescription of anti-depressants too easily,
- Long waiting time to access community and acute services,
- Lack of continuity of care within all maternity teams (Midwives, Health Visitors, Social Workers, Home Treatment Teams),
- Range and effectiveness of assessment tools used by professionals,
- Non-adherence to agreed care plan e.g. service users have to repeat their experience over and over again,
- Lack of available support groups and community services,
- Service users having to source their own support through the internet, social media or by speaking with other mothers,
- "Postcode lottery" in relation to community services such as Sure Start programmes,
- Stigma associated with mental health issues – with services users being afraid to be open and honest in case their baby will be taken away,
- Greater awareness during antenatal classes that perinatal mental health illnesses can occur,

A number of woman complained about the lack of specialist services available to women who experience mental ill health during or after pregnancy in Northern Ireland compared to the rest of the United Kingdom. This was particularly reinforced by service users who live outside of the Belfast locality and who have limited or no support from partners or families.

> *"If i didn't live within the Belfast locality, I don't know what would have happened to me and my baby"*

During our fieldwork, the majority of service users told us they didn't receive the "right service, by the right professional, at the right time". Service users expressed frustration with service provision, and some stated that were left to deal with their illness on their own or with support from their partner or families. Some service users highlighted their frustration with GPs, midwives, health visitors, community mental health teams, and voluntary and community organisations. The women we spoke with stated that they did seek help, but that the significance of their symptoms and associated risks were not always recognised by GPs or other professionals.

Some service users told us that the referral process to access appropriate services in a timely fashion is too lengthy and can take up to 6 months or more. Service users stated that many professionals are not aware of what services are available or how to access care in their locality.

> *"I had to fight to access services. When you're ill, you don't have the energy to fight, but I had no choice!"*

Service users, especially first time mothers also highlighted that the new model of maternal care can have a major influence on whether or not a mother develops perinatal mental health illnesses in the postpartum phase. For example, if a mother and baby are assessed and deemed fit for discharge, they will be discharged within 6-12 hours from the maternity hospital. Many service users stated that they would have welcomed greater flexibility and the opportunity to stay longer in hospital. Service users highlighted that the lack of sleep, feeding difficulties and other parenthood challenges can often trigger perinatal mental health illnesses. Service users felt that if they stayed longer in hospital postpartum, they would have received greater support from midwives and help prevent their illness and the resultant effect of this on their baby.

Experiences of Mothers with Mild-Moderate Perinatal Mental Health Illnesses

Many service users with mild-moderate perinatal mental ill health issues highlighted mixed experiences. There is a large cohort of mothers and fathers living within the community suffering from mild to-moderate illnesses. Service users told us that more needs to be done to raise awareness within the community in relation to prevention, early detection and signposting to services and further support. Service users considered that the voluntary and community sector can and should play a greater role in delivering support. RQIA was informed that HSC trusts currently have no service level agreements in place to deliver any support services to women affected by perinatal mental health.

Service users informed RQIA that some voluntary and community services are available in different trusts. However, the majority of mothers are not aware of them. Charities and voluntary organisations provide support groups and volunteer services within trust areas which can involve weekly visits by a support worker for the first few months postpartum.

A programme developed by AWARE NI ("Mood Matters Parent and Baby Programme") was found by service users to be helpful in providing education for parents through the various stages of pregnancy and beyond to provide them with the knowledge and skills to look after their mental health and well-being, and to give their child the best start in life.

Service users also emphasised the inequality of community services provided by Sure Start Programmes. Many mothers and fathers from outside the top 20-25% deprived areas develop perinatal mental health illnesses. These service users would also benefit from the Sure Start Programmes, especially first time mothers and fathers. Many service users would like to have access to mother and baby groups, baby yoga, and even the opportunity to get out of the house and speak with other mothers and fathers.

RQIA was informed that the HSC Board in partnership with the Public Health Agency is developing a 'Directory' of core mental health services across Northern Ireland via an online App, which will include perinatal mental health. Service users welcomed the development of this 'Directory'. RQIA expects that this will link to all sectors and sources of information such as the voluntary and community sector, mental health/maternal apps, perinatal blogs and perinatal Facebook pages.

Experiences of Mothers with Severe Perinatal Mental Health Illnesses

Service users who had access to the Specialist Perinatal Mental Health team within the Belfast Trust (team of three) highlighted that this service was critical in their recovery. Service users highlighted that without this very small specialist team, they do not know what would have happened to them or their baby. Service users told us that they were able to access the team which includes a specialist psychiatrist, community psychiatric nurse and a social worker. They also emphasised the importance of continuity of care. Services users from other trusts stated they would welcome a similar specialist service in the other four HSC Trusts.

A large number of service users highlighted that the development of a regional MBU in Northern Ireland is crucial for:

1. those women who become very unwell during pregnancy and do not make sufficient recovery to be discharged before childbirth
2. those women who become acutely unwell postnatally
3. those women at high risk of relapse

Some women with severe mental ill health such as postpartum psychosis admitted to a general adult psychiatric unit told us that they had to share these facilities with patients with long-term mental health illnesses and patients over the age of 60.

Service users also told us that facilities used at present do not have appropriately trained staff to allow contact with their baby. As a result their baby requires to be cared for by their partner, family member or foster families.

3.2 Impact on Partner/Husband/Family

Perinatal mental illnesses can have damaging consequences for the woman's partner or family. During the review we also considered the impact on partners, husbands and families.

Service users told us that there is an expectation that they are going to be the best mother in the world, however, when they suffer from perinatal mental ill health their world is turned upside down. They told us that a person can fall very ill quickly and their partner, husband or family can feel powerless. As a result, their partner, husband or family has to take over; however, there is insufficient advice or information available to them. Many service users highlighted that their husband and family had to research perinatal mental health themselves to identify local help and support services.

Service users informed us of the knock on effects perinatal mental ill health problems can have on their partner, husband and family. They have to cope with the worry and stress associated with caring for both their new born child and their loved one, as well as dealing with other commitments such as work. This can all lead to potential mental health problems such as depression, anxiety, and stress. During focus groups, many service users told us that their partner/husband is now accessing services such as medication, cognitive behavioural therapy and counselling from charities such as 'Lifeline' to deal with their own mental health problems.

Chapter 4: Conclusions

HSC organisations throughout Northern Ireland acknowledged the lack of specialist perinatal mental health services. HSC providers and commissioners accept the need to develop specialist perinatal mental health services to ensure service users, families and carers receive the necessary specialist services in appropriate environments to meet their needs.

The review team wishes to emphasise the importance of reviewing good evidence based practice to ensure any specialist service is developed effectively and efficiently to meet need.

To provide some guidance for key decision makers within Northern Ireland, the review team has highlighted the recent paper from the *Joint Commissioning Panel for Mental Health (www.jcpmh.info)*[33], which provides guidance in relation to what a good perinatal mental health service would look like.

A good specialised perinatal service should be organised on a hub-and-spoke basis so that inpatient MBU serve the needs of large populations and are closely integrated with specialised community perinatal mental health teams provided by trusts in each locality.

Specialised community perinatal mental health teams

A good specialised community perinatal mental health team should be a member of the Royal College of Psychiatrists' quality network. It should assess and manage women with serious mental illness or complex disorders in the community who cannot be appropriately managed by primary care services. It should:

- respond in a timely manner and have the capacity to deal with crises and emergencies and assess the patients in a variety of settings including their homes, maternity hospitals and outpatient clinics
- have close working links with a designated mother and baby unit
- manage women discharged from inpatient mother and baby units
- work collaboratively with colleagues in maternity services (including providing a maternity liaison service) and in adult mental health services with women with prior or longstanding mental health problems

A good community perinatal mental health service should offer pre-conception counselling to women with pre-existing mental health problems and those who are well but at high risk of a postpartum condition.

[33] http://www.rcpsych.ac.uk/pdf/perinatal_web.pdf

Mother and Baby Units

During the fieldwork in primary and secondary care services, professionals had mixed views in relation to the development of a regional MBU. HSC trusts highlighted that numbers are very small with less than 4 per 1000 births or circa 100 admissions per year in Northern Ireland.

Many professionals however, fully supported the need for a regional MBU co-located with general adult mental health, maternity services and the local community perinatal mental health teams. Some professionals questioned the need for such a unit due to travel commitments/demands on the family. The review team considered that these concerns did not outweigh the need for an appropriate inpatient unit. Mother and Baby units (MBU) offer advice, support and assistance in the care of the infant when the mother is ill, while also meeting the emotional and developmental needs of the infant; for example, specially trained nurses allow the mother to sit with them during feeding which allows the mother to bond via touch, smell, and face-to-face contact.

A good mother and baby unit should be accredited by the Royal College of Psychiatrists' quality network and meet their standards. It should:

- provide care for seriously mentally ill women or those with complex needs who cannot be managed in the community in late pregnancy and in the postpartum months
- provide expert psychiatric care for seriously ill women while at the same time admitting their infants, avoiding unnecessary separation of mother and infant
- offer advice, support and assistance in the care of the infant while the mother is ill, meeting the emotional and developmental needs of the infant
- provide a safe and secure environment for both mother and infant
- offer timely and equitable access such that mothers are not admitted to general adult wards without their baby prior to admission
- be closely integrated with specialised community teams to promote early discharge and seamless continuity of care

RQIA considers that the evidence provided by this review clearly demonstrates the need for development of both community specialist perinatal mental health teams within HSC trusts and a regional MBU: This evidence is further supported by the following:

- NICE guidelines, CG192 for Antenatal and Postnatal Mental Health, 2014
- Royal College of Psychiatrists, CR197:Perinatal mental health services: recommendations for the provision of services for childbearing women, 2015
- Perspective study completed by the Specialist Perinatal Mental Health Consultant Psychiatrist in Northern Ireland, 2013
- NIAMH, Maternal Mental Health is Everyone's Business: Supporting Women and their Families', 2014
- AWARE NI, Northern Ireland Perinatal Mental Health is Everyone's Business, 2016

Throughout the review we were told about the lack of psychology input throughout the services in Northern Ireland and this also needs to be addressed within the specialist teams and in maternity hospitals and neonatal units.

Recommendation 9	**Priority 1**
The Department of Health should work collaboratively with all key stakeholders including the Public Health Agency, HSC trusts, General Practitioners and service users to develop and progress a model for the development of specialist perinatal mental health teams in each HSC trust.	

RQIA also recommends that a single regional MBU be established in Northern Ireland. A number of factors need to be considered as part of this project. During the review, the main negative factor that emerged in relation to development of an MBU was the effect that it could have on the rest of the family in terms of travel and also having to deal with other children, in the absence of an established wider family unit.

Given this concern, consideration should be given to the development of a sufficient infrastructure to deal with the challenges and costs of family travel and the impact on other children of separation from their mother. Consideration also has to be given to the links between the MBU and the specialist teams to ensure effective transition back to specialist teams/trust community teams on discharge from the MBU.

Recommendation 10	**Priority 3**
The Department of Health should work collaboratively with all key stakeholders to develop and progress a model for a single regional Mother and Baby Unit in Northern Ireland.	

RQIA also recommends that key decision makers visit both specialist teams and an MBU to gain a better understanding of their structures before deciding on the future provision of perinatal mental health services in Northern Ireland.

Recommendation 11	**Priority 1**
Key decision makers should visit both specialist teams and a Mother and Baby Unit within the United Kingdom before making any decision on the future provision of perinatal mental health services in Northern Ireland.	

Chapter 5: Summary of Recommendations

Recommendation 1	**Priority 2**
The HSC Board must ensure that each HSC trust provides a perinatal clinical psychology service for their maternity hospitals and neonatal intensive care units.	

Recommendation 2	**Priority 1**
In the absence of a mother and baby unit, HSC trusts should provide appropriate equipment and facilities within all relevant general adult psychiatric inpatient units to meet the needs of a mother and her baby and older children during visits.	

Recommendation 3	**Priority 3**
The HSC Board should work with HSC trusts to develop a coding system to capture and report on statistical information to inform the future requirements for perinatal mental health services.	

Recommendation 4	**Priority 1**
The Department of Health should request the Public Health Agency to establish a regional group to examine and develop perinatal mental health services with agreed terms of reference and timelines. The delivery and implementation of a work plan by this group should be monitored by the Maternity Strategy Implementation Group, and the Department of Health.	

Recommendation 5	**Priority 2**
The HSC Board should ensure that community based peer support services are developed within an overall plan for specialist perinatal mental health services in Northern Ireland in collaboration with relevant voluntary organisations and Sure Start.	

Recommendation 6	**Priority 1**
Each HSC trust should review the communication protocols in place between primary and secondary care to ensure effective communication and information sharing.	

Recommendation 7	**Priority 1**
The Public Health Agency should work collaboratively with the HSC Board to ensure that all General Practitioners are made fully aware of the revised Integrated Perinatal Mental Health Care Pathway and of the voluntary and community organisations who can offer support to woman experiencing perinatal mental health in their locality.	

Recommendation 8	Priority 1
In the absence currently of a specialist perinatal mental health service, each HSC trust must ensure appropriate staff receive additional training in understanding the distinctive features and risks of perinatal mental illness.	

Recommendation 9	Priority 1
The Department of Health should work collaboratively with all key stakeholders including the Public Health Agency, HSC Trusts, General Practitioners and service users to develop and progress a model for the development of specialist perinatal mental health teams in each HSC trust.	

Recommendation 10	Priority 3
The Department of Health should work collaboratively with all key stakeholders to develop and progress a model for a single regional Mother and Baby Unit in Northern Ireland.	

Recommendation 11	Priority 1
Key decision makers should visit both specialist teams and a Mother and Baby Unit within the United Kingdom before making any decision on the future provision of perinatal mental health services in Northern Ireland.	

Appendix 1: Abbreviations

Belfast Trust	Belfast Health and Social Care Trust
BPAD	Bipolar affective disorder BPAD
CPN	Community Psychiatric Nurse
CBT	Cognitive behavioural therapy
DoH	Department of Health
EIPT	Early Intervention Transformation Programme
EPDS	Edinburgh Postnatal Depression Scale (EPDS)
FHA	Family Health Assessment
GP	General Practitioner
HSC	Health and Social Care
HSC Board	Health and Social Care Board
HSC Trusts	Health and Social Care Trusts
HADS	Hospital Anxiety and Depression Scale
ICPs	Integrated Care Partnerships
ICAMHS	Infant, child and adolescent Mental Health Service
MH	Mental Health
MAPA	Managing Aggression Potential Aggression
MBU	Mother and Baby Unit
NCT	National Childbirth Trust
NICE	National Institute for Health and Care Excellence
NICU	Neonatal Intensive Care Unit
NIAMH	Northern Ireland Association for Mental Health
NIMATS	Northern Ireland Maternity system
Northern Trust	Northern Health and Social Care Trust
NSPCC	National Society for the Prevention of Cruelty to Children
PHA	Public Health Agency
PEPP	Pregnancy and Early Postnatal Care Plan
PND	Post Natal Depression
PQC	Promoting Quality Care
SCNS	Safeguarding Children Supervision for Nurses
SIGN	Scottish Intercollegiate Guidelines Network published
SLA	Service Level Agreement
South Eastern Trust	South Eastern Health and Social Care Trust
Southern Trust	Southern Health and Social Care Trust
ToR	Terms of Reference
UKTIS	United Kingdom Teratology Information Service
UNOCINI	Understanding the Needs of Children in Northern Ireland
Western Trust	Western Health and Social Care Trust

Appendix 2: National Perinatal Policies and Guidelines

2002	Department of Health	Women's Mental Health: Into the Mainstream Strategic Development of Mental Health Care for Women
2007	Stillbirth and neonatal death charity (Sands)	Pregnancy Loss and the Death of a Baby: Guidelines for professionals
2008	Healthcare Commission	Towards better births: A review of maternity services in England. Service Review
2011	Royal College of Obstetricians and Gynaecologists	Guidelines on Management of Women with Mental Health Issues during pregnancy and the postnatal period
2012	2012 Scottish Intercollegiate Guidelines	Management of perinatal mood disorders
2012	2012 Royal College of Psychiatrists	Quality Network for Perinatal Mental Health Services
2012	2012 Joint Commissioning Panel of Mental Health	Guidance for commissioners of Mental Health perinatal mental health services
2012	2012 NHS Commissioning Board	Specialised commissioning specifications: Perinatal mental health services
2012	2012 National Institute of Health and Clinical Guideline (NICE)	Clinical Guideline for Caesarean
2013	2013 Improving Access to Psychological Therapies (IAPT)	Perinatal Positive Practice Guide.
2014	2014 National Institute of Health and Clinical Guideline (NICE)	Clinical Guideline Update for Antenatal and Postnatal Mental Health Care
2015	MBRRACE-UK: Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK	Deaths from psychiatric causes in Saving lives: Improving Mother's Care
2015	Royal College of Psychiatrists	CR197:Perinatal mental health services: recommendations for the provision of services for childbearing women
2016	2016 NICE Quality Standard (QS 115)	Antenatal and postnatal mental health
2016	Sands Guidelines	Pregnancy Loss and the Death of a Baby: Guidelines for professionals 4th edition 2016
2016	The British Psychological Society	Perinatal Service Provision: The role of Perinatal Clinical Psychology

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