



From bumps to babies: perinatal mental health care in Wales

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everyone's business



Abstract

This report provides an overview of the findings from the Perinatal Mental Health in Wales project, a collaboration between NSPCC Cymru/Wales, National Centre for Mental Health (NCMH), Mind Cymru and Mental Health Foundation, with support from the Maternal Mental Health Alliance Everyone's Business Campaign.

The aim of this project was to explore perinatal mental health provision in Wales and understand how perinatal mental health care was experienced by women and their partners. In achieving this aim, this project weaves together the accounts of women, and partners affected by perinatal mental health conditions, health professionals working in the perinatal period, and third sector professionals involved in delivering perinatal mental health services in Wales. This report uses the term perinatal mental health problems, conditions, difficulties or illnesses to describe the range of mental health conditions that can be experienced by women during pregnancy or in the year after birth (called the perinatal period). This includes depression, anxiety, eating disorders, obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD) and psychotic disorders, such as postpartum psychosis.

This report focuses upon: barriers to the identification of perinatal mental health problems; the development of specialist community perinatal mental health services; access to specialist perinatal mental health care; third sector perinatal mental health provision; and support for families affected by perinatal mental health problems. This report demonstrates that important progress has been made in the provision of perinatal

mental health care to women and their families in Wales. Where previous gaps existed, there are now specialist community perinatal mental health services in six out of the seven health boards. This project demonstrates that women experiencing perinatal mental health problems are already benefitting from these new specialist services.

However, this project also shows that women in Wales are still not receiving all aspects of care that they need to help them recover from perinatal mental health problems. Critical improvements are needed across the perinatal mental health pathway to better support women and their families facing these conditions. It is important that improvements are made in universal services to ensure that barriers to the identification of perinatal mental health problems are addressed and removed. The area in which a woman lives still determines the perinatal mental health care they can access. It is therefore essential that further investment is put into specialist perinatal mental health services to address the disparity in service provision between health boards in Wales. This would enable all specialist perinatal mental health services in Wales to 'Turn Green' on the Maternal Mental Health Alliance (MMHA) map of specialist perinatal mental health services. It is also vital that appropriate mother and baby unit provision is made available in Wales for the women and their families affected by the most severe perinatal mental health conditions. This report argues that these shortfalls need to be addressed before Wales can lead the way in delivering high quality, consistent perinatal mental health care to all women and their families in Wales.

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Foreword

As many as one in four women experience a mental health problem during pregnancy or in the first year after the birth of their baby. These are the most common serious health problems that women suffer from at this crucial time in their lives, and this can have a devastating impact on them and their families. As a result, and because so many of these women don't get the care they need, suicide has remained for decades a leading cause of maternal deaths in the UK. With the right treatment and support, women and their families can recover. However, recent data suggests that women in only about a quarter of areas in the UK have access to specialist services that meet national guidelines. This is causing huge avoidable suffering for women and their families, and we also know that these conditions cost society £8.1 billion for each year of women giving birth across the country.

The Maternal Mental Health Alliance Everyone's Business campaign has been campaigning to improve the provision of specialist perinatal mental health services across the UK, so that women everywhere can access the care they are entitled to. Specialist physical health care by obstetricians, midwives and maternity hospitals is an unquestioned necessity, but when it comes to specialist care of mental health at this time, health services have for too long been complacent and neglectful. On behalf of women and families throughout the UK, we are demanding equitable access to specialist perinatal mental health services because, in addition to providing expert care to women and their families, these services act as catalysts for change across the whole pathway, providing expertise and delivering training to a range of health and social care professionals including GPs, health visitors and midwives.

We are encouraged by the excellent progress in Wales over the last three years, with funding from Welsh Government allocated to each health board to establish or enhance some specialist service in all areas, but mothers across Wales are still a long way from receiving care that meets national standards. As this report outlines, the area in which women live still determines the level of care they can access should they become unwell. Furthermore, there is still no mother and baby unit for Wales, meaning women who need inpatient care either

need to travel across the border or receive treatment in general psychiatric wards, forcibly separated from their baby. These deficiencies must be addressed to give women access to the care they need to recover and thrive as new mothers. The report has also given a voice to women and their partners who have been affected by perinatal mental illness. It is so important to listen to the views of these experts by experience and allow them to inform how services develop and what information families need when they are planning to have a child.

I am delighted to see these four organisations coming together to improve our understanding of perinatal mental health care across Wales and identify the remaining challenges to ensuring women and families across Wales receive the high quality services they need. Wales now has a unique opportunity to show it is leading the way among the nations of the UK and I urge Welsh Government to heed the recommendations of this report and act swiftly to finally repair a longstanding neglect of the health of women and babies.

Alain Gregoire
Chair, Maternal Mental Health Alliance UK

This project has been a partnership between four organisations; NPSCC Cymru/Wales, National Centre for Mental Health, Mind Cymru and the Mental Health Foundation. Its success has been underpinned by our shared belief that women in Wales should have access to high quality services, information and support for their mental wellbeing in the perinatal period.

Recent investment in specialist services are an encouraging development but this report highlights a number of challenges to overcome and gaps in provision to address. However, by working together and harnessing the passion and commitment of everyone involved in perinatal mental health across Wales and beyond, we are optimistic that Wales can deliver for women, their children, partners and family.

NPSCC Cymru/Wales, National Centre for Mental Health, Mind Cymru and the Mental Health Foundation



Abbreviations

| | |
|----------------|---|
| ABMU | Abertawe Bro Morgannwg University Health Board |
| ACT | Acceptance and Commitment Therapy |
| APP | Action on Postpartum Psychosis |
| CBT | Cognitive Behavioural Therapy |
| CCQI | The Royal College of Psychiatrists, Centre for Quality Improvement |
| CMHT | Community Mental Health Teams |
| CPN | Community Psychiatric Nurse |
| COP | Community of Practice |
| EPDS | Edinburgh Postnatal Depression Scale |
| FOI | Freedom of Information Request |
| GAD-2 | Generalized Anxiety Disorder scale |
| GPs | General Practitioners |
| MBRRACE | Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries |
| MBU | Mother and Baby Unit |
| NCMH | National Centre for Mental Health |
| NICE | The National Institute for Health and Care Excellence |
| NSPCC | The National Society for the Prevention of Cruelty to Children |
| OCD | Obsessive Compulsive Disorder |
| PRAMS | Perinatal Response and Management Service |
| PTSD | Post-Traumatic Stress Disorder |
| PHQ-9 | Patient Health Questionnaire |
| RCOG | Royal College of Obstetricians & Gynaecologists |
| WCVA | Wales Council for Voluntary Action |
| WG | Welsh Government |
| WHSSC | Welsh Health Specialised Services Committee |
| WTE | Whole Time Equivalent |



Perinatal mental health in Wales overview

Over
33,000
women give birth in
Wales each year (2015)¹



Almost **9,000**
new mums in Wales
will experience perinatal
mental health problems
each year³



90% of health
professionals feel they
would benefit from
additional training on
perinatal mental health



There were almost
3,000 referrals to
the specialist community
perinatal mental health
teams and universal provi-
sion in Wales in 2017



Wales does not have a
Mother and Baby Unit
(MBU) to support women
who need specialist
inpatient care



**Dads/partners and other
family members can be
affected** by perinatal mental
health problems



1 in 4
women in the UK
experience perinatal mental
health problems²



59%
of health professionals
face challenges in talking
to mums and their partners
about perinatal mental health
problems



**Six health
boards** in Wales
now have a specialist
community perinatal
mental health service
in place



Two
of the specialist
community perinatal
mental health services
in Wales have signed up to
The Royal College of
Psychiatrists, Quality
Network for Perinatal Mental
Health Services (CCQI)



Seven
third sector organisations deliver perinatal
mental health services in Wales

61% of health professionals had not
received training on infant mental health

Figure 1. Perinatal Mental Health in Wales Overview

¹Source: Stats Wales (2017) Live births rates by area figures for Wales in 2015.

²Source: Howard et al (2018)

³Calculated using Stats Wales (2017) Live births rates by area figures for Wales in 2015, and Howard et al's (2018) prevalence rates on perinatal mental health problems in the UK.

Recommendations

Training

- Perinatal mental health should be incorporated into pre-registration training for all mental health practitioners and all health professionals working in the perinatal period. Training should include how to recognise and appropriately respond to the full range of perinatal mental health conditions, from mild to severe, and address the association between perinatal mental health and infant mental health
- The **All Wales Perinatal Mental Health Steering Group** to complete the training and competency model for Wales, taking account of the learning from the Competency Framework for England and the Perinatal Mental Health Curricular Framework for Scotland
- Once completed, the **Welsh Government** should implement and evaluate the training and competency model for Wales, to ensure that health professionals working in the perinatal period have sufficient training for their role
- The **Managed Clinical Network (MCN)** should develop a standardised post-registration training course that perinatal mental health teams can deliver to all health professionals involved in the care of women in the perinatal period, as a way of building capacity within health care. This recommendation builds on the Welsh Government's response to Recommendation 16 of the National Assembly for Wales, Children, Young People and Education Committee report into Perinatal Mental Health (2017)

Awareness and information

- **Key stakeholders** work together to develop a joint public awareness raising campaign on perinatal mental health problems, with the aim of tackling stigma and improving women and their family's knowledge of these conditions and where to obtain help
- Women and their families need clear and consistent information on the effects that pregnancy and childbirth can have upon mental health. **Public Health Wales** should update Bump, Baby & Beyond with the latest evidence about prevalence and signs and symptoms of the full range of perinatal mental health conditions (from

mild to severe), where to obtain help, and how to promote positive mental health in the perinatal period

- The **MCN** should produce and/or distribute a range of consistent, good quality information resources on perinatal mental health conditions (from mild to severe), which can be given to women and their families affected in Wales. Women with lived experience should be involved in the design of these resources to ensure they are appropriate and relevant
- All local **Family Information Services** should ensure that they hold and disseminate information about all third sector perinatal mental health services and local peer support groups for mums and their families
- The **MCN** should produce and/or distribute a range of consistent, good quality information resources on perinatal mental health conditions (from mild to severe) specifically for partners and family members

Service standards

- **The Welsh Government** should provide additional funding to health boards to address disparity in the level of perinatal mental health service provision and to ensure that these specialist services are able to provide all aspects of care that women need to help them recover. This would enable all specialist perinatal mental health services in Wales to 'Turn Green' on the Maternal Mental Health Alliance (MMHA) map of specialist perinatal mental health services
- **The Welsh Government** ensure that all **health boards** provide the financial investment for the specialist community perinatal mental health services to sign up to the Royal College of Psychiatrists' quality standards for perinatal mental health services for review and accreditation

- **The Welsh Government** and **health boards** should carry out regular evaluation of perinatal mental health services, including clinical audits, to support service developments and explore the experiences of women and their families receiving specialist care
- **Third sector** organisations facilitating perinatal mental health peer support in Wales should work towards achieving the perinatal mental health third sector Quality Assurance Principles

Integration

- Improved partnership working between **specialist and third sector perinatal mental health services** to maximise local support available for women and their families affected
- **The Welsh Government** should promote a more integrated approach to promoting and protecting positive perinatal mental health and infant mental health, with a particular focus on supporting mums affected by perinatal mental health problems to build positive relationships with their babies/children

Data collection

- The **MCN** should ensure that the completed unified framework for data collection becomes fully integrated into perinatal mental health services. This will ensure that admissions data being collected across perinatal teams in Wales is consistent and can be used to illustrate demand and inform future service development

Implementation

- **The Welsh Government** should establish a dedicated assurance group with membership from relevant stakeholders in the perinatal mental health sector to monitor the implementation of its response to the National Assembly for Wales' Children, Young People and Education Committee recommendations

- As a key priority, **the Welsh Government** should establish the MCN so they can provide national leadership on implementing the National Assembly for Wales Children, Young People and Education Committee recommendations, and provide the necessary expertise to further develop perinatal mental health services in Wales

Access to specialist services

- In addressing the disparity in the level of service provision between health boards in Wales, **the Welsh Government** should ensure that there is improved access to psychological therapies for women and their families affected by perinatal mental health problems.
- **The Welsh Government** and **health boards** should work with the MCN to address barriers to accessing specialist perinatal mental health services for women and their families, including a consideration of appropriate facilities to host groups, transport, and creche facilities.
- **The Welsh Government** and **health boards** should work with the MCN to design fit for purpose mother and baby unit (MBU) provision in Wales which supports women and their families
- The **MCN** should develop protocols for accessing MBU provision and a universal pathway for admission to ensure that specialist provision is accessed by those that need it
- The effect of perinatal mental health problems on partners and family members should be recognised and taken into account by **all health professionals** working in the perinatal period
- All **perinatal mental health** services in Wales should have a unified and clear pathway in place to refer dads/partners and other family members to if they are identified as needing support within their own mental health in the perinatal period

Perinatal mental health in Wales

vision for the future



Priority areas



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Figure 2. Vision for the Future

1. Introduction

The past three years have marked an important time in the development of perinatal mental health care. Within this period, there has been a growing momentum towards improving perinatal mental health across the UK. This includes increased Government investment towards improving specialist perinatal mental health care for women and their families, and a growing social recognition about the impact of these conditions on those affected.

In England, developing services and improving outcomes for women with perinatal mental health problems and their families has been identified as a national priority. To support the delivery of these ambitions, the UK Government ring fenced £365 million for NHS England's perinatal mental health community services development fund (between 2015/16 and 2020/21) (NHS England, 2016). As a result of this investment, the Welsh Government received additional funding as a 'Barnett Consequential' for spending in Wales. In the past three years, the Welsh Government have developed policy frameworks on perinatal mental health and implemented new services to support women and families affected by these conditions. One of the Welsh Government's Together for Mental Health Delivery Plan (2016-2019) priorities for action is to ensure that all children have the best possible start in life which is enabled by giving parents/care givers the support they need (Welsh Government, 2016a). Within this priority there is a specific focus on providing better outcomes for women, their babies and families with, or at risk of, perinatal mental health problems by establishing accessible specialist community perinatal service in every health board in Wales (Welsh Government, 2016a). In June 2016, the Minister for Health and Social Services announced that the Welsh Government was investing £1.5 million per year to improve community specialist perinatal mental health services across Wales (BBC, 2016; Welsh Government, 2016b). Following this announcement, the Welsh Government asked each health board to submit a collaborative and multi-disciplinary proposal for a specialist perinatal mental health service that would meet the needs of the local population (see Children, Young People and Education Committee, 2017). The Welsh Government funding was also used to establish a Community of Practice and the All Wales Perinatal Mental Health Steering Group. The group

is managed by Public Health Wales and brings together practitioners, third sector organisations and women with lived experience to support the development of services and share good practice.

In 2017, the National Assembly's Children, Young People and Education Committee launched an inquiry into perinatal mental health in Wales, as part of their work on the First 1,000 days and the association between poor parental mental health and the impact on children's health and development. The inquiry focused on the Welsh Government's approach to perinatal mental health, patterns of inpatient care, level of specialist provision, clinical pathways, integration of perinatal mental health, bonding and attachment and health inequalities. This inquiry has been a key driver for change in Wales, as it evidenced developments in perinatal provision and set out 27 key recommendations for improving perinatal mental health care. Encouragingly, the Cabinet Secretary for Health and Social Services accepted or partially accepted 22 of the recommendations made in the inquiry report⁴, which included establishing a Managed Clinical Network (MCN), which will be instrumental in driving forward progress in Wales.

These national developments have been set against a backdrop of growing recognition of the prevalence and impact of perinatal mental health problems on women and their families across the UK. In an independent evaluation, the Maternal Mental Health Alliance *Everyone's Business* campaign⁵ has been identified as a key catalyst for change in perinatal mental health care⁶ (Granville et al., 2016). In 2013, the Maternal Mental Health Alliance launched the *Everyone's Business* campaign with the aim of tackling stigma surrounding maternal mental health issues and highlighting the unequal provision of specialist mental health services for mums and their families across the UK. The campaign produced visually powerful maps to highlight gaps in specialist provision across the UK, which have demonstrated progress in specialist provision. In 2015, the mapping exercise by the *Everyone's Business* campaign revealed that specialist perinatal mental health services were unequally distributed, with women in half of the UK having no access to specialist perinatal mental health services (see Appendix One) (Maternal Mental Health Alliance, 2015). New maps released in 2018,

⁴ See: <http://www.assembly.wales/laid%20documents/gen-ld11290/gen-ld11290-e.pdf>

⁵ The *Everyone's Business* campaign was originally a three-year (2013–2016) project that was funded by Comic Relief and hosted by Action on Postpartum Psychosis (APP), that called for all women throughout the UK with perinatal mental health conditions to receive the treatment they need, when and where they need it. A further grant of £750,000 was secured in 2016 from Comic Relief to sustain and build on the successful momentum of the *Everyone's Business* campaign.

⁶ The evaluation found that the *Everyone's Business* campaign made a significant impact upon establishing maternal mental health as a political priority, achieving national funding commitments, influencing national funders and local commissioning decisions, strengthening the case for improved perinatal mental health services; and increasing the focus on perinatal mental health in the devolved nations (Granville et al., 2016).

showed that while many more women live in an area where local specialist perinatal mental health services are now available, in a quarter (24 per cent) of areas in the UK, new mums still have no access to these specialist services. In addition to the work of the campaign, the profile of perinatal mental health problems has also been raised through the media. This has included the ground-breaking EastEnders storyline about a young mother's experience of postpartum psychosis and her struggle to get help after the birth of her son (BBC, 2016). A growing list of celebrities, including Adele⁷ and Fern Britton⁸ who have spoken out about their struggles with postpartum depression has also contributed towards the increased visibility of perinatal mental health problems.

There has been much progress in perinatal mental health care across the UK in the past few years. This progress is promising, but it is clear that more can and should be done to address perinatal mental health problems and improve the lives of women and their families affected by these conditions. This report aims to present a picture of perinatal mental health provision in Wales, and how this care is being experienced by women and their partners affected by perinatal mental health problems. It shines a spotlight on the positive developments in perinatal mental health care, and identifies where further improvements are needed.

Project aims

1. To identify and map out what services are available across statutory and voluntary sectors in Wales for women and their families experiencing perinatal mental health difficulties
2. To identify where specialist perinatal mental health

services are meeting national standards and where improvements are needed

3. To illustrate examples of best practice in perinatal mental health services and identify where enhancements are needed to better support women and their families
4. To explore women's and partners' experiences of perinatal mental health problems in Wales

To capture a better understanding of perinatal mental health provision in Wales and how it's experienced by women and their families, this project draws upon the accounts of women, and partners affected by perinatal mental health problems; health professionals working in the perinatal period; and third sector professionals supporting women in the perinatal period in Wales.

Report structure

Chapter Two introduces evidence on the prevalence of perinatal mental health problems, and demonstrates the impact that these conditions can have upon women, their children and partners. Chapter Three gives an overview of the methodology for this project. Chapters Four to Eight showcase the main findings from this project, including the barriers to the identification of perinatal mental health problems (Chapter Four); specialist perinatal mental health care in Wales (Chapter Five); accessing specialist perinatal mental health care (Chapter Six); third sector perinatal mental health provision in Wales (Chapter Seven); and supporting families affected by perinatal mental health problems (Chapter Eight). Chapter Nine concludes this report by presenting a vision for the future in which Wales leads the way in providing perinatal mental health care.



⁷See: <http://www.bbc.co.uk/newsbeat/article/37832445/adele-speaks-about-her-postnatal-depression-after-the-birth-of-her-son-angelo>

⁸See: <https://www.express.co.uk/celebrity-news/646925/Fern-Britton-shares-postnatal-depression-experience-for-Sport-Relief>

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

Perinatal mental health problems experienced by women in Wales each year⁹

This includes depression, anxiety disorders, obsessive compulsive disorders, post-traumatic stress disorders, eating disorders, bipolar disorder, and borderline personality disorder.

Rate: 270/1000 maternities

8,985

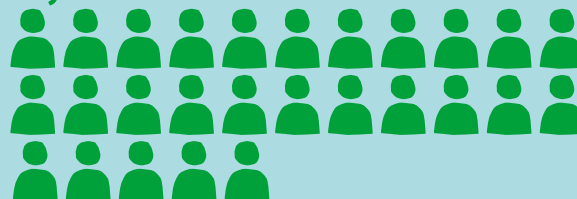


Anxiety disorders

Anxiety disorders include symptoms such as excessive and uncontrollable nervousness, fear, apprehension and worry.

Rate: 150/1000 maternities

4,992



Depression

A depressive illness with symptoms such as low mood, anxiety and irritability, guilt or low self-worth, low energy and poor concentration, disturbed sleep or appetite.

Rate: 110/1000 maternities

3,601



Obsessive compulsive disorder (OCD)

A severe anxiety disorder, characterised by intrusive or inappropriate thoughts, obsessions and compulsions.

Rate: 20/1000 maternities

666



Post-traumatic stress disorder (PTSD)

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

Rate: 8/1000 maternities

266



Postpartum psychosis

A severe mental illness that typically affects women in the weeks after giving birth, with mood and other symptoms such as confusion, delusions, paranoia and hallucinations.

Rate: 1-2/1000 maternities

33-66



Figure 3. Estimated numbers of women affected by perinatal mental illnesses in Wales each year

⁹ **Note:** Some women may experience more than one of these conditions. Estimates calculated using recent prevalence figures for the UK (Howard et al., 2018) and live births rates by area figures for Wales in 2015 (StatsWales, 2017). Each icon represents 150 women. Half an icon represents 75 women.

2. The impact of perinatal mental health conditions

The significance of perinatal mental health problems

During pregnancy and the year after birth, women can be affected by a number of mental health problems, from depression and anxiety; to obsessive compulsive disorder (OCD); post-traumatic distress disorder (PTSD); eating disorders and postpartum psychosis. These conditions can be mild to extremely severe (Bauer *et al.*, 2014). Perinatal mental illness is one of the most common complications that a woman can experience when having a baby (Bick & Howard, 2010), with recent UK research suggesting that 1 in 4 women can be affected (Howard *et al.*, 2018). Some women who experience perinatal mental health problems may experience it for the first time in relation to pregnancy or child birth, and others may have a pre-existing mental health condition which persists, deteriorates or reoccurs during pregnancy or after the birth of a baby. If perinatal mental illnesses go untreated they can have long-term implications for the well-being of women, their babies and families (Jones *et al.*, 2014).

There are a number of risk factors that make it more likely that a woman will experience perinatal mental health problems, including a perinatal or family history of mental illness, socio-economic factors and social adversity (Ayers & Delicate, 2016; Howard *et al.*, 2014b; Stewart *et al.*, 2003). For example, women with a history of bipolar disorder are at an increased risk (approximately 50 per cent) of experiencing a severe mental health problem in the perinatal period (Di Florio, Smith and Jones, 2013; Dolman *et al.*, 2016; Jones *et al.*, 2014). Women who have previously experienced a severe perinatal mental illness, such as postpartum psychosis or severe depression have a 55 per cent chance of it recurring in a subsequent pregnancy (Di Florio *et al.*, in press). Perinatal mental health problems are also more likely to occur if women live in social adversity, (e.g. living in poverty or with domestic violence) (Ayers & Delicate, 2016; Deal & Holt, 1998; Howard *et al.*, 2013; Stewart *et al.*, 2003) or if they are teenage mothers (Center on the Developing Child at Harvard University, 2009). However, these are risk factors rather than determinants of illness, and that perinatal mental health problems can affect all women from all parts of society (Hogg, 2013).

Depression and anxiety

Depression and anxiety are the most common mental health problems experienced by women in the perinatal period (Howard *et al.*, 2014b; O'Hara & Wisner, 2013). Pregnancy is a time of increased vulnerability for the development of depression and anxiety (Biaggi *et al.*, 2016; Meltzer-Brody *et al.*, 2018), with recent UK

population estimates of 11 per cent for depressive disorders and 15 per cent for anxiety disorders (Howard *et al.*, 2018). Depression and anxiety in pregnancy also represent two of the strongest risk factors for experiencing postpartum depression (Heron *et al.*, 2004; Milgrom *et al.*, 2008). Prevalence figures for postpartum depression vary, but are estimated to be 13 per cent in high-income counties and 20 per cent in low and middle-income counties (Meltzer-Brody *et al.*, 2018; Fisher *et al.*, 2012). A recent systematic review has also indicated that perinatal anxiety is highly prevalent in the postpartum period, with anxiety disorders affecting 10 per cent of women (Dennis *et al.*, 2017).

Obsessive compulsive disorder (OCD)

The perinatal period represents a time of increased vulnerability for women to experience OCD (Forray *et al.*, 2010). OCD is a severe anxiety disorder, characterised by intrusive or inappropriate thoughts, obsessions and compulsions (Lord *et al.*, 2011). Comprehensive research into perinatal OCD has traditionally been a neglected area of study until recent years (Forray *et al.*, 2010; Uguz and Ayhan, 2011). Prevalence rates of OCD during the perinatal period have been reported to vary in range (Lord *et al.*, 2011; Sharma & Sommerdyk, 2015), but it is thought to affect around 1 in 100 women in pregnancy, and 2-3 in every 100 women postnatally (Royal College of Psychiatrists, 2015). A recent UK study found a rate of 2 per cent for perinatal OCD (Howard *et al.*, 2018). The perinatal period is a time of high risk for the rapid onset of OCD symptoms, with studies reporting that up to 40 per cent of women with OCD experienced the onset in the perinatal period (Forray *et al.*, 2010; Russell *et al.*, 2013; Sharma & Sommerdyk, 2015; Uguz and Ayhan, 2011). There is also evidence to indicate that up to 50 per cent of women with pre-existing OCD can experience a worsening of symptoms in the perinatal period, particularly after giving birth (Forray *et al.*, 2010; Lord *et al.*, 2011). Women with a history of OCD are at risk of experiencing a recurrence of symptoms in the postpartum period, with studies reporting rates of reoccurrence between 25 and 75 per cent after having a baby (Uguz and Ayhan, 2011). Due to the lack of awareness of the association between OCD and pregnancy and childbirth, OCD in the perinatal period often goes undiagnosed and untreated (Forray *et al.*, 2010; Sharma & Sommerdyk, 2015).

Post-traumatic stress disorder (PTSD)

A growing body of empirical research suggests that PTSD may be a mental health concern for women who are

pregnant or who have given birth (Dekel *et al.*, 2017; Yildiz *et al.*, 2017). Research suggests that the onset of PTSD can occur for the first time, reoccur or worsen during the perinatal period (Howard *et al.*, 2014b). PTSD can present in pregnancy due to traumatic events such as accidents, interpersonal violence or natural disasters (Anniverno *et al.*, 2013), and it can develop after having a baby, as a result of a difficult or traumatic birth (Ayers & Ford, 2012; Yildiz *et al.*, 2017). If women have a history of PTSD this can also be re-triggered by events during pregnancy and birth (Halvorsen *et al.*, 2013). There is limited evidence about the prevalence of PTSD in the perinatal period and estimates vary considerably. A recent UK study found a rate of just less than 1 per cent (0.8 per cent) for perinatal PTSD (Howard *et al.*, 2018).

Postpartum psychosis

The perinatal period is also associated with an increased risk of severe mental illness (Jones *et al.*, 2014). Postpartum psychosis is the most severe type of mental illness which occurs suddenly after childbirth, often in the first few postpartum days (Heron, 2007). Typical symptoms include (but are not limited to) delusions and hallucinations, mood changes (both elation and depression), bizarre or disorganised behaviour, confusion, disorientation and insomnia (Jones & Smith, 2009; Monzon *et al.*, 2014). Although postpartum psychosis is less common than other perinatal mental health conditions, it still affects between 1 and 2 women in 1000 maternities (Meltzer-Brody *et al.*, 2018; Harlow *et al.*, 2007; Munk-Olsen *et al.*, 2006; Valdimarsdottir *et al.*, 2009). Postpartum psychosis should always be considered a medical emergency because of its rapid onset, the severe symptoms experienced, and the potential for catastrophic consequences for women and their babies (Ayers & Delicate, 2016; Jones & Smith, 2009). These disorders require immediate intervention and in most cases inpatient psychiatric treatment (Meltzer-Brody *et al.*, 2018), ideally within a mother and baby unit (MBU). MBUs provide specialist inpatient psychiatric care for mothers and their babies up to one year after childbirth (Gillham & Wittkowski, 2015). They are designed and resourced to offer specialist treatment to mums for their mental health difficulties, while also supporting them to meet the physical and emotional needs of their infants and to develop healthy relationships (Joint Commissioning Panel for Mental Health, 2012).

Impact on women

Research has shown that undiagnosed or untreated perinatal mental health problems can cause significant suffering for women (Bauer *et al.*, 2014). The second Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries (MBRRACE) into Maternal Deaths in the UK revealed that mental illness was one of the leading causes of death for mothers during pregnancy and in the year after birth (Knight *et al.*, 2015). Almost a quarter of women who died between six weeks and one

year after pregnancy died from mental-health related causes (Knight *et al.*, 2015). One in seven of the women died by suicide (Knight *et al.*, 2015). Perinatal mental illness can also cause feelings of embarrassment, guilt and shame for women as they often feel they have failed as mothers (Dolman *et al.*, 2013; Howard *et al.*, 2014a; Lang, 2013; NCT, 2017; RCOG, 2017). These conditions can also instigate isolation, affect women's self-esteem and negatively impact upon their partner and family relationships (Bauer *et al.*, 2014; Burke 2003; Chew-Graham *et al.*, 2008; Lang, 2013; RCOG, 2017).

Impact on partners

Research has shown that partners and other family members play a critically important role in supporting women affected by perinatal mental health problems. Partner support has been found to protect against perinatal mental health problems (Lancaster *et al.*, 2010; Pilkington *et al.*, 2015), help women recover when they are affected (Pilkington *et al.*, 2015), and buffer the effects of these conditions on babies and other children (Chang *et al.*, 2007). While partners and other family members are important sources of support for women affected, research suggests that partners and other family members also experience perinatal mental health problems. This includes depression, anxiety, PTSD and OCD. Research from NCT (2015) suggests that more than one in three (38 per cent) new fathers in the UK have concerns about their mental health. Findings from a meta-analysis indicate that the prevalence estimate for prenatal and postnatal paternal depression is approximately 8 per cent (Cameron *et al.*, 2016). Research has suggested that fathers are at increased risk of experiencing postnatal depression if their partner has also experienced perinatal mental health problems (Areias *et al.*, 1996; Matthey *et al.*, 2000; Dudley *et al.*, 2001; Goodman 2004; Roberts *et al.*, 2006). Goodman (2004) indicate that prevalence rates of postpartum depression among men whose partners were also experiencing maternal mental health problems, ranged from 24 to 50 per cent. A systematic review by Leach *et al.* (2016) demonstrates that between 4 and 16 per cent of fathers experience anxiety during the prenatal period, and between 2 and 18 per cent experience anxiety postnatally.

Paternal anxiety and depression has a profound impact on fathers' wellbeing, functioning and the quality of their intimate relationships (Fletcher *et al.*, 2014; Fletcher, Garfield, & Matthey 2015; Ramchandani *et al.*, 2011). Perinatal depression has also been reported to affect child development and mental health, when it is not identified and addressed (Baldwin & Black, 2017; Fletcher *et al.*, 2011; Letourneau *et al.*, 2012; O'Brien, 2017; Ramchandani *et al.*, 2011; Sweeney & MacBeth, 2016). Early intervention is therefore key in supporting fathers with perinatal mental health problems (Fletcher *et al.*, 2011). However, recent research has demonstrated that there are considerable challenges in supporting fathers with these conditions (Darwin *et al.*, 2017). A recent UK

study has shown that fathers may feel reluctant or unable to express their needs about what help and support they require with perinatal mental health problems (Darwin *et al.*, 2017). These feelings are exacerbated by dads questioning the legitimacy of their own experiences with perinatal mental health problems, feeling like they should be prioritising their partner's needs, and being excluded by over stretched health services (Darwin *et al.*, 2017). When fathers do seek help with postnatal depression and anxiety, research has shown that their needs are not understood or met by health services as there is a lack of support and tailored treatment options for fathers with these conditions (Baldwin & Bick, 2017; O'Brien, 2017).

Impact on infants and children

Substantial evidence suggests that if perinatal mental health problems in mums and dads/partners are not identified, treated and managed effectively, they can have adverse impacts upon infant development and child outcomes (Sweeney and MacBeth, 2016; Webb, Ayers & Rosen, 2018). Some studies have demonstrated that mothers' mental health can impact upon babies before they are born, with perinatal mental illnesses increasing the risk of early delivery and smaller size/lower weight at birth. These in turn are risk factors for impaired cognitive and social developmental outcomes in babies (Männistö, *et al.*, 2016; Talge *et al.*, 2007; Satyanarayana & Sirinivasan, 2011). A growing body of evidence has also suggested that perinatal mental health problems adversely impact upon the interactions and care between mums and babies, which can increase the risk of children experiencing behavioural, social or cognitive difficulties (Bauer *et al.*, 2014; Center on Developing Child, 2009; Galloway & Hogg 2016; Howard *et al.*, 2014a; Oates, 2006; Royal College of Midwives, 2014; Stein *et al.*, 2014; Sutter-Dally *et al.*, 2011).

Evidence about early brain development and the way in which the foundation for a child's social and emotional development is created through their interactions with their caregivers illustrates just how essential sensitive and attuned care towards infants is at this time (Center on Developing Child, 2009; Royal College of Midwives, 2009). To optimise their emotional and social development, infants need to develop a secure positive attachment to a primary caregiver during the first year of their life (Galloway & Hogg, 2015). This early attachment sets the template for later relationships and can influence physical, social, emotional and cognitive outcomes (Galloway & Hogg, 2015). However, research shows that the symptoms that women can experience as a result of perinatal mental health conditions can make sensitive and responsive parenting difficult and can undermine a parent's ability to develop healthy and attuned relationships with their babies (Hogg, 2013). If not identified, treated and managed effectively, mental health conditions during pregnancy and the first years of a child's life can affect maternal bonding, leaving infants at risk of developing insecure attachments and experiencing

poor long-term outcomes (Bauer *et al.*, 2014; Galloway & Hogg 2015; Howard *et al.*, 2014a; Oates, 2006; Stein *et al.*, 2014; Sutter-Dally *et al.*, 2011). Research has also shown that difficulties in early attachment can contribute to the development of mental health problems later in life (Milkulicer & Shaver, 2012). The risk of adverse child outcomes becomes elevated when women experience persistent and severe perinatal mental health problems (Netsi *et al.*, 2018) and when women are from more socio-economically disadvantaged populations (Lovejoy *et al.*, 2000; Pearson *et al.*, 2013).

It is important to highlight that whilst perinatal mental illnesses increase the risk of children experiencing negative outcomes, this is not inevitable and does not always lead to problematic parent-child relationships or poor outcomes for children (Stein, 2014). Stein (2014) indicates that even when perinatal mental health problems do have a negative impact upon children, the effect sizes are mostly moderate or small. With good and effective care women can recover and children can go on to achieve their full potential (Hogg, 2013). This is why it is essential that all professionals working in the perinatal period are skilled and confident in their ability to detect difficulties in the mother-baby relationship and offer support to families to promote positive infant mental health and build secure attachment relationships.

If left untreated, perinatal mental health conditions can have a range of devastating impacts upon women, their children and families. However, much of this suffering can be prevented through early detection and prompt treatment (Galloway & Hogg, 2015). The economic argument for screening and treating parental mental health problems are compelling, with evidence suggesting that the cost to UK society of not treating women's perinatal mental health problems is £8.1 billion for every annual cohort of women giving birth (Bauer *et al.*, 2014). Most of these costs (72 per cent) relate to the long-term adverse consequences for the child (Bauer *et al.*, 2014). As Webb, Ayers & Rosen (2018) suggest from a public health perspective, a strategy for preventing and effectively treating perinatal mental health problems has the potential to prevent long-term burdens of ill-health for mums, partners and children, and reduces the likelihood of intergenerational transmission of trauma. This is why it is critically important to identify women and their families who are at risk of experiencing perinatal mental health conditions. Having valid and reliable measures available for the screening of perinatal mental health and wellbeing in universal services is an essential part of this public health strategy (Webb, Ayers & Rosen, 2018).

The importance of early identification

Primary care practitioners such as midwives, health visitors and general practitioners (GPs) have enhanced contact with most families during the perinatal period and are ideally placed to identify and offer early support to families affected by perinatal mental health problems

(Royal College of Midwives, 2014). Screening of pregnant women in primary care settings provides an opportunity to assess the mental health needs of women and facilitate entry into more enhanced care for those that need it (Buist *et al.*, 2002; Heyningen *et al.*, 2018). It is UK policy that all women are asked about their mental health and wellbeing in pregnancy and following birth to help detect potential mental health problems and prevent serious adverse outcomes (Redshaw and Henderson, 2016). NICE guidance (2014) recommends that at first contact with primary care or during the booking visit, health professionals should be asking women two depression identification questions (sometimes referred to as the 'Whooley Questions') and the Generalized Anxiety Disorder Scale (GAD-2) questions as part of a general discussion about mental health and well-being. If a woman responds positively to either of these questions, it is recommended that a fuller clinical assessment is carried out using the Edinburgh Postnatal Depression Scale (EPDS), the Patient Health Questionnaire (PHQ 9) or a referral is made to a GP. If severe mental health problems are suspected a referral to a mental health professional is recommended. The same identification process is recommended for every subsequent contact with primary care during the perinatal period.

Depression identification questions

During the past month, have you often been bothered by feeling down, depressed or hopeless?

During the past month, have you often been bothered by having little interest or pleasure in doing things?

Generalized anxiety disorder scale

Over the last 2 weeks, have you been feeling nervous, anxious or on edge?

Over the last 2 weeks, have you not been able to stop or control worrying?

Through the All Wales Maternity Records, it is standard practice for midwives in Wales to be routinely asking women about current and previous mental health problems (including bipolar affective disorder, psychosis, depression, schizophrenia, suicidal ideation), any treatment and support received for anxiety, depression, OCD, panic disorder, phobias, pregnancy related mental health problems, or PTSD, any previous traumatic birth experiences, and family history of mental health problems. In the All Wales Maternity Records, it also suggests that midwives ask the Whooley questions.

One of the greatest barriers to women receiving the care they need, is low levels of recognition. Studies have found that the identification of perinatal mental health problems

is poor, with less than 50 per cent of postnatal depression cases detected in routine clinical practice (Gavin *et al.*, 2015). Prenatal identification rates for depression have been reported at 41 per cent (Goodman & Tyler-Viola, 2010) and postnatal rates ranging from 29 to 43 per cent (Fairbrother & Abramoqitz, 2007; Hearn *et al.*, 1998). These identification rates are consistent with mental health problems outside of the perinatal period, and relate to attitudinal barriers, such as stigma and beliefs about screening and treatment, and practical barriers such as knowledge, accessibility and time pressures (Buist, O'Mahen & Rooney, 2015).

Redshaw & Henderson (2016) argue that it is not known how widely screening tests are used across the UK or what proportion of women have discussions with health professionals about their emotional and mental health. One important issue that has emerged related to this is the difference in professionals' and mothers' perceptions of screening. While professionals report asking mothers about their mental health, research with women suggest that some do not recognise that they have been asked about their emotional well-being, do not recognise their mental health history as important, or do not recognise their mental health needs (Laing, 2013; Khan, 2015). A recent UK-wide survey of mothers, highlights positive improvements over the past five years in the proportion of women being asked about their mental health. RCOG (2017) found that the majority of women (84 per cent) had been asked about their mental health and wellbeing by at least one health care professional in the perinatal period. Only 8 per cent of women who had given birth in the last year had not been asked, compared with 24 per cent of women who had given birth 4–5 years ago. However, research indicates that there are some marked differences between women who are asked about their mental health in the perinatal period. Redshaw & Henderson (2016) found that non-white women, those living in deprived areas, and those who had received less education, were less likely to be asked about their mental health, to be offered treatment, and to receive support. For Redshaw & Henderson (2016) these inequalities demonstrate that women most likely to need support, are least likely to be offered it and may be at risk of serious adverse outcomes.

Self-reporting and the disclosure of perinatal mental health problems by women are also critical to the effectiveness of screening in primary care. However, research suggests that women can be reluctant or unable to disclose their perinatal mental health problems because of the stigma associated with these conditions. The stigma attached to perinatal mental health problems, including shame; embarrassment; concerns about being judged as a bad mother; and a fear of having children removed, have been identified as factors driving women's reluctance to seek treatment and support from healthcare professionals (Chew-Graham, 2009; Cymru Well Wales, 2017; Dolman *et al.*, 2013; Edwards and Timmons, 2005; Howard *et al.*, 2014a; Lang, 2013; NCT,

2017; RCOG, 2017; Shakespeare *et al.*, 2003). Stigma as a pervasive barrier to care and treatment is not unique to perinatal mental health problems. A significant body of international research has shown that stigma has been identified as factor in people's reluctance to seek help for any mental health illness (see for example, Corrigan *et al.*, 2014; Gulliver *et al.*, 2010; Knaak *et al.*, 2017; Parcesepe & Cabassa, 2013).

Research has also shown that a lack of understanding about the signs and symptoms of perinatal mental health problems (referred to as poor mental health literacy), mean that some women and their families struggle to differentiate between 'normal' adjustment difficulties associated with becoming new parents, and those symptoms warranting treatment and support (Bayrampour *et al.*, 2018; Fonseca *et al.*, 2015; Khan, 2015; Lang, 2013). Practical barriers, such as availability, accessibility and affordability have also been found to restrict new mums' access to help and treatment, particularly as they often have to balance child care, and changes to their financial situation (Buist, O'Mahen & Rooney, 2015).

Time has also been highlighted as a significant barrier to the identification of perinatal mental health problems. An overstretched health care service, with increasing demands, overwhelming pressures and workforce shortages, has been found to impact upon the time and continuity of care needed to develop trusting relationships with women so they will disclose perinatal mental health issues (Buist, O'Mahen & Rooney, 2015; Dennis & Chung-Lee, 2006). Women report experiences of rushed health care appointments with health visitors, midwives and GPs, with little time to discuss their perinatal mental health concerns (Hogg, 2013; Khan, 2015; Lang, 2013; NCT, 2017; RCOG, 2017). A lack of knowledge, confidence and necessary training to help professionals spot the signs of perinatal mental health problems has also been identified as a barrier to the identification of these problems (Rowan *et al.*, 2010).

Specialist perinatal mental health services

When perinatal mental health problems are detected, timely access to appropriate services for women is vital. Early identification alone does not benefit women and their families, as it needs to be supported by clear referral and care pathways to ensure women and their families get the support they need (Howard *et al.*, 2018). Women who are at risk of or suffering from perinatal mental health problems will require a range of different

support depending on their needs and the severity of the condition they experience (Royal College of Midwives, 2014). Treatment and support for perinatal mental health problems is provided by a combination of universal and specialist services, and can range from community based therapeutic support for women with mild conditions, through to medication and specialist inpatient care for women experiencing moderate to severe mental health conditions (Royal College of Midwives, 2014). Specialist community perinatal mental health services play a vital role in meeting the needs of women and their families affected by perinatal mental health conditions. These services have the knowledge and skills necessary to aid the prevention, detection and the therapeutic management of perinatal mental health problems (Joint Commissioning Panel for Mental Health, 2012; The British Psychological Society, 2016) and to support mums to develop healthy and attuned relationships with their babies (Stein, 2014).

As indicated in the introduction to this report, there have been positive developments in specialist provision across the UK. In 2015, a mapping exercise by the Everyone's Business campaign revealed that women in half of the UK did not have access to specialist perinatal mental health services. New maps released in 2018, show that this gap has narrowed and that many more women live in an area where local specialist perinatal mental health services are now available. However, the maps show that in a quarter of the UK new mums still do not have access to these vital specialist services. The difficulties women experience in accessing specialist services when they are in place has been highlighted in research. Empirical studies have found that only 12-30 per cent of women who have been identified as needing help, will receive any kind of treatment (Bowen; Bowen & Butt, 2012; Buist, O'Mahen & Rooney, 2015). In a UK wide survey of mothers, the RCOG (2017) found that over half (55 per cent) of the women who reported experiencing perinatal mental health problems were not referred on to services or given any advice about organisations to contact for further help. Progress in the availability of specialist support should be celebrated, but it is clear that not all women across the UK have equal access to these services, and these gaps mean that we are failing to prevent the harms caused by perinatal mental illnesses effectively, putting at risk the safety and wellbeing of women, their children and families (Hogg, 2013).

3. Overview of methodology

Method

To explore perinatal mental health provision in Wales and understanding how perinatal mental health care is experienced by women and their families, this project draws upon the combination of online surveys, interviews and an online mapping exercise. Data collection was carried out between June and October 2017.

There were three different online surveys. Surveys were completed by women who had experienced a perinatal mental health problem while living in Wales, and by the partners of women who had experienced a perinatal mental health problem. These surveys focused on mental health problems before, during and after the birth of a baby, contact with health professionals, help and support, and suggestions for improving perinatal mental health care in Wales. The surveys also contained demographic questions, including where they lived (by local authority), age and ethnicity. Interviews and surveys were completed

with health professionals who were working with women and their families in the perinatal period (including perinatal mental health teams), and third sector professionals involved in delivering perinatal mental health services in Wales. These interviews and surveys focused on mental health assessments, interventions and support, partnership working, training and suggestions for improving perinatal care in Wales. The survey also contained demographic questions including health board in which they worked, current job role, description of main job role, length of service in current role, type of team they worked in, and staffing structure for the team. The surveys and interviews were complemented by a desktop mapping exercise to identify third sector organisations delivering perinatal mental health services in Wales.

In this report, the qualitative data collected from the surveys and interviews with women, partners, health professionals, and third sector professionals is differentiated by distinctive colours (see Table 1).

| Participants | Text colour | Colour |
|--|-------------|--------|
| Women who have experienced perinatal mental health problems | Purple | |
| Partners of women who have experienced perinatal mental health problems | Orange | |
| Third Sector Professionals involved in delivering perinatal mental health problems | Blue | |
| Health Professionals working in the perinatal period | Green | |

Table 1: Participant data colour code

Participants

127¹¹ participants took part in this research, which included 67 women with experience of perinatal mental health problems, 6 partners of women with experience of perinatal mental health problems, 45 health professionals

working in the perinatal period and 8 third sector professionals delivering perinatal mental health services in Wales. These participants completed 123 surveys and 9 interviews (see Table 2). The data was analysed using robust thematic analysis and simple descriptive statistics.

| Participants | Number of completed surveys | Number of completed interviews |
|--|-----------------------------|--------------------------------|
| Women with experience of perinatal mental health problems | 67 | N/A |
| Partners of women with experience of perinatal mental health problems | 6 | N/A |
| Health professionals working in the perinatal period | 44 | 7 |
| Third sector professionals delivering perinatal mental health services | 6 | 2 |
| | Total = 123 | Total = 9 |

Table 2: Summary of participant numbers

Limitations

The findings from this study must be viewed in light of its limitations. These include issues with the samples recruited, such as small numbers of participants and unrepresentative population samples, meaning that generalisations could not be drawn from the findings. The sample also did not include general practitioners, general adult psychiatrists and family members, such as parents, grandparents, aunt and uncles. The inclusion of these groups would have added important and additional insight into this study. Due to the changing nature of the third sector, the desktop mapping exercise may not have captured all third sector organisations delivering perinatal mental health services in Wales.

Ethics

This research was approved by the NSPCC Research Ethics Committee in April 2017. All research within the NSPCC is guided by a comprehensive ethics policy based on the ESRC Framework for Research Ethics and the Government Social Research Unit professional guidance.

Further detail

Appendix Two contains further details about the methodological approach, sample and limitations of this project.

¹¹ Please note that some of the participants interviewed also completed a survey, and this has been accounted for in the final participant figure.

Research findings

4. Barriers to identifying perinatal mental health problems

Key findings

- Only 23 per cent of women recalled being given any information or resources about perinatal mental health conditions
- 73 per cent of women in this study recalled being asked about their mental health and well-being by a health professional
- 59 per cent of health professionals felt they faced challenges in talking to mums & partners about perinatal mental health
- 90 per cent of health professionals felt they would benefit from further training on perinatal mental health

“If I or my partner/family had been more aware of the symptoms, we may have sought help earlier” (Mum)

As indicated in Chapter Two, early identification of perinatal mental health problems is an important first step in a pathway to supporting women and their families affected by perinatal mental health problems. The current study found that although there were some excellent examples of perinatal mental health problems being identified early by universal services and support being put in place for women in Wales, there were also complex factors that acted as barriers to prompt identification and treatment. These barriers operate on different levels, including personal, such as a lack of understanding about perinatal mental health conditions and the stigma related to these conditions; and professional, such as time constraints and training. Many of the barriers to identification reported in this study are not new and have been echoed in previous research (see Bayrampour *et al.*, 2018; Buist, Mahen and Rooney, 2015; Higgins *et al.*, 2018; Khan, 2015; Lang, 2013; NCT, 2017; RCOG, 2017; Shakespeare *et al.*, 2003). However, they are important to highlight as they were found to contribute to the underreporting and underdiagnoses of perinatal mental health problems for women in Wales.

Personal barriers

Encouragingly, almost three quarters of women (N= 49, 73 per cent) in this study had been asked about their mental health and wellbeing by a health professional. Most women recalled being asked by a health visitor (N=42, 62 per cent), midwife (N=29, 43 per cent) or GP (N=24, 35 per cent)¹². The qualitative survey data indicate that primary care practitioners were important sources of support for women experiencing perinatal mental health problems. Women described being supported to disclose their perinatal mental health problems and they talked about receiving excellent care from GPs, midwives and health visitors.

¹² Some women may have been asked by more than one health professional, and participants were able to tick multiple options in the survey.

“My health visitor at the time was very supportive and so was my GP at my post-natal check-up. They made me realise I was suffering from PND [postnatal depression]” (Mum)

“I really would like to praise the way my health visitor helped me. She knew how difficult I found asking for help so took some of that stress away by making a referral to the mental health team for me. She also provided “listening visits” to try and bridge the gap between my initial referral and my first appointment” (Mum)

However, out of the 49 women who were asked about their mental health and wellbeing, half (N=24, 48 per cent) felt that they faced challenges in talking to health professionals about perinatal mental health problems. Having the knowledge to recognise signs and symptoms, overcoming stigma and the response from health professionals, were key obstacles that women faced.

Women disclosing perinatal mental health problems to health professionals is an important aspect of early identification. However, when women were asked to describe challenges they faced in accessing professional help or support with perinatal mental health problems, they reported being unable or reluctant to talk to health professional's due to low levels of knowledge about signs and symptoms, and the stigma attached to these conditions. Consistent with other studies (Barrampour *et al.*, 2018; Bilszta *et al.*, 2011; Buist *et al.*, 2005; Fonseca *et al.*, 2015; McCarthy and McMahon, 2008), women described having a lack of understanding about the full range of perinatal mental health conditions, poor recognition of symptoms, and difficulties assessing the severity of their experiences.

“With the first baby everything is so new & unfamiliar that it's difficult to know what should be ‘normal’. My baby was 7 months old when I was finally diagnosed by my GP, by which time I was severely depressed” (Mum)

“I had no idea that you could experience scary thoughts about the baby and that it was called postnatal anxiety - I thought I was genuinely losing my mind” (Mum)

An absence of sufficient, accessible and good quality information resources on perinatal mental health conditions was reported to be a factor in the difficulty of recognising signs and symptoms: ‘*there isn't enough information or help out there*’ (Mum). NICE guidance (2015) recommends that all women should be provided with culturally relevant information on mental health problems in pregnancy and the postnatal period. In this study, over half of the women (N=44, 65 per

cent) and 5 out of 6 of the dads/partners indicated that they would have liked additional information on perinatal mental health problems. This included:

- Signs and symptoms of the full range and spectrum of conditions
- Local support services
- Third sector groups
- Factsheets on medication in breastfeeding
- Helpful books and websites
- Stories/case studies of women who had experienced perinatal mental health problems
- Information about how to support partners and the wider family members affected by perinatal mental health problems

As part of improving the education around perinatal mental health problems, women described the importance of including discussions about perinatal mental health in antenatal classes. This was thought to have the potential to raise awareness of perinatal mental health problems to mums and their partners and teach parents about maintaining positive mental health in the perinatal period.

“We need more mention of perinatal mental illness during parent craft classes to raise awareness” (Perinatal Team Manager)

Women identified stigma as an obstacle to the disclosure of perinatal mental health problems. Similar to other studies (Bayrampour *et al.*, 2018; Edwards & Timmons, 2005; Fonseca *et al.*, 2015; McLoughlin, 2013; Moore *et al.*, 2017), women described downplaying or masking their perinatal mental health problems because they were **‘too embarrassed’** (Mum), or ashamed. Women talked about their fears of being judged as a bad mother, and having their children removed by social services.

“The fear of my son being taken off me or that what I was experiencing wasn’t normal and that I was going to be looked at as being an awful person and a bad mother” (Mum)

Health professionals also recognised women’s reluctance to disclose perinatal mental health problems due to stigma; **‘a lot of the time they think they’re mad, bad, crazy and if they admit that they will have their children taken away’** (Health Visiting Lead). Health professionals suggested that routinely talking to all women about perinatal mental health and providing good quality information on these conditions was one way of tackling stigma and encouraging more women to speak out when they need help.

When a woman does ask for help with perinatal mental health problems, the way that health professionals respond is crucial to ensure that the right treatment and support is put in place (Khan, 2015). Some women in this study, felt their disclosures were dismissed, downplayed or not taken seriously enough when they asked for help. Women described having to **‘push for what I got’** (Mum) and having to **‘fight to be listened to’** (Mum) to get help and support in Wales with their perinatal mental health problems.

“I had to fight to be listened too. I knew I had depression. They kept telling me it was baby blues but I knew it wasn’t. I felt fobbed off by my doctors when I went to them for help” (Mum)

“My health visitor not taking me seriously! Had I been diagnosed in a timely manner I don’t think I would have deteriorated as I did” (Mum)

Professional and organisational barriers

Midwives, health visitors and general practitioners (GPs) have enhanced contact with most families during the perinatal period, and as such are ideally placed to detect perinatal mental health problems early (Redshaw & Henderson, 2016). However, similar to other studies (Bayrampour *et al.*, 2018; Higgins *et al.*, 2018; Khan, 2015; Lang, 2013), findings from this research suggests that health professionals encounter challenges identifying and responding to perinatal mental health problems. 59 per cent (N= 26) of health professionals in this study reported facing challenges in talking to mums and their partners about perinatal mental health problems. This included heavy workloads, time pressures and perinatal mental health training.

The data indicates that health professionals are working in increasingly difficult circumstances, with mounting workload pressures and time restrictions. For health professionals, a lack of time was identified as a constraint in adequately screening, identifying and supporting women and their partners with perinatal mental health problems: *'No time to offer them support'* (Midwife). Women also identified time as a barrier to receiving appropriate help and support with perinatal mental health problems. Women described appointments with midwives and health visitors being rushed and too focused on the health of the baby, rather than upon their mental health needs.

“Midwives don’t have much time - the baby is their concern rather than the crying mother because they are stretched too thin. They need more time with each patient” (Mum)

As previous research has shown, disclosing an emotional problem in a rushed health appointment is not always easy or realistic (NCT, 2017; Khan, 2015). In their report, NCT (2017) suggest that when questions about emotional well-being feel rushed, it can end up being a tick box exercise, rather than an open conversation about how a woman is feeling and coping.

A lack of training was also identified as a barrier to the identification and management of perinatal mental health problems. Given the important role that health professionals play in the early detection of perinatal mental health problems, it is important that all health professionals working with women in the perinatal period receive training on how to recognise and appropriately respond to the full range of perinatal mental health conditions (mild to severe). However, findings reveal some gaps in the provision of training for health professionals in Wales.

“I have had no formal training in perinatal mental health” (Midwife)

“Many women are not being picked up as needing support. Some GPs & Health Visitors are not well trained enough to respond to a woman asking for help” (Third Sector Professional)

Survey data indicate that only 18 per cent (N= 8) of the health professionals who took part had a perinatal mental health component in their pre-qualification training. Evidence given at the National Assembly’s Children, Young People and Education Committee inquiry into Perinatal Mental Health indicated that limited perinatal mental health content featured in the initial training for some professional groups (e.g. psychiatrists, general practitioners and midwives). However, it is essential that adequate perinatal mental health training is incorporated into pre-registration courses for all mental health practitioners and health professionals working in the perinatal period.

Survey data from this study show that over half of the health professionals (N= 27, 61 per cent) had received training on perinatal mental health in their current role. It is however important to note that as 31 per cent (N=14) of the sample

worked in perinatal mental health or generic mental health teams, it is likely that this figure would be less for other health practitioners. The content, time and method of delivery for this post registration training differed quite considerably. Some health professionals described attending university courses or specialist perinatal mental health training; *'one day training on PMH delivered by Mind'* (Midwife). Others talked about receiving short mandatory updates, or completing online modules. Health professionals indicated that they wanted to improve their perinatal mental health knowledge and skills, with 90 per cent (N=40) reporting that they would benefit from additional training in this area.

Encouragingly, the new specialist perinatal mental health teams in Wales are already driving change across the perinatal pathway by providing expertise and delivering perinatal mental health training to a range of health care professionals, including GPs, midwives and health visitors. Perinatal mental health teams described raising awareness of all perinatal mental health conditions, signs and symptoms, and referral pathways for women identified as needing specialist services.

"We have done lots of presentations with the midwives, health visitors, GPs. We are doing lots of awareness sessions. We are doing sessions about our team, but we are also doing awareness sessions of things to look out for, red flags, when to refer, just to try and upskill really"
(Perinatal Team Practitioner)

It is encouraging that many health professionals have received training in their current role and that work is already being done to upskill and enhance the knowledge of perinatal mental health in primary care. It is however, important that post-registration training is consistent and available for all health professionals involved in the care of women in the perinatal period.

Practice example: training around the UK

In England, The Tavistock and Portman NHS Foundation Trust worked in partnership with Health Education England (HEE) to develop a skills competency framework for perinatal mental health care, to support all professionals working with mums and their families in the perinatal period. The framework aims to build perinatal mental health capability in the workforce by identifying required skills and helping health professionals to assess their training needs. The online tool allows professionals to assess the competencies in the framework relevant to their role and informs them of the skills, knowledge and abilities they require to fulfil the responsibilities of their role. For further information, see: <https://perinatalcompetency.e-lfh.org.uk/>.

Since 2006, NHS Scotland has had a Perinatal Mental Health Curricular Framework in place, which aims to inform and assist with the development of a national program of education in perinatal mental health (including preregistration, undergraduate, post registration and postgraduate education programmes). The framework aims to provide practitioners with knowledge in the prevention, detection and management of perinatal mental health problems. For further information see: <http://www.nes.scot.nhs.uk/education-and-training/by-discipline/nursing-and-midwifery/resources/publications/perinatal-mental-health-curricular-framework.aspx>

Future development

The All Wales Perinatal Mental Health Steering Group (AWPMHSG) are developing a training and competency model which will identify the level of necessary knowledge and skills about perinatal mental health for different health professional roles within the perinatal period.

Conclusion

This chapter has shown that a range of barriers operate at different levels (personal, professional and organisational), which impact upon the identification and early treatment of perinatal mental health problems in Wales. Evidence suggests that a multifaceted approach is needed to ensure that women and their families affected by perinatal mental health problems are identified at the earliest opportunity and offered the help and support they need. Women and their families need good quality, accessible information about the signs and symptoms of all perinatal mental health problems, so they can recognise when they are unwell and seek help. There is also more work to do in Wales to ensure that every health

professional working with women in the perinatal period receives pre- and post-registration training on perinatal mental health conditions that they need to practice effectively. This training is vital to ensure that health professionals are confident in recognising signs and symptoms and know how to support women and their families affected by perinatal mental health problems in Wales. Much more needs to be done on a national level to address and tackle the stigma surrounding perinatal mental health problems, so women and their families will be more confident in talking to health professionals about their conditions.

Recommendations

1. Perinatal mental health should be incorporated into pre-registration training for all mental health practitioners and all health professionals working in the perinatal period. Training should include how to recognise and appropriately respond to the full range of perinatal mental health conditions, from mild to severe, and address the association between perinatal mental health and infant mental health
2. The **All Wales Perinatal Mental Health Steering Group** to complete the training and competency model for Wales, taking account of the learning from the Competency Framework for England and the Perinatal Mental Health Curricular Framework for Scotland
3. Once completed, **the Welsh Government** should implement and evaluate the training and competency model for Wales, to ensure that health professionals working in the perinatal period have sufficient training for their role
4. The **Managed Clinical Network (MCN)** should develop a standardised post-registration training course that perinatal mental health teams can deliver to all health professionals involved in the care of women in the perinatal period, as a way of building capacity within health care. This recommendation builds on the Welsh Government's response to Recommendation 16 of the National Assembly for Wales, Children, Young People and Education Committee report into Perinatal Mental Health (2017)
5. **Key stakeholders** work together to develop a joint public awareness raising campaign on perinatal mental health problems, with the aim of tackling stigma and improving women and their family's knowledge of these conditions and where to obtain help
6. Women and their families need clear and consistent information on the effects that pregnancy and childbirth can have upon mental health. **Public Health Wales** should update Bump, Baby & Beyond with the latest evidence about prevalence and signs and symptoms of the full range of perinatal mental health conditions (from mild to severe), where to obtain help, and how to promote positive mental health in the perinatal period.
7. The **MCN** should produce and/or distribute a range of consistent, good quality information resources on perinatal mental health conditions (from mild to severe), which can be given to women and their families affected in Wales. Women with lived experience should be involved in the design of these resources to ensure they are appropriate and relevant

5. Specialist perinatal mental health care in Wales

Key findings

- There have been significant developments in perinatal mental health care in Wales
- There is a specialist community perinatal mental health service in six out of the seven health boards in Wales
- Inconsistencies remain in the level of care offered by specialist community perinatal mental health services in Wales

“Everything changed really dramatically from that point” (Lead Perinatal Nurse Specialist)

When perinatal mental health problems are detected, timely access to appropriate support is vital for women affected. Women who experience these conditions require a range of services depending upon the type and severity of the illness experienced. Some women will need help and support from specialist perinatal mental health services. This chapter highlights the recent developments of specialist community perinatal mental health services across Wales.

History of perinatal mental health care in Wales

Prior to the investment from the Welsh Government in 2016, there was a growing momentum in Wales for raising awareness of perinatal mental health conditions, and supporting women affected by these difficulties. For example, in 2014 The International Marcé Society for Perinatal Mental Health¹³ held a Biennial Scientific conference in Swansea, with the focus on creating change in perinatal mental health. The conference was attended by over 500 delegates from across the world who came together to discuss the latest evidence about perinatal mental health care and how to drive change in Wales and beyond. Prior to the investment in 2016, two health boards had a dedicated perinatal service in place offering a basic level of support. In Abertawe Bro Morgannwg University (ABMU) the Perinatal Response and Management Service (PRAMS) was set up in 2008 to provide dedicated specialist mental health assessment and treatment to women presenting with perinatal mental illness within the Bridgend locality. Since 1998, there was also the gradual development of a perinatal mental health community team in Cardiff and Vale. Additionally, following the establishment of a multi-disciplinary special interest group, a perinatal clinic was set up in Pembroke Dock in 2012 as a pilot project one day a week.

In addition to these established services, other health professionals were working to raise the agenda of perinatal mental health and enhance support to women and their families, often with this work being done over and above their dedicated roles.

“I’d started to carry a caseload, but I was told that I had to do it over and above what I was already doing...So I was working doubly hard, and doing this, and I thought you know I’m not giving this up, I’m not letting this go, this is really important” (Lead Perinatal Nurse Specialist)

¹³The Marcé Society is an international society which promotes, facilitates and communicates about research into all aspects of the mental health of women, their infants and partners around the perinatal period. For further information see: <https://marcesociety.com/>

Service development

The Welsh Government funding for new or enhanced specialist community perinatal mental health services was described by some health professionals as a watershed moment for perinatal mental health care in Wales; *'it felt like winning the lottery'* (Lead Perinatal Nurse Specialist). Health professionals described the Welsh Government investment as a welcomed step forward in addressing previous gaps in specialist perinatal mental health provision. However, the amount of funding received and the way it was allocated placed limitations on the development of specialist services across Wales.

In areas where specialist perinatal mental health services did not previously exist, it was felt that not enough time or expertise had been put into determining levels of staff and resources needed to meet the local needs of women and their families. This meant that the funding allocation for new services only allowed for a basic service model to be developed.

“Then when I actually sat down with my strategic manager and figured out how much everybody costs, reality suddenly hit in... so it was like right okay this really is a skeleton, sort of, this really is basic, but we can do this, we can start something here” (Lead Perinatal Nurse Specialist)

“We weren't part of putting the bid in. I think the initial project manager was somebody that worked for the trust on a secondment for six months. They actually put the bid in and unfortunately had it been us, we would have actually you know, sort of perhaps really sold the fact that it's it's such a large area and the amount of births, I think the person that initially put the bid in was non-clinical but we have done a lot of mapping and benchmarking” (Perinatal Team Manager)

Health professionals described how the allocation of funding based on birth rate, excluded other important considerations such as geography and social deprivation, which were thought to impact upon need/demand on services.

“...but the thing that wasn't taken into account when we got our funding was the level of deprivation in [our health board] ... [its] one of the leading health boards in Wales for deprivation, socio economic problems and so it might not be severe mental illness, but it's that sort of resilience the lack of, the social sort of complex emotional psychological needs” (Clinical Nurse Specialist in Perinatal Mental Health)

Chapter Seven contains a more detailed discussion of the challenges faced by perinatal mental health teams in delivering services.

Service provision

This study shows that most health boards now have some form of perinatal mental health provision, but with considerable inconsistencies in the level of provision across Wales. Six health boards have a dedicated perinatal mental health service focusing on the assessment and treatment of women experiencing perinatal mental health problems, but there remain considerable variations in the model of care that perinatal services deliver (see Table 5). Clear differences were identified in relation to referral criteria and in who can refer into perinatal services. Examples were given of some perinatal services not accepting referrals from GPs or

health visitors. There were also marked differences in the period of time in which services supported women, with some services being open to women one year after birth, and some only one month postnatally. There were also inconsistencies in staffing and interventions available between teams. With the very limited funding and resources that was allocated to Powys, it was not possible to develop a dedicated perinatal mental health service for the health board. Instead, Powys used the investment to improve perinatal mental health support in universal services, by focusing on the identification and early intervention of women with mild to moderate perinatal mental health problems.



| Health board | Live birth rate ¹⁴ | Operational date | Service description |
|-------------------------|-------------------------------|---|--|
| ABMU | 5,515 | Integrated service fully functioning January 2017 | Dedicated specialist mental health assessment & treatment service for women presenting with serious perinatal mental illnesses in pregnancy and in the year after birth, and anxiety and distress following traumatic births. |
| Aneurin Bevan | 6,574 | October 2016 | Providing assessment, care & treatment to women who are pregnant or postnatal and are at risk of, or affected by mild-moderate mental illness. The team gives specialist advice, guidance and support to women with more severe and enduring mental health problems. |
| Betsi Cadwaladr | 7,086 | February 2018 | Providing prevention, detection and treatment of mental health problems affecting women in pregnancy and the postnatal year. |
| Cardiff and Vale | 5,873 | Developing gradually since 1998 | Providing assessment, treatment & intervention for women experiencing, or at risk of developing moderate to severe mental health problems during pregnancy or in the postnatal period. |
| Cwm Taf | 3,441 | June 2016 | Primarily provides specialist assessment & intervention for women who experience serious mental illness, but will provide information, advice and support for mild/moderate conditions as deemed appropriate. |
| Hywel Dda | 3,667 | Integrated service fully functioning in June 2016 | The assessment, diagnosis and short-term treatment of women affected by psychological and emotional problems in the preconception, antenatal and postnatal period up to one year after delivery. |
| Powys | 1,123 | April 2017 | Powys was not able to establish a dedicated perinatal mental health service in their health board. Funding was used to build capacity and improve support for women experiencing mild to moderate perinatal mental health problems in universal services. |

Table 3. Description of Specialist Community Perinatal Mental Health Services¹⁵

¹⁴Source: Stats Wales (2017) Live births rates by area figures for Wales in 2015.

¹⁵The descriptions of services were gathered from the interview and survey data. While these descriptions were accurate at the time of writing, these may change as services develop.

Staffing¹⁶

The staffing structure for perinatal mental health provision vary considerably among the health boards, both in relation to mix of disciplines and amount of staff per team (see Figure 4). Numbers of staff range between 4 and 17 (full and part-time), with some teams only having one or two full time members of staff working within the service. Six out of the seven teams have a consultant psychiatrist that specialises in perinatal mental health, but none of these are full time. In Figure 4 the full-time members of staff are represented by purple icons, and part-time by orange icons.

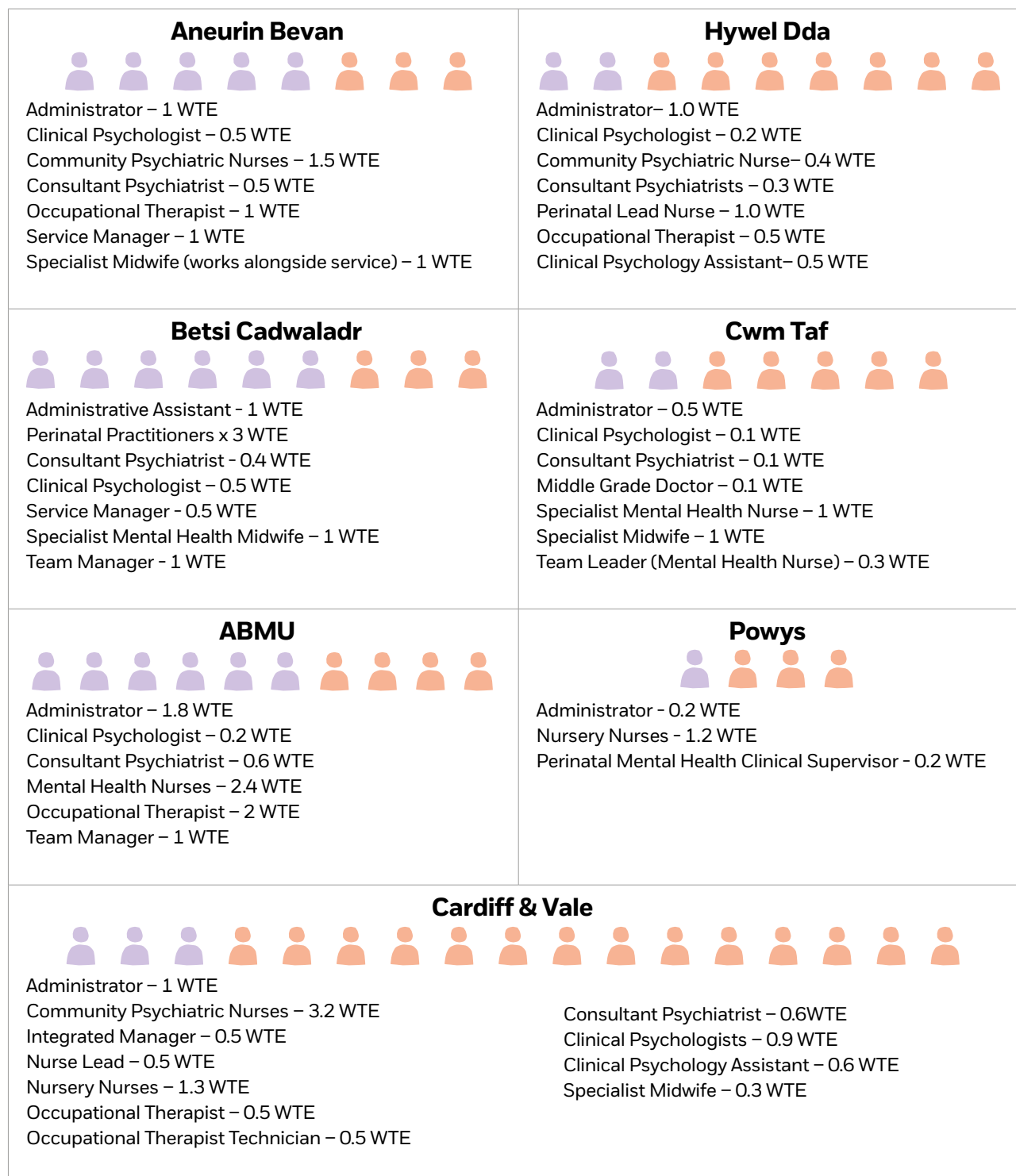


Figure 4. Staffing structure within specialist community perinatal mental health services in Wales

¹⁶Please note that the staffing structure featured was correct at the time of writing, but this may be subject to change as services develop.

Interventions

Interventions targeting perinatal mental health problems are crucial in diminishing many of the negative impacts upon women and their families (Rominov & Pilkington, 2016). A range of interventions for the treatment of perinatal mental health problems exist, including psychological and talking therapies, complementary approaches, community support programmes, and pharmaceutical treatments (Easter *et al.*, 2015).

The survey and interview data indicate that perinatal mental health services in Wales offer a range of interventions to women, including:

- Preconception advice and planning
- Medication advice and prescribing
- Electroconvulsive therapy
- Psychological therapies, including: acceptance and commitment therapy (ACT), mindfulness, REWIND therapy, cognitive behavioural therapy (CBT)
- Play and development groups
- Psychological coping skills
- Counselling
- Listening visits
- Complementary therapies
- Peer support
- Exercise (such as walking groups)
- Self-help

However, data from this study indicates that there are inconsistencies in the number and type of interventions available across health boards. The lack of psychological interventions is drawn out as particularly problematic.

“Well we can’t offer a lot really with regards to interventions, we can, we can refer into primary care mental health” (Clinical Nurse Specialist in Perinatal Mental Health)

Service standards

One of the aims of this research was to explore the extent to which perinatal mental health services were meeting national quality standards, as outlined in the Centre for Quality Improvement (CCQI). In the summer of 2017, a representative from each specialist community perinatal mental health service in Wales was asked to complete a self-review audit of the second edition of the service standards (published in 2014) for perinatal community mental health services¹⁷. The perinatal teams were asked to go through each section (access and referral; assessment; discharge; care and treatment; infant welfare and safeguarding; staffing and training; recording and audit) and rate whether they had met, partially met, or did not meet the standards. To analyse progress, the number of categories in each standard was identified and it was noted which had been met by teams (see below)¹⁸. There are limitations to this method. Notably, the self-complete checklist as not a full and official CCQI review. It did not involve the peer review or benchmarking process that is a critical part of the official reviewing in determining if standards have been achieved. As such, these findings cannot determine whether teams have met the official CCQI standards. These findings can only offer a snapshot of progress and an indication of areas for improvement.

Centre for quality improvement

The quality network works with perinatal services to improve the standards of mental health care for new mums. They support services to evaluate their performance against a range of standards and reflect on findings through a peer review process, sharing best practice, and approaches to service improvement through an active network (Royal College of Psychiatrists, 2018).

¹⁷See: <https://www.rcpsych.ac.uk/pdf/Perinatal%20Community%20Standards%20Cycle%203.pdf>

¹⁸Type One includes 118 categories; Type Two includes 47 categories; and Type Three contains 10 categories.

CCQI standard types: perinatal community mental health services

- **Type 1:** failure to meet these standards would result in a significant threat to patient safety, rights or dignity and/or would breach the law.
- **Type 2:** standards that a good service would be expected to meet.
- **Type 3:** standards that an excellent service should meet or standards that are not the direct responsibility of the service.

As Powys does not have a dedicated perinatal mental health team, they were excluded from this exercise. The assessment was carried out on the six specialist perinatal mental health teams in Wales. Two of the perinatal teams were already part of the official CCQI review, and provided their workbooks to be used as data for this assessment¹⁹. The assessment of the data using the quality standards framework indicate that 87 per cent of basic standards are being met by perinatal mental health teams in Wales. It also shows that almost two thirds (70 per cent) of standard type two and over half (60 per cent) of standard type three were being met by perinatal mental health teams in Wales (see Figure 5).

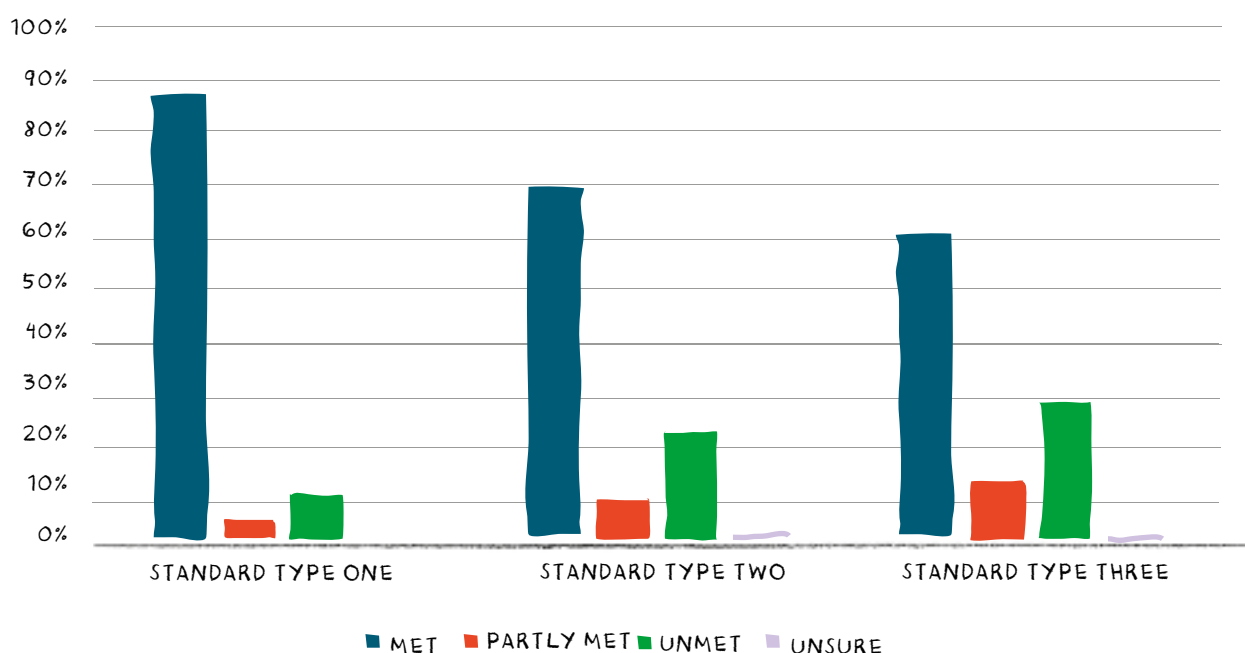


Figure 5. Percentage of type of standard being met by specialist community perinatal mental health teams in Wales

It is encouraging that newly established or developed perinatal teams in Wales are meeting many of the standards needed for a good or excellent service. However, limited funding to establish services has resulted in most perinatal mental health services being unable to meet all of the CCQI quality standards: *'we can only reach a certain standard with what we have got'* (Clinical Nurse Specialist in Perinatal Mental Health). This means that despite the encouraging progress that has been made, the majority of specialist perinatal mental health teams are not currently able to provide all aspects of care that women need to help them recover. This is highlighted in the recent Maternal Mental Health Alliance Everybody's Business campaign maps, where two areas in Wales are green, but the rest of the health boards remain amber or red (see Appendix One).

¹⁹ It is important to note that the workbooks differed slightly to the second edition of the service standards checklist we asked other teams to complete, in that they included several additional categories for the teams to measure their progress against. To ensure that the data we collected could be comparable, we have only used the data from the workbook that featured in the second edition standards.

Future development

The All Wales Perinatal Mental Health Steering Group have been working with stakeholders, women with lived experience and the third sector to develop Guidance on the framework for integrated Perinatal Mental Health Services in Wales. This includes standards to support equitable access to and provision of perinatal services in Wales, and to aid the collection of data to develop a clear picture of service demand, uptake and implementation of the standards. The standards focus on identification, information, assessments, post assessments, interventions, and data collection. The guidance is due to be published in late 2018.

Conclusion

This chapter shows encouraging developments in the provision of perinatal mental health care in Wales. Following investment from the Welsh Government there is now a specialist community perinatal mental health service in six out of the seven health boards in Wales, addressing many previous gaps in provision. However, this chapter also indicates that there are clear areas where critical improvements are needed in perinatal mental health care. Differences in funding allocation has meant that there are inconsistencies in the types and level of service provision provided across health boards in Wales. Despite improvements in perinatal mental health care, the area in which a woman lives still determines the specialist care they can access when it is needed. This is clear in Powys, where despite the progress they are making in other parts of the perinatal pathway (i.e. upskilling health professionals in universal services), women experiencing perinatal mental health problems do not have access to a specialist perinatal mental health service. Findings also reveal that the majority of perinatal mental health services in Wales are not able to provide all aspects of care that women need, and are therefore not able to meet all CCQI quality standards. Further investment is needed to address the disparity in the specialist service provision between health boards in Wales. This would enable all specialist perinatal mental health services in Wales to 'Turn Green' on the Maternal Mental Health Alliance (MMHA) map of specialist perinatal mental health services. There is a clear "invest to save" economic case for addressing perinatal mental health problems. Bauer et al's (2014) research shows that the cost to the public sector of perinatal mental health problems is five times the cost of improving services. This means that providing additional investment to specialist perinatal mental health services to address the disparity in the level of service provision across Wales, and to ensure that all services can provide all aspects of care that women need to help them recover (enabling them to meet quality standards (CCQI)), would save the Welsh Government money in the long term.

Recommendations

8. **The Welsh Government** should provide additional funding to health boards to address disparity in the level of perinatal mental health service provision and to ensure that these specialist services are able to provide all aspects of care that women need to help them recover. This would enable all specialist perinatal mental health services in Wales to 'Turn Green' on the Maternal Mental Health Alliance (MMHA) map of specialist perinatal mental health services
9. **The Welsh Government** ensure that all **health boards** provide the financial investment for the specialist community perinatal mental health services to sign up to the Royal College of Psychiatrists' quality standards for perinatal mental health services for review and accreditation
10. In addressing the disparity in the level of service provision between health boards in Wales, **the Welsh Government** should ensure that there is improved access to psychological therapies for women and their families affected by perinatal mental health problems

6. Accessing specialist perinatal mental health care

Key findings

- Many women in Wales are benefiting from new specialist perinatal mental health services
- Barriers to accessing specialist perinatal mental health services remain, including insufficient resources and funding, long waiting times, and demand outweighing capacity
- There were almost 3,000 referrals to the specialist community perinatal mental health teams in Wales in 2017

“Once I got the right support it was superb, it was getting it that caused the problem” (Mum)

All women affected by perinatal mental health problems should be able to access appropriate care when needed. NICE guidance (2015) indicates that this should include access to specialist perinatal mental health teams and inpatient care for women experiencing severe mental health conditions. This chapter shows that a number of barriers exist which impact upon the accessibility of specialist perinatal mental health services in Wales.

Accessing services

As some women in this study experienced perinatal mental health care before the new services became operational, this section focuses exclusively upon the responses of the 32 women (47 per cent) who indicated that they had sought help with their perinatal mental health problem within a year (approximately) of the announcement of funding from Welsh Government to establish Specialist Perinatal Mental Health Services.

Women and partners described how vital specialist perinatal mental health services were in supporting them with perinatal mental health problems. The stories of women who had been referred and supported by perinatal mental health teams clearly evidenced how important these services were to their treatment and care. Words like ‘*amazing*’ (Mum), ‘*incredible*’ (Mum), ‘*outstanding*’ (Mum), were used to describe the care women received from the perinatal mental health teams. Women commented not only on the compassion and expertise of the practitioners, but on the effectiveness of the specialist care and treatment they received.

“The perinatal team in [Aneurin Bevan] are amazing. Thanks to them, especially [Perinatal Team Leader] I have bonded amazingly with my daughter and I’m getting to enjoy being a mother” (Mum)

“The PRAMS team is incredible in Bridgend” (Mum)

However, findings from this study indicate that even when a woman has been identified as needing specialist care, and specialist services are in place, accessing these services can be difficult for many women. Over half of the women (N= 17, 56 per cent) felt that it was very difficult or difficult to access perinatal mental health services in their local area (see Figure 6). When asked what challenges they faced in accessing services, women described insufficient resources and funding for specialist perinatal mental health services, and waiting times to access this care.

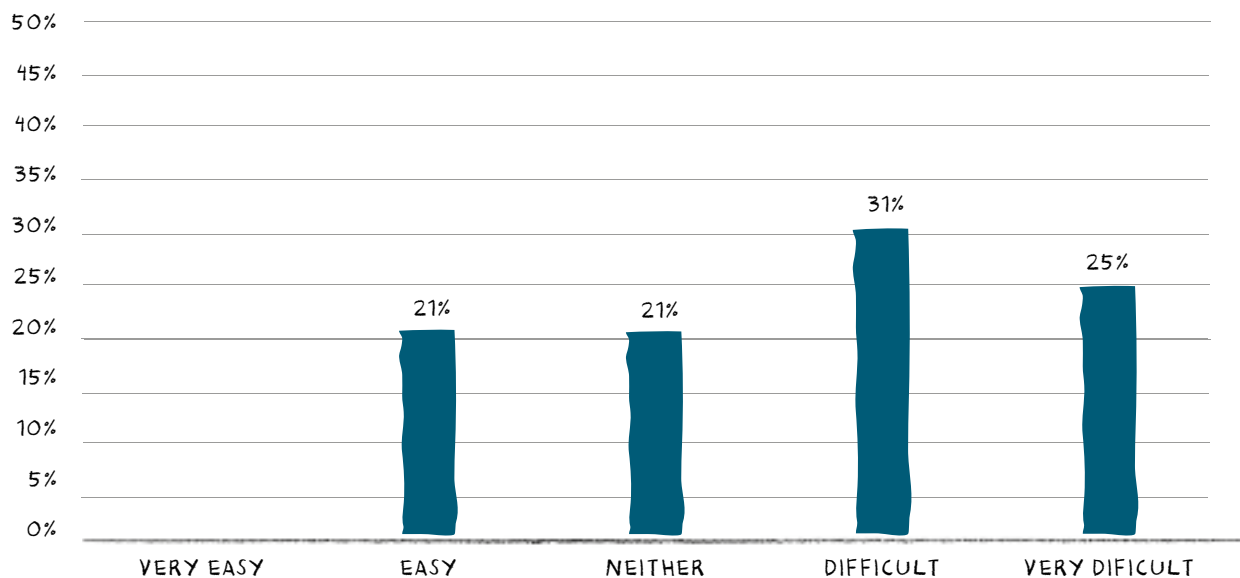


Figure 6. Percentage of women who determined ease of access to perinatal mental health services in local area

Three quarters of women (N= 24, 75 per cent) felt that there were not enough perinatal mental health services in their local area: *‘there was virtually nowhere to go’* (Mum). Regional variations in specialist perinatal mental health support was also highlighted. The term *‘postcode lottery’* (Mum) was used to describe the disparity in regional provision across Wales.

“Such a postcode lottery. If I lived in Cardiff I would have had the input far sooner” (Mum)

“I saw no evidence in Powys of perinatal mental health support” (Mum)

Women also commented on the limited resources, staffing, and funding available for specialist perinatal mental health services.

“There are limited resources. I am currently benefiting from 1:1 and group sessions with PRAMS but they have only in the past few months opened up in Swansea and their resources are limited” (Mum)

Limited resources meant that women often had *'to wait much longer than is suitable'* (Mum) to access specialist care. NICE guidelines (2015) recommend that when a woman with a known or suspected mental health problem is referred in pregnancy or the postnatal period, they should be assessed for treatment within 2 weeks of referral, and they should receive psychological interventions within 1 month of initial assessment. The qualitative survey data indicates that there are long waiting times for women trying to access perinatal mental health interventions.

“Very long waiting times. Was referred to counselling when pregnant with second baby, received counselling when baby was 16 [months] old” (Mum)

When asked what could improve access to services, women and their partners described the need for more investment to expand the reach of perinatal mental health services and for a more diverse range of interventions to treat perinatal mental health problems; *'different counselling styles, medication reviews'* (Mum).

“There needs to be more funding put into mental health services so it is accessible to everyone” (Mum)

Challenges in delivering accessible services

Specialist perinatal mental health teams faced a number of challenges in delivering accessible care, and meeting the local needs of women and their families. There was a high demand on specialist services and this created limitations on the number of women that could be supported by these services; *'we have had over 500 referrals since we started'* (Perinatal Team Leader). On an all Wales level, data suggests that perinatal mental health teams received almost 3,000 referrals in 2017 (see Table 4).

| Health board | Referrals 2017 |
|------------------------|----------------|
| Abertawe Bro Morgannwg | 998 |
| Aneurin Bevan | 588 |
| Betsi Cadwaladr | 98 (May-Dec) |
| Cardiff and Vale | 440 |
| Cwm Taf | 313 |
| Hywel Dda | 522 |
| Powys | 27 |

Table 4. Number of referrals into perinatal mental health services (and universal provision in Powys) in Wales in 2017

It is important to highlight the disparity in referral figures as seen in Table 3, and the challenges encountered in collecting accurate data on referrals into perinatal mental health services. When collecting these figures, health boards were in different stages in the development of their specialist perinatal mental health services. It is likely that new services may have experienced a spike in referrals. Some services had also not been established for a full year and therefore their figures will not capture a full picture of demand. As noted in Chapter Five, there are also clear differences in referral criteria and who can refer into specialist perinatal mental health services, which is likely to impact on referral figures. Health professionals also talked about the inconsistency in data being collected in health boards, and the difficulties they experience in accessing accurate data on referrals from their own data management systems. The referral figures collected therefore need to be viewed with caution, as they do not give a complete and accurate picture of the demand on services.

Future development

All Wales Perinatal Mental Health Steering Group are creating a unified data collection framework to ensure there will be a consistency of data collected across the perinatal teams. This will offer a more accurate picture of the demand on the perinatal services in the future.

Findings suggest that demand for specialist perinatal mental health services was outweighing capacity and teams were not able to meet the needs of all women and their families.

“The biggest challenge is the number of women. The huge volume of referrals for such a small team and although I think we are doing a fab job, I think we could do better, but we need more staff to do that cos the demand and the capacity don’t don’t balance” (Clinical Nurse Specialist in Perinatal Mental Health)

Insufficient funding, staffing and ‘*a lack of resource*’ (Perinatal Team Leader) were frequently cited as major constraints for many perinatal mental health teams in dealing with high demands. Repeated examples were given of there not being enough staff to meet the needs of the women in their locality and practitioners having to ‘juggle’ and prioritise needs. This was leaving some women without help and support when it was needed.

“You are juggling all of the time. It’s very difficult I think. In reality it is quite difficult to do that because you are working with people and needs change from day to day so you have to prioritise and then that’s another challenges because then when you prioritising that lady, then what happens to this lady. So she might be worse but this lady still needs you, you know and when there is just two of us it is like how do you manage it?” (Clinical Nurse Specialist in Perinatal Mental Health)

Size and rurality of some health boards was also raised as an issue for perinatal mental health teams. Examples were given of practitioners having to use most of their working day to travel to see patients; ‘*you could be travelling for one hundred miles just to see one person from your base*’ (Perinatal Team Leader). Health professionals indicated that there was a need for more investment so they could take on more staff in order to cope with high demands.

“Staff, people on the ground, yeah, we need specialist midwives, we need specialist health visitors, we need some more specialist perinatal nurses, we need the psychologist to have more hours...we’ve got very good staff but I clearly think we need more resources and more validity given to the significance and benefits of focussing on perinatal mental health”
(Lead Specialist in Perinatal Mental Health)

Some perinatal mental health teams described having to put measures in place to manage increasing demands on the service. Several health practitioners described making changes to referral criteria or limiting who could refer into the service as a way of preventing unmanageable volumes of referrals.

“So when we first set up we would take women, women that were postnatal we would take up to 6 months...We changed that to one month, which isn’t, doesn’t sit with us very well, doesn’t sit with me very well, because most women hadn’t presented by one month postnatal, it’s usually 6, 8, 10 weeks on and it’s not something that is permanent, but we had to something because the demand capacity was just like whoosh” (Clinical Nurse Specialist in Perinatal Mental Health)

There was however an acknowledgement that within these boundaries services were flexible and they would try and meet the needs of women.

Perinatal mental health teams also talked about unrealistic expectations from other health professionals about the number of women that they could support and the types of treatment they offered. Many perinatal mental health teams described being inundated with inappropriate referrals, which was reported to contribute to the unmanageable demands on the service. Perinatal teams talked about the work they were doing with other health professionals to try and manage expectations.

“Sometimes you have a lot of midwives ringing saying, ‘I saw a lady, booked her in she was tearful, can I refer her to you?’” (Perinatal Team Lead)

All of the perinatal mental health teams talked about doing some form of awareness raising with health professionals to inform them about their service, what they offered, and the women they could support. Some of the perinatal mental health teams also described innovative ways of managing expectations, such as developing a telephone advice line, where health professionals could ring for advice and support from the specialist service before making a referral.

“We operate a telephone advice line now. Prior to people giving us sending in a referral to us. It only started June this year, because we were inundated with referrals and a lot of them caused us to have a lot of DNA [did not attend] rates in our clinic...So, we needed really to start educating referrers around what we were, around what would be acceptable to us and what we could help with” (Perinatal Team Lead)

Another barrier to the delivery of accessible perinatal mental health services included unsuitable locations to house perinatal mental health teams and to host support groups or clinics. Some health professionals indicated that space and resources had not been adequately considered in the allocation of new and developed perinatal mental health services, as and a consequence teams were ‘shoe horned’ into space that was not fit for purpose. Many of the perinatal mental health teams talked about being housed in temporary office space and having to move numerous times.

“I’ve moved offices four times now since January and I am currently in what I am being told is a temporary base, but we will stay there until they find us another base. So, you know, it has been hard sometimes to keep the momentum and the energy alive in the team” (Perinatal Team Lead)

Other health professionals described having insufficient space to host support groups or clinics, and having to use community spaces that were often inappropriate or difficult for women to access.

“The other thing is the venue, which seems a silly thing, but finding somewhere for these women to have a group. You know the first psychological coping skills group we held in the sexual health clinic, the GUM clinic. They literally had to walk though there pregnant, through the GUM clinic where you go to get your HIV test” (Perinatal Nurse Specialist)

Despite the difficulties in delivering accessible services, the data suggests that perinatal mental health teams are working hard to meet the needs to women and to develop and improve their services. Accounts were given of perinatal mental health team members working above and beyond to help and support women.

“I’m full time and there’s not enough hours in the day for me, however, this is what we’ve got at this moment in time, so everybody’s working over and above, you know, and they’re snatching bits and pieces everywhere and I know we’re not supposed to do that, we’re all supposed to have a work-life balance and stuff, but I think that demonstrates our passion and our determination” (Perinatal Nurse Specialist)

Health professionals also described the cohesion between the perinatal mental health teams working in Wales. Many talked about sharing examples of good practice and innovation and helping to develop services.

Accessing specialist inpatient care

The majority of women experiencing these conditions can be cared for by perinatal mental health teams in the community. However, women experiencing the most severe conditions may require specialist inpatient care. Admission to Mother and Baby Units (MBUs) are nationally recommended for women that need inpatient care (NICE, 2015). Since 2013, there has not been a MBU in Wales for women who need specialist inpatient care²⁰. Data collected in this project evidence the need and demand for this type of specialist service in Wales; *'we need a mother and baby unit'* (Mum).

Future development

The AWPMSHG is developing a unified framework for how health boards can capture data on MBU admissions in England and perinatal admissions to adult psychiatric wards in Wales. This work is expected to be completed in 2018. This will be a significant step forward in gaining accurate data to determine the level of demand for inpatient admissions.

With an absence of a mother and baby unit in Wales, women who need specialist inpatient care are admitted for treatment in adult psychiatric wards or in MBUs in England, or risks are taken to support them in the community. None of these options were perceived to provide women in Wales with the care they needed. Generic adult psychiatric wards are not an appropriate place for a mother experiencing perinatal mental health problems.

“...I was not in an appropriate environment when I was in a general psychiatric unit & there was absolutely no provision for my partner & son to visit during the day. They weren't allowed to come to my room, we used to spend the time wandering the hospital corridors” (Mum)

A Freedom of Information (FOI) request to the Welsh Health Specialised Services Committee (WHSSC) revealed that between 2016-2018²¹ there were 16 admissions to MBUs in England. However, it is important to caveat these figures, as they only represent records of admissions funded by Wales. These figures do not reflect actual numbers of women who needed admission as they exclude those who have refused to go or those admitted to generic psychiatric wards in Wales. As there is no official data available on the number of women admitted to generic psychiatric wards in the perinatal period, these figures are undoubtedly a gross underestimation of demand for MBU admissions. There is no reason to believe that the epidemiology for perinatal mental illness will be different in Wales from other parts of the UK and Europe, which have estimated a rate for admission to be around 1 in 600 deliveries. In Wales, this would equate to around 55 women each year being admitted to psychiatric hospital in the perinatal period.

Not having MBU provision in Wales creates emotional and financial consequences for women and their families. Health professionals gave emotive accounts of women and their families having to travel significant distances to be admitted to MBUs in Nottingham, Derby, Exeter, Birmingham, Manchester, London and Staffordshire.

²⁰ See Children, Young People and Education Committee's (2017) report on Perinatal Mental Health in Wales for a discussion of why the MBU in Wales closed down in 2013

²¹ The FOI was carried out in Jan 2018 and as such the data for 2017/18 is incomplete.

“It took them 10 hours to get there...It was horrendous because you have to stop with the baby every two hours cos it was a new born and you have to take a 30 min break after a two hour drive and then they got congested up somewhere...They got there 10 o'clock in the night. It was just awful, what a terrible thing to do to that woman who was psychotic” (Perinatal Nurse Specialist)

Health professionals described the financial burden that admission to MBUs in England placed upon families. Examples were given of partners and family members having to take time away from work and having to pay to stay in hotels when visiting their partner and baby. These financial pressures were perceived to add further stress to an already traumatic experience for families.

“It costs them a fortune. There is nowhere to stay; he has to stay over in hotels. She has had overnight leave in hotels because it's too far to travel to have an overnight leave” (Clinical Nurse Specialist in Perinatal Mental Health)

Some health professionals raised concerns about Welsh language provision and how MBUs in England would be unable to provide services in Welsh. This was felt to be potentially harmful to families who were Welsh speaking, and did not reflect an equitable service for all women.

“We have to think of the mums in parts of Wales that their first language is Welsh...I feel are they having an equitable service as well really because if they were going to go into a mother and baby unit, they perhaps would want someone to speak Welsh to them. As they want to speak Welsh to their baby. So there is some deficits there” (Perinatal Team Manager)

It was also clear that health professionals working in perinatal mental health teams faced a multitude of difficulties in accessing beds in MBUs in England. Health professionals talked about a lack of clarity about who was responsible for locating beds; *‘It's clunky even internally within our organisation about who's responsible for doing that’* (Perinatal Team Manager), and the time needed to manage this process.

“It took me my whole week, my whole week. I only work two and a half days, I did nothing else. Everybody gave me coffee and I was on the phone constantly. I rang 13 units, I submitted three applications in for a bed, because you have to put an application in to get it refused. So even the system is not helpful. Each one of the them could have said we don’t have a bed, or that is not going to achieve the priority that we need or it doesn’t meet the criteria” (Perinatal Nurse Specialist)

Health professionals also talked about the difficulties they faced in providing continuity of care for women in MBUs in England and in managing women’s discharge when they come home.

“For us to get there you know it’s a day, well to get to a ward round it just doesn’t happen so discharge planning and all of that is much more difficult” (Clinical Nurse Specialist in Perinatal Mental Health)

During the course of this project, the Welsh Government announced its commitment to developing specialist inpatient perinatal mental health support for new mothers and their babies in Wales, as part of the budget agreement with Plaid Cymru for 2018-19 and 2019-20. A subgroup of the AWPMSHG has been working with the WHSSC joint Committee to explore options for the future configuration of inpatient services in Wales. In July 2017, three options were presented to the WHSSC joint Committee, which included; use IPFR Process through a secured contract; a single regional mother and baby unit to be established for Wales; and a regional mother and baby unit established for Wales in the south and services contracted in England for the North. At the time of writing a decision has not been reached about the type of inpatient provision for Wales.

Conclusion

This chapter demonstrates that some women in Wales are benefiting from specialist perinatal mental health support, and that perinatal services are working hard to address women’s needs. However, this chapter also shows that many women may not be currently receiving the level of services required to meet their needs. A range of barriers exist which are preventing women from accessing specialist services and health professionals delivering accessible care and support. Large demands on services, insufficient staffing levels, unrealistic expectations from health professionals leading to inappropriate referrals, and insufficient space to house teams and groups means that perinatal teams are stretched beyond capacity and unable to deliver services that are accessible to all women who need it. This chapter also shows that women experiencing the most severe perinatal mental health conditions, are not able to access appropriate inpatient care in Wales, as recommended by NICE guidelines. Consequently, women and their families are faced with additional emotional and financial burdens that could be avoided if women in Wales had access to MBU provision. The Welsh Government must make sure that all women in Wales needing specialist inpatient care have equitable access to MBU provision as a matter of urgency. This provision needs to be well integrated with specialist services so women can access seamless perinatal mental health care.

Recommendations

11. **The Welsh Government and health boards** should work with the MCN to address barriers to accessing specialist perinatal mental health services for women and their families, including a consideration of appropriate facilities to host groups, transport, and creche facilities
12. **The Welsh Government and health boards** should carry out regular evaluation of perinatal mental health services, including clinical audits, to support service developments and explore the experiences of women and their families receiving specialist care
13. **The MCN** should ensure that the completed unified framework for data collection becomes fully integrated into perinatal mental health services. This will ensure that admissions data being collected across perinatal teams in Wales is consistent and can be used to illustrate demand and inform future service development
14. **The Welsh Government and health boards** should work with the MCN to design fit for purpose mother and baby unit (MBU) provision in Wales which supports women and their families
15. **The MCN** should develop protocols for accessing MBU provision and a universal pathway for admission to ensure that specialist provision is accessed by those that need it



7. Third sector perinatal mental health care in Wales

Key findings

- Seven third sector organisations deliver perinatal mental health services in Wales
- Third sector services provide unique and highly valued perinatal mental health care in Wales
- Integration with statutory services, visibility, and funding are key challenges for third sector organisations delivering perinatal mental health care

“We are there for the mums that fall through the gaps’ (Third Sector Professional)

This study aims to identify and map out third sector organisations in Wales delivering dedicated perinatal mental health services to women and their families. This chapter describes the size and scope of the sector, and the important contributions made by these organisations in supporting women and their families with perinatal mental health problems. This chapter also highlights the challenges experienced by the sector in delivering perinatal mental health services.

Third sector service provision

The definition of the third sector is broad and includes ‘community associations, self-help groups, voluntary organisations, charities, faith-based organisations, social enterprises, community businesses, housing associations, cooperatives, and mutual organisations’ (WCVA, 2010: 5). Through a detailed desktop mapping exercise (see Appendix One), seven third sector organisations were identified as providing perinatal mental health services for women in Wales²² (see Table 7 overleaf). This included Birth Story Listeners, Families Together, Making Mums Matter, Pre and Post Natal Depression Advice and Support (PANDAS), PMH Cymru²³, Serenity and Swansea Trauma Support. These organisations are diverse, ranging from large national charities, to social enterprises, and small local peer support groups. The types of support offered by these organisations also differ. Some organisations such as Swansea Trauma Support and Serenity support women with specific conditions like birth trauma or postpartum psychosis, whereas others focus more on supporting women with mild perinatal mental health problems. Some organisations such as PMH Cymru and Families Together provide information and support to the partners and families of women affected by perinatal mental health problems.

²²It must be noted that the mapping exercise may not have fully captured the size and size and scope of the perinatal mental health third sector in Wales.

²³Just before this report was due to be published, PMH Cymru had to close due to insufficient funding.

| Perinatal mental health service | Locality | Service description |
|--|---|--|
| Birth Story Listeners | North Wales | Offering support and befriending to women who experienced a traumatic birth or perinatal mental health difficulties, through online peer support groups and small befriending groups in the community. |
| Family Action & Atal Y Fro: Families Together Project | Based in North and South Wales. | Supporting families through volunteer-led tailored peer support, designed to improve parents emotional and mental health, reduce social isolation and improve the attachment relationship between parent and baby. |
| Mind; Making Mums Matter | Powys, Mid Wales | A post-natal service supporting mums to manage the everyday, nurture themselves and dispel the many myths of motherhood. |
| Pre and Post Natal Depression Advice and Support (PANDAS) | Local groups based in Risca and Swansea, South Wales. | Providing help and support to parents and their families experiencing perinatal mental illness, through local and online support groups, and a helpline |
| PMH Cymru | Cardiff, South Wales | Taking a family approach to perinatal mental health difficulties by offering a 'wrap around' service, prevention and early intervention in the community. |
| Serenity | North Wales | Supporting women and their families who have suffered from postpartum psychosis or depression, through a monthly drop in support group, one to one sessions, and awareness raising. |
| Swansea Trauma Support | South Wales | Helping women affected by trauma, by offering a Post-Traumatic Stress Disorder (PTSD) recovery programme, independent professional advocacy, and private counselling. |

Table 5. Description of third sector perinatal mental health services in Wales

Throughout the duration of this project, a number of UK based organisations were also identified that support women and their families affected by perinatal mental health problems. These organisations offer support to women in Wales, but do not have a dedicated perinatal mental health service or support groups running in Wales. For example, Action on Postpartum Psychosis (APP) run a peer support service called PPTALK, which is an online support forum, open to anyone affected by postpartum psychosis. While the scope of this project was focused exclusively upon third sector services operating in Wales, it was clear that these UK wide organisations provide important support to women and their families affected by perinatal mental health problems in Wales.

Staffing

It was not possible to ascertain exact numbers of people employed or volunteering within third sector organisations delivering perinatal mental health services in Wales. This data was either not kept, known, or accessible by those who took part in the research. However, data collected suggests that there are a small number of people employed to coordinate or facilitate third sector perinatal mental health services in Wales. The findings suggest that overall, most services were being delivered by volunteers (see Figure 7).

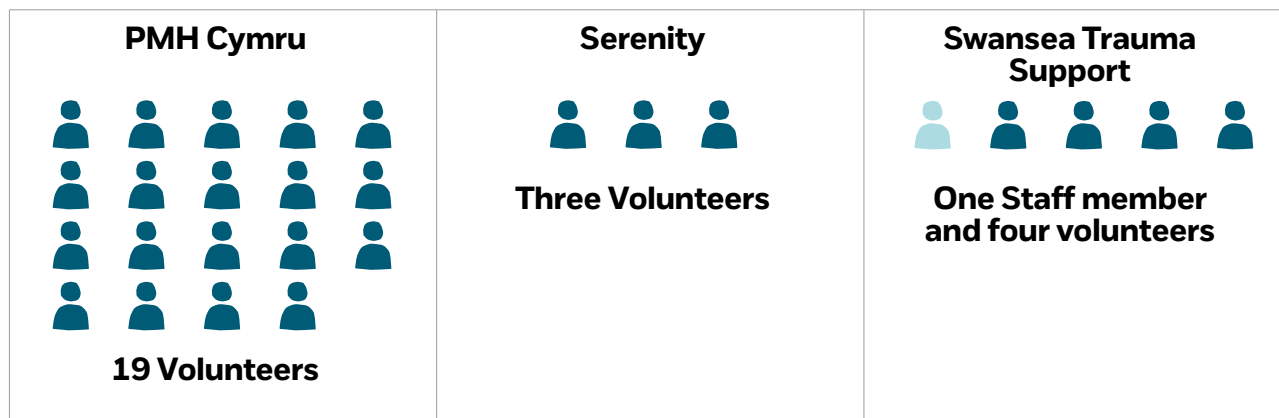


Figure 7. Examples of staffing structures within third sector perinatal mental health services in Wales

Interventions

The survey and interview data indicates that third sector perinatal mental health services in Wales offer a range of support to women and their families, including:

- Online and face to face peer support groups for women and partners
- Befriending
- Signposting
- Counselling
- Advocacy
- Emotional support and capacity building
- Friendship groups
- Mindfulness
- Fitness groups

It was not possible to determine numbers of women supported by third sector organisations, as this data was often not collected by services. The qualitative data from the interviews and surveys did however indicate that there was a high demand for third sector perinatal mental health services in Wales *'we have got a lot of mums...a lot'* (Third Sector Professional).

Contribution of the third sector

It was evident that the third sector provide an important contribution to supporting women and their families affected by perinatal mental health problems in Wales: *'I have sought help from PMH Cymru - they are a fantastic resource'* (Mum). Out of the 29 women (43 per cent) who sought help for perinatal mental health problems outside of specialist perinatal mental health services, over half (N=17, 58 per cent) received support by charities or voluntary organisations. This included peer support groups, befriending services, and online forums and networks. The importance of the third sector in supporting women with perinatal mental health problems was recognised by health professionals. The survey data shows that out of the 27 women (40 per cent) who had been referred by a health professional to a perinatal mental health service in Wales, 8 (29 per cent) had been offered peer support, mentoring, or befriending as an intervention. Peer support was reported to be particularly important and effective for women experiencing perinatal mental health problems in Wales.

"I found the peer group very useful as I was able to talk to other Mums that had been through similar experiences to my own" (Mum)

A growing evidence base suggests that access to the ‘right kind’ of peer support can have positive impacts upon women experiencing perinatal mental health difficulties (Jones *et al.*, 2014; Reynolds *et al.*, 2016). Research demonstrates that peer support programmes can protect against developing postnatal depression, reduce symptoms of stress, and relieve loneliness and isolation (Dennis *et al.*, 2009; Reynolds *et al.*, 2016).

Data indicates that the third sector have an important and specific role in the perinatal pathway. Third sector organisations were described as offering particular types of support to women who experience mild to moderate perinatal mental health problems and would normally ‘*fall though the gaps in services*’, as they would not meet thresholds for a referral into specialist perinatal mental health teams.

“...a lot of the mums coming to us had anxiety and they were being referred to perinatal teams, but they were not being seen, because they sort of didn’t need medication and the team felt that they didn’t need the support that they could offer. I understand that the perinatal team are so so stretched and they have a lot of people coming to them that I thought well why can’t we be you know the team beside them that are offering that support to mums that are just not adjusting, not coping well. Mums with you know a bit of anxiety all surrounding the baby. So we are there to fill them little gaps” (Third Sector Professional)

Third sector services were described as being complementary and adding value to specialist perinatal mental health teams, as they could offer early self-help, peer and social support to mums and their partners finding it hard to adjust to parenthood or those experiencing mild to moderate perinatal mental health conditions.

Practice example

In recognition of the lack of services for parents who experience mild or moderate anxiety and depression in the perinatal period, NSPCC developed the Pregnancy in Mind programme (Reynolds *et al.*, 2016). Pregnancy in Mind is a preventative mental health service designed to support parents who are at risk of, or experiencing mild to moderate anxiety and depression during pregnancy and the first year after birth. The service aims to minimise the impact of anxiety and depression on parents, and to support them to provide sensitive, responsive care to their babies. Pregnancy in Mind is an antenatal group intervention delivered by professionals during the middle trimester of pregnancy. Pregnancy in Mind is currently being delivered in three areas in England (Leeds Bradford, Swindon, Tidworth) and will be available in Swansea in Wales in the summer of 2018. For more information visit: <https://NSPCC.org.uk/>.

Third sector professionals also described the importance of working with and alongside specialist perinatal mental health services to enhance the support available for women experiencing the full spectrum of perinatal mental health difficulties.

“Longstanding charities like ourselves have a lot to offer and that partnership working would be beneficial to all concerned – particularly the patient” (Third Sector Professional)

There are many examples in literature that demonstrate the gains achieved through effective multi-agency partnerships between voluntary sector and specialist perinatal mental health services (see Beyon & Wafula, 2012; McCaul and Stokes, 2011).

Practice example

In England, Hampshire Lanterns was set up in 2014 in liaison with the Hampshire Perinatal Mental Health Service. It is a peer-support service run by mums who have experienced or are experiencing mental health problems during the perinatal period. Hampshire Lanterns set up group meets, including soft-play and picnics, as well as ward visits and patient support. They have an active Facebook group which is supported by the perinatal mental health team. Hampshire Lanterns also provide valuable patient perspectives for the perinatal team, by inputting into development areas, and delivering joint educational training. The co-working relationship between the perinatal team and Hampshire Lanterns has enabled them to apply become a formal charity and expand to supporting more women locally. They are also always looking at ways they can support the wider family, including dads and siblings.

Some perinatal mental health and third sector services recalled being integrated and working well together; *“We work very closely with [Families Together], they have lots of referrals from us”* (Perinatal Nurse Specialist), but most described being fragmented. Working in a multiagency way was a key challenge raised by third sector professionals.

Challenges

Third sector professionals described working hard to establish partnerships with specialist perinatal mental health services.

“I have been trying to build up a relationship with the perinatal team for a while now, for about a year and it has only been the past three months that we have had the referrals through” (Third Sector Professional)

However, some third sector professionals reported a reluctance or organisational barriers preventing partnership working. Reluctance to work in partnership was reported to be linked to issues of information sharing, trust and safety.

“I think there’s a real sense of um, ah the third sector’s like really ungoverned and people go off and do their own thing and you lose any control of information and people get confused about confidentiality and information sharing” (Perinatal Team Manager)

“I think there was a lot of trust issues because we are so new, like I said we are so new, the type of training our volunteers have had there is all this sort of, you know safeguarding issues, which I feel now I have got to the point where I have covered it now, I have covered it. That is where I think the trust is starting to come in more” (Third Sector Professional)

Rules about confidentiality and information sharing between agencies were presented as problematic to joint working. There were also concerns that third sector organisations did not have the same safeguarding procedures in place as specialist perinatal mental health services and this could leave women at risk if they needed more intensive support. Some perinatal mental health teams also talked about being restricted by internal protocols which prevented them from referring into and recommending third sector perinatal mental health services.

Quality assurance principles

Comic Relief and the Maternal Mental Health Alliance have commissioned Mind and the McPin Foundation to develop a set of bespoke Quality Assurance Principles for third sector organisations facilitating maternal mental health peer support. The principles resulting from this work will aim to assure the quality and consistency of online and face to face peer support in perinatal mental health. These principles will form part of the wider work being done to ensure that peer support in the perinatal period promotes positive outcomes and is:

- Safe for women and babies
- Accessible to all and inclusive
- High quality and evidence-based
- Trusted by clinical services
- Measuring and delivering outcomes and achieving maximum impact.

The Quality Assurance Principles are expected to be launched in early 2019.

Another challenge identified was the lack of visibility of third sector organisations delivering perinatal mental health services across Wales. Health professionals talked about a lack of knowledge about third sector support available in their locality. Practitioners also drew attention to the rapid changing nature of the sector due to funding and resource limitations.

“I think knowledge of what’s out there, I think things change so rapidly. Even since I’ve been in post services have come and gone”
(Perinatal Team Manager)

Health and third sector professionals described how a directory or database of local third sector provision would help to provide an informed picture of the sector, and partnership working between statutory and third sector perinatal mental health services, and avoid the ‘*duplication of support groups*’ (Third Sector Professional).

The final challenge raised by third sector professionals was the issue of insufficient funding. Although this project did not specifically explore how third sector services were funded, many indicated that they were self-funded and relied upon donations, or were projects that were funded for a limited amount of time. This meant that provision could only be provided when sufficient funding was in place.

“Another challenge I have is that third sector services such as mine are not funded, so I am constantly battling to keep afloat financially to be able to continue offering this support” (Third Sector Professional)

Difficulties in maintaining sufficient levels of funding for self-funded third sector services was illustrated by PMH Cymru having to close down due to insufficient funds, between the data collection and the completion of this project.

Conclusion

This chapter shows that there are a small number of third sector organisations delivering dedicated perinatal mental health services in Wales. These services are perceived as having a specific role in the perinatal pathway, in complementing existing statutory services by extending the local emotional and social support available to mums and their families in Wales. Third sector organisations do however face a number of challenges in delivering perinatal mental health services in Wales, including barriers to multi-agency working, visibility and a lack of funding to sustain their work.

Recommendations

16. **Third Sector** organisations facilitating perinatal mental health peer support in Wales should work towards achieving the perinatal mental health third sector Quality Assurance Principles
17. Improved partnership working between **specialist and third sector perinatal mental health services** to maximise local support available for women and their families affected
18. All local **Family Information Services** should ensure that they hold and disseminate information about all third sector perinatal mental health services and local peer support groups for mums and their families



8. Supporting families affected by perinatal mental health problems

Key findings

- Four out of six of the dads/partners experienced mental health problems in the perinatal period
- 61 per cent of health professionals had not received training on infant mental health in their current role
- 84 per cent of the health professionals felt they would benefit from additional training on infant mental health

“It’s nan, gran, dad, whoever, aunty, uncle. I think it is including everybody really” (Perinatal Team Practitioner)

The final theme in this study relates to the impact that perinatal mental health problems have upon partners, children and wider family members.

Support for partners and families

Similar to other studies (Chang *et al.*, 2007; Lancaster *et al.*, 2010; Pilkington *et al.*, 2015) this research shows that dads/partners and other family members play an important role in supporting women affected by perinatal mental health problems. Women described their feelings of gratitude and guilt of having to be supported and cared for by their partners and family members while they were unwell.

“Thankfully I have a very supportive and able husband who took the role of both parents during the time that I was unwell. This minimised the effects my illness had on the children (age 7 & new-born) but obviously put him under a huge amount of pressure and caused me a lot of guilt and shame” (Mum)

While family support was perceived as vital in helping women to recover from these illnesses, women expressed their concerns about the impact that their perinatal mental health problems had upon the well-being of their partners and family members.

“My partner found my anxiety and depression a real struggle. I was hard work to live with. There were times when he contemplated leaving” (Mum)

“It also put my parents through a lot of stress to the point my mother had to go on anti-depressants” (Mum)

Partners of women also described how perinatal mental health problems affected their own mental health and well-being.

“It had caused upset. I struggled to cope with the fact that I had two people to care for and no help” (Partner)

Four out of six of the dads/partners who took part in this research experienced perinatal mental health problems, including depression, anxiety, obsessive thoughts and PTSD. One dad/partner experienced mental health problems for the first time in the perinatal period, and three of the dads/partners had a history of mental health problems which resurfaced while their partner was pregnant or in the year after they had a baby.

As paternal depression and anxiety have been found to impact upon dads’/partners’ wellbeing, the quality of their relationships and upon child development, early identification of these problems is essential. NICE guidance (2014) states that health professionals should ‘take into account and, if appropriate, assess and address the needs of partners, families and carers that might affect a woman with a mental health problem in pregnancy and the postnatal period’. In this research, none of the dads/partners who identified as having a parental mental health problems felt like they received any support to manage their condition; “*Given pill nothing more, no groups or referrals. Felt ignored and unimportant*” (Partner). Three out of four of the dads/partners who experienced paternal mental health problems indicated that they would have liked additional support to help them manage their condition: “*I would have liked a mental health consultation and suggestions for support groups*” (Partner)

Within all perinatal mental health teams in Wales, the importance of engaging, including and supporting families of those affected by perinatal mental health problems was well recognised.

“I think we all think, you know we have got two patients; mum and baby, potentially three with dad and then the extended family as well” (Perinatal Team Manager)

All of the perinatal mental health teams described providing some level of informal support to the partners and families of women experiencing perinatal mental health problems. This included involving dads/partners and families in the assessment of the women’s condition, and providing advice and information about perinatal mental health conditions.

“We always offer advice and guidance to partners anyway. It is part and parcel of our assessment and when we visit at home we like to see the partners as well just to make sure they are in touch with what’s going on with the lady” (Perinatal Nurse Specialist)

While perinatal mental health teams talked about some information and support to families, this was described as relatively limited. Some of the teams reflected on provision for partners being ‘really poor’, with support often being informal and provided on an ad hoc rather than a routine basis. Some health professionals talked about their dissatisfaction of only being able to offer dedicated support to mums, and there being an absence of specific support groups for dads/partners.

“It’s all about mums and it can’t be. It’s got to be about the dads too, mental health impacts on the whole family, there’s a huge ripple affect”
(Health Visitor Lead)

Practice example

Action on Postpartum Psychosis (APP) have developed an information guide specifically for partners. The Insider Guide focuses on what postpartum psychosis is; treatment options; partners role during hospitalisation; recovery; and planning for the future. The partners guide can be downloaded from the website: <https://www.app-network.org/partners-2/>

However, many of the perinatal mental health teams talked about how support for dads/partners was an important area that they would like to develop in the future. Some teams had been exploring the types of support that they could develop for dads/partners.

Future development

The Cardiff and Vale Perinatal Mental Health Service has recently carried out a scoping exercise, to explore what type of dedicated provision exists for fathers affected by perinatal mental health problems across the UK. The exercise sought to map the content of existing groups, format, venue and frequency, as well as some of the successes and failures in establishing new support groups for dads. Cardiff and Vale Perinatal Mental Health Service hope to use the information gathered to explore the possibility of providing more support to dads affected by perinatal mental health problems.

A number of third sector organisations in Wales also provide information and support to the families of women affected by perinatal mental health problems. This includes one to one support or counselling for partners, information on perinatal mental health conditions, and signposting to other relevant organisations. For example, the Families Together Perinatal Support Service provides support to families facing multiple and complex needs, including perinatal mental health problems. The project supports families to overcome the challenges they face through tailored support for all family members, increasing confidence, wellbeing, and resilience, ensuring the safety of all family members and developing their capacity to plan for the future.

Supporting the mother-baby relationship

This project also highlights the importance of supporting mums and their partners to develop healthy and attuned relationships with their babies. Women in this project described their concerns that perinatal mental health problems had caused difficulties in bonding with their babies. Statements like ‘*couldn’t bond with child*’ (Mum); ‘*affected bonding with baby*’ (Mum) and ‘*very difficult to bond with baby*’ (Mum) were common among the women’s narratives. Some women were also worried that their difficulties in bonding could cause long-term consequences for their children.

“... I believe that my ability to bond with my child has been affected & I fear this may have consequences later on” (Mum)

The difficulties that mums can experience in bonding with their child, and the feelings of shame, guilt and inadequacy that can accompany this has been well documented. In the Boots Family Trust (2013) report, 28 per cent of mothers experiencing perinatal mental health problems talked about having problems bonding with their child. Evidence about the importance of sensitive and attuned care towards babies, to create the foundations for social, emotional and cognitive development, points towards the importance of supporting mums to develop nurturing relationships with their babies (Center on Developing Child, 2009; Royal College of Midwives, 2009). It is essential that all professionals working in the perinatal period are skilled and confident in their ability to detect difficulties in the mother-baby relationship and offer support to families to promote positive infant mental health and build secure attachment relationships.

Given the strong commitment in Wales towards ensuring that all babies have the best start in life, it is vital that all health professionals working with women in the perinatal period receive training on perinatal and infant mental health, and how to support health attachments and bonding between parents and children. The survey data from health professionals suggests that there are some considerable gaps in training on infant mental health. Only 6 (13 per cent) of health professionals reported having an infant mental health component in their pre-qualification training. Over half (N=27, 61 per cent) reported not receiving infant mental health training in their current role.

“Really wish I could have done that, infant mental health training. I have never done any, only what I have read. I don’t even know where it is available” (Perinatal Nurse Specialist)

Survey data indicates that health professionals are keen to improve their knowledge, skills and training around infant mental health, with 84 per cent (N=37) highlighting that they would benefit from additional training on infant mental health. These findings highlight the need to refocus attention on the mother-infant relationship, and ensure that health professionals working in the perinatal period have sufficient training and skills to support women to build healthy relationships with their babies. Essential to this is a more integrated approach to perinatal and infant mental health education.

Practice example

Baby Steps is a relationship based perinatal education and support programme developed by the NSPCC to support vulnerable families facing additional adversity. The programme is designed to sit alongside mainstream provision, with groups being co-delivered by health and family support practitioners, working together to engage traditionally ‘hard to reach’ parents and support them to manage the emotional and physical transition to parenthood. Baby Steps also supports mums and dads to care for their new baby and reduce the stress that often comes with looking after a new-born. A large-scale evaluation of the programme has shown a decrease in symptoms of anxiety and depression and improvement in parent-infant attachment and the quality of their relationships with their babies. For further information see: <https://NSPCC.org.uk/services-and-resources/childrens-services/baby-steps/>

Encouragingly, the research shows that supporting mums to develop healthy relationships with their babies, and training health professions on infant mental health was a developing priority for the specialist community perinatal mental health teams. Most of the perinatal mental health teams talked about providing training for primary care practitioners about the impact of perinatal mental health upon infant mental health.

“We have fully adopted and embraced the [Two in Mind’s] Maternal and Infant Mental Health training and we offer that bi-monthly, and we are always over-subscribed” (Perinatal Nurse Specialist)

Practice example: training

Two in Mind was a project led by the mental health charity Mind Cymru, with the aim of optimising the social and emotional environment of the infant. To do so they developed early intervention resources for all family practitioners including Enjoy your Bump, Enjoy Your Baby and Enjoy your Infant. They also built capacity in primary care by training family practitioners in the accredited Level 3 qualification and Level 2 certificate in Maternal and Infant Mental Health.

Resources for practitioners

Brain Story Certification

A free, in-depth course for anyone who wants to learn more about the science of brain development. Available at: <https://www.albertafamilywellness.org/training>

NSPCC Breakthrough or Breakdown Resource

5 short films on how to support parents affected by perinatal mental health problems. Available at: <https://NSPCC.org.uk/services-and-resources/research-and-resources/pre-2013/breakdown-or-breakthrough/>

Conclusion

Findings suggest that there is a need to offer support to the families of those affected by perinatal mental health problems. It is important to offer support and information to dads/partners and family members to help them understand perinatal mental health problems. It is also important to support dads/partners and other family members with their own mental health problems in the perinatal period. Findings also indicate that a more integrated approach is needed between perinatal and infant mental health education and training, to ensure that all health professionals working in the perinatal period can support mums to develop healthy and attuned relationships with their babies.

Recommendations

19. The **MCN** should produce and/or distribute a range of consistent, good quality information resources on perinatal mental health conditions (from mild to severe) specifically for partners and family members
20. The effect of perinatal mental health problems on partners and family members should be recognised and taken into account by **all health professionals** working in the perinatal period
21. All **perinatal mental health services** in Wales should have a unified and clear pathway in place to refer dads/partners and other family members to if they are identified as needing support within their own mental health in perinatal period
22. **The Welsh Government** should promote a more integrated approach to promoting and protecting positive perinatal mental health and infant mental health, with a particular focus on supporting mums affected by perinatal mental health problems to build positive relationships with their babies/children

9. Conclusions

from good to excellent: a vision for the future

“I do feel that there is more out there to help women and families with what I went through but mental health is lacking in funding and understanding” (Mum)

Perinatal mental health conditions are a significant public health concern, as they affect one in four women in the UK (Howard *et al.*, 2018) and can have devastating impacts upon women, their children and families. Many of the negative impacts of these conditions can however be mitigated through early identification and prompt treatment by universal and specialist services. The accounts of women, partners, health and third sector professionals in this study, indicate that Wales has made important progress in providing perinatal mental health care to women and their families. The majority of women indicated that they were asked about their mental health and well-being by a health professional while they were pregnant or after they had a baby. It was also clear that primary care professionals were important sources of support for women who were identified as needing help and support with their perinatal mental health condition. Funding from the Welsh Government has allowed for the establishment or development of specialist community perinatal mental health services in most health boards across Wales. These services were shown to provide invaluable support to women and their families affected by perinatal mental health conditions in Wales. This progress should be celebrated.

However, this study also demonstrates that critical improvements are needed across the pathway in Wales, at universal, specialist and inpatient levels. Improvements must be made in universal services to ensure that personal, professional and organisational barriers to the identification of perinatal mental health problems are addressed and removed. Clear improvements are also needed across specialist community perinatal mental health services. There remain unacceptable inconsistencies in the level of perinatal mental health services, and the types of support provided across health boards in Wales. This means that, despite improvements, the area in which a woman lives still determines the specialist care they can access when it is needed. Further investment is needed to address the disparity in the specialist service provision between health boards in Wales.

This would enable all specialist perinatal mental health services in Wales to ‘Turn Green’ on the Maternal Mental Health Alliance (MMHA) map of specialist perinatal

mental health services. There is a clear “invest to save” economic case for addressing perinatal mental health problems, with the cost to the public sector being five times the cost of improving services (Bauer *et al.*, 2014). This means that providing additional investment to specialist perinatal mental health services to address the disparity in the level of service provision, and to ensure that services can provide all aspects of care that women need to help them recover (enabling them to meet quality standards (CCQI)), would save the Welsh Government money in the long term. It is also essential that appropriate mother and baby unit provision is made available for women and their families affected by the most severe perinatal mental health conditions, as recommended by NICE guidelines. These shortfalls need to be addressed before Wales can lead the way in delivering high quality perinatal mental health care to women and their families.

Many of the improvements identified and the recommendations made in this report support the priority areas raised in the National Assembly’s Children, Young People and Education Committee inquiry into perinatal mental health. This report echoes recommendations about the need to raise awareness of perinatal mental health conditions, training for health professionals working in the perinatal period, additional funding to address service variations, and inpatient care. Together, this report and the inquiry into perinatal mental health present a clear way forward for the improvements needed in perinatal mental health care in Wales.

The Welsh Government now needs to provide strong leadership to ensure that the recommendations accepted from the inquiry into perinatal mental health, and the vision presented in this report are translated into reality for women and their families across Wales. Key to this will be the Welsh Government establishing clear timelines for the implementation of the accepted recommendations from the recent inquiry and monitoring the implementation. Establishing a perinatal mental health Managed Care Network should be a priority action, to help provide national leadership to further develop perinatal mental health services in Wales.

Recommendations

23. **The Welsh Government** should establish a dedicated assurance group with membership from relevant stakeholders in the perinatal mental health sector to monitor the implementation of its response to the National Assembly for Wales' Children, Young People and Education Committee recommendations.
24. As a key priority, **The Welsh Government** should establish the **MCN** so they can provide national leadership on implementing the National Assembly for Wales Children, Young People and Education Committee recommendations, and provide the necessary expertise to further develop perinatal mental health services in Wales.

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Appendix one: maternal mental health alliance: everyone's business campaign maps

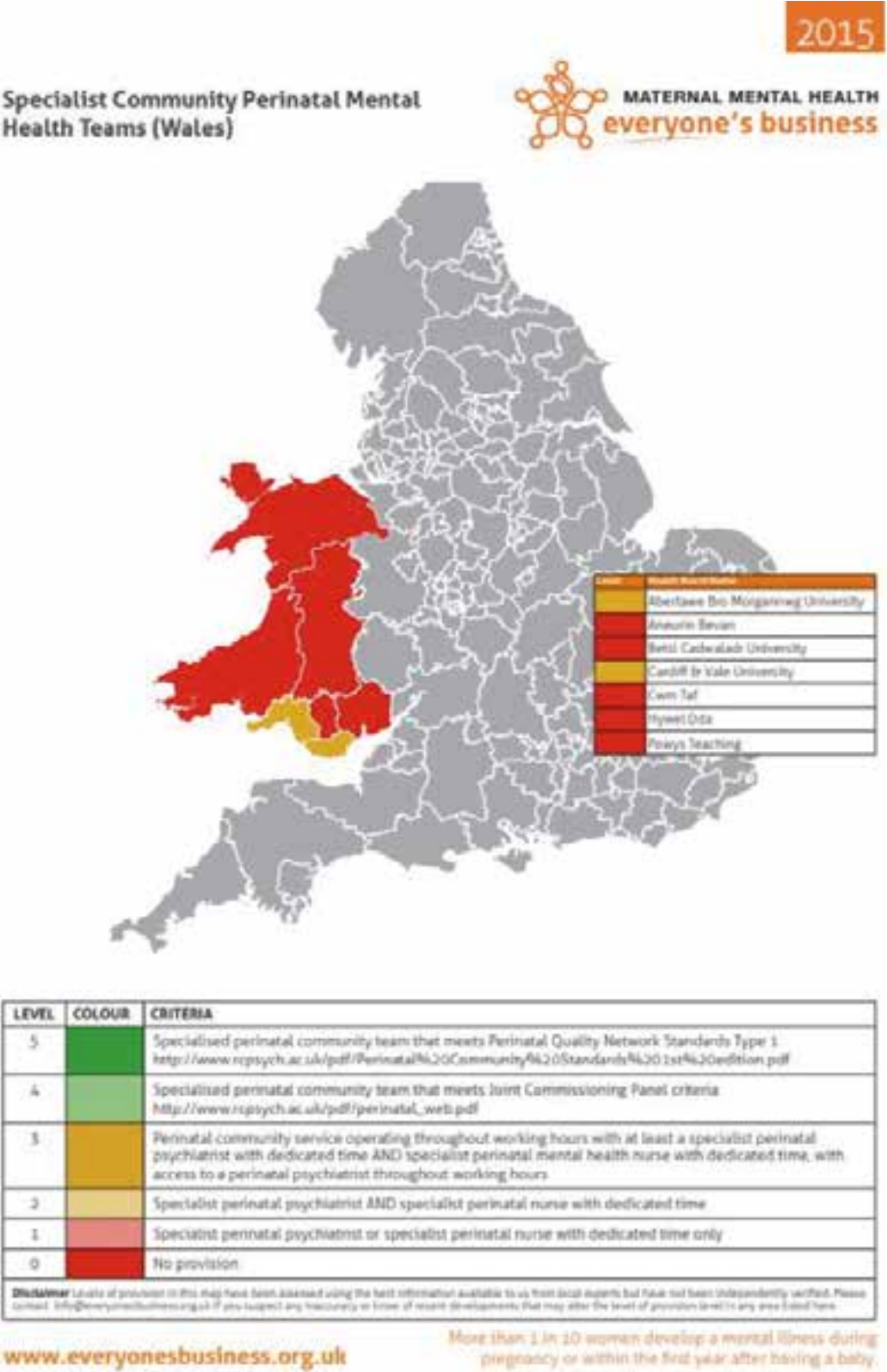
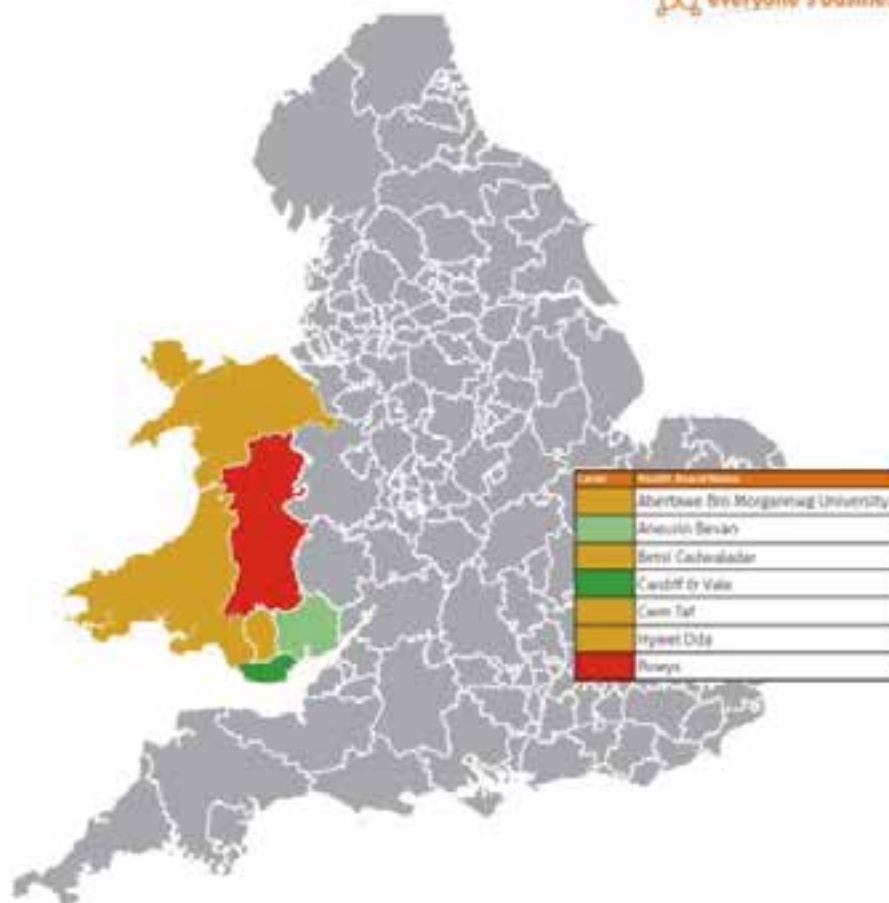


Figure 8. Everyone’s Business Campaign Map 2015

Specialist Community Perinatal Mental Health Teams (Wales)

2017 DATA
(RELEASED APRIL 2018)

MATERNAL MENTAL HEALTH
everyone's business



| LEVEL | COLOUR | CRITERIA |
|-------|--------|---|
| 5 | | Specialised perinatal community team that meets Perinatal Quality Network Standards Type 1 http://bit.ly/2jouu4d |
| 4 | | Specialised perinatal community team that meets Joint Commissioning Panel criteria http://bit.ly/2AhWYeX |
| 3 | | Perinatal community service operating throughout working hours with at least a specialist perinatal psychiatrist with dedicated time AND specialist perinatal mental health nurse with dedicated time; with access to a perinatal psychiatrist throughout working hours |
| 2 | | Specialist perinatal psychiatrist AND specialist perinatal nurse with dedicated time |
| 1 | | Specialist perinatal psychiatrist or specialist perinatal nurse with dedicated time only |
| 0 | | No provision |

Disclaimer: Details in this map and levels of provision have been assessed using the best information available at the time of printing. Please contact info@womensperinatalteams.org.uk if you suspect any inaccuracies.

More than 1 in 10 women develop a mental illness during pregnancy or within the first year after having a baby.

www.maternalmentalhealthalliance.org/campaign



Figure 9. Everyone's Business Campaign Map 2017

Appendix two: Detailed methodology

Research questions

This research aims to capture a better understanding of perinatal mental health provision in Wales and how it's experienced by women and their families. In doing so, this project was guided by a number of aims:

1. To identify and map out what services are available across statutory and voluntary sectors in Wales for women and their families experiencing perinatal mental health difficulties
2. To identify where specialist perinatal mental health services are meeting national standards and where improvements are needed
3. To illustrate examples of best practice in perinatal mental health services and identify where enhancements are needed to better support women and their families
4. To explore women's and partners' experiences of perinatal mental health problems in Wales

Methods

To better understand perinatal mental health provision in Wales and how it's experienced by women and their families, this project draws upon online surveys, interviews and a desktop mapping exercise.

There were three different online surveys. Surveys were completed by women who had experienced a perinatal mental health problem while living in Wales. This survey focused on experiences of mental health problems before, during and after the birth of a baby, contact with health professionals, help and support, and suggestions for improving perinatal care in Wales. It contained 55 questions, including 35 predetermined single or multiple-choice questions (closed questions) and 20 questions that participants could answer freely (open questions). The second survey was completed by the partners of women who had experienced a perinatal mental health problem. This survey focused on experiences of mental health before and after the birth of a child, help and support received, and suggestions for improving perinatal care in Wales. It contained 52 questions, including 35 predetermined single or multiple-choice questions and 17 questions that could be answered freely. The third survey was designed for health professionals working with women in the perinatal period and/or professionals working in the third sector who were involved in delivering perinatal

mental health services in Wales. The focus of this survey was on mental health assessments, interventions and support, partnership working, training and suggestions for improving perinatal care in Wales. This survey contained 50 questions, including 29 predetermined single or multiple-choice questions and 17 questions that could be answered freely. In four questions, participants were asked to provide quantitative information, including number of referrals into perinatal mental health services, to mother and baby units in England and inpatient psychiatric wards.

All surveys contained demographic questions to help gain a picture of the participants who took part in the research. All three surveys were available in English and Welsh. The design of the survey questions was informed by the aims of the research and key areas identified in perinatal mental health care within the literature review. Snap survey software was used to design and host the surveys. The surveys were open for a period of four months between June and September 2017. The surveys were developed in consultation with the research advisory group and piloted by a number of key stakeholders, women and their partners with experience of perinatal mental health conditions, to ensure that the survey design and content was appropriate for the intended audience (see Figure 10 and 11).

Interviews were conducted with specialist perinatal mental health teams in Wales. They focused upon the history of the service, funding, interventions offered, training, partnership working and ideas about future direction for the service. Interviews were also carried out with professionals working in the third sector who were involved in delivering perinatal mental health services. These interviews focused on service history, support provided and ideas about future directions for services in Wales. All interviews were carried out by the principal researcher, and were conducted in offices, coffee shops and over the phone. Interviews lasted between 15 minutes and two hours, and were conducted between June and October 2017.

The surveys and interviews were complemented by a desktop mapping exercise to identify third sector organisations delivering perinatal mental health services. This included a detailed online search of provision across Wales, utilising databases such as Dewis Cymru to identify local provision, contacting UK organisations to find out if they had Welsh support groups, and asking key stakeholders and existing participants about local groups they work with.



Figure 10 and 11: Picture of survey feedback from the project advisory group

Recruitment

The participants in this study were recruited through various means. A call for participants was emailed to known contacts and networks (including All Wales Perinatal Mental Health Steering Group and the National Centre for Mental Health's Research Data base). The email contained information about the project, a link to the appropriate survey and details of the project.

The survey was also advertised online through social media (see Figure12), blogs²⁴, newsletters and websites. Hard copies of the survey were also distributed at conferences and events. Existing participants were asked to disseminate the survey to anyone they felt would be interested in taking part in the research.

Perinatal Mental Health in Wales

Are you a mum who has experienced a perinatal mental health problem?

- 1 in 10 women experience mental health problems when they are pregnant or within the first year of having a baby (the perinatal period).
- Perinatal mental health problems can include depression, anxiety, obsessive compulsive disorder, eating disorders, post-traumatic stress disorder, and more rarely postpartum psychosis.
- NSPCC Wales, National Centre for Mental Health and Mind Cymru are doing some research to explore what it is like for women and their partners to access perinatal mental health support in Wales.
- We would like to invite mums aged 18+, who have experienced any perinatal mental health problem (either diagnosed or self-identified) while living in Wales, to share your experiences with us by filling in our online survey (available in English & Welsh).

If you have any questions, please contact
Dr. Sarah Witcombe-Hayes
 Senior Policy Researcher, NSPCC Wales
Sarah.Witcombe-Hayes@NSPCC.org.uk



NSPCC **NCMH** 

WYBODAETHU WELSH PERINATOL MENTAL HEATH CYMRU

Figure 12: Social media research advert for women with lived experience

²⁴See for example: <http://www.ncmh.info/2017/06/29/perinatal-mental-health-survey-launched/>

Sample

A non-probability sampling approach was adopted for this project. This meant that the sample was not representative of the population as a whole. Purposeful sampling was used to identify and select individuals that were knowledgeable and experienced in perinatal mental health (Lawrence *et al.*, 2015; Patton, 2002). Convenience sampling, which is a type of non-probability sampling, involving the selection of the most accessible and available participants (i.e. those who are easy to locate) (Bryman, 2012), and snowball sampling, which asks participants to suggest other potential participants for involvement in research (Tranter, 2013), were also used.

Criteria for participation included:

- Health professionals working with women in the perinatal period within Wales
- Third sector professionals who were involved in delivering perinatal mental health services in Wales
- Women over the age of 18 who had experienced perinatal mental health problems while living in Wales
- Partners over the age of 18 who had a partner who had experienced perinatal mental health problems while living in Wales

For the women and partners who took part in this research, there was no inclusion or exclusion criteria related to the timing of the episode of perinatal mental illness (i.e. how long ago a woman experienced a perinatal mental health problem). This allowed for a more diverse range of perspectives, including women who were currently seeking help (with some being supported by new services), and those who could offer a retrospective view on their experiences of perinatal mental health care.

127 participants took part in this research, which included 67 women with experience of perinatal mental health problems, 6 partners of women with experience of

perinatal mental health problems, 45 health professionals working in the perinatal period and 8 third sector professionals delivering perinatal mental health services in Wales. These participants completed 123 surveys and 9 interviews (see Table 2).

Women

67 women who experienced perinatal mental health problems took part in the survey. The majority of women identified as White English/Welsh/Scottish/Northern Irish/ British (N= 62, 92 per cent) (see Table 6), and three quarters were aged between 25–44 (N=52, 76 per cent). The respondents were from 20 of the 22 local authorities across Wales, with higher numbers living in Bridgend (N=8, 11 per cent) and the Vale of Glamorgan (N=8, 11 per cent) (see Figure 13). Before experiencing perinatal mental health problems, half of the women (N=34, 50 per cent) indicated that they had a history of mental health problems. Women described experiencing:

- Depression
- Anxiety
- Panic disorders
- Eating disorders (such as bulimia)
- Intrusive thoughts
- Generalised phobias
- Borderline personality disorders
- PTSD
- Bipolar affective disorder
- Psychosis
- Self-harm and suicide attempts

As indicated in Figure 14, during pregnancy or in the year after birth, over three quarters of the survey respondents experienced depression (N=57, 85 per cent), and/or anxiety (N=55, 82 per cent). Obsessive thoughts were experienced by 35 per cent (N=24) of women and PTSD by 26 per cent (N=18). Psychosis, and chronic mental illness were experienced by 3 per cent (N=6) of the respondents.

| Ethnic group | Frequency | Percent |
|--|-----------|---------|
| White English/Welsh/Scottish/ Northern Irish/ British | 62 | 62 |
| Any other White background | 2 | 2 |
| Irish | 1 | 1 |
| Caribbean | 1 | 1 |
| Any other Mixed /Multiple ethnic background | 1 | 1 |

Table 6: Ethnicity of respondents (women with lived experience)

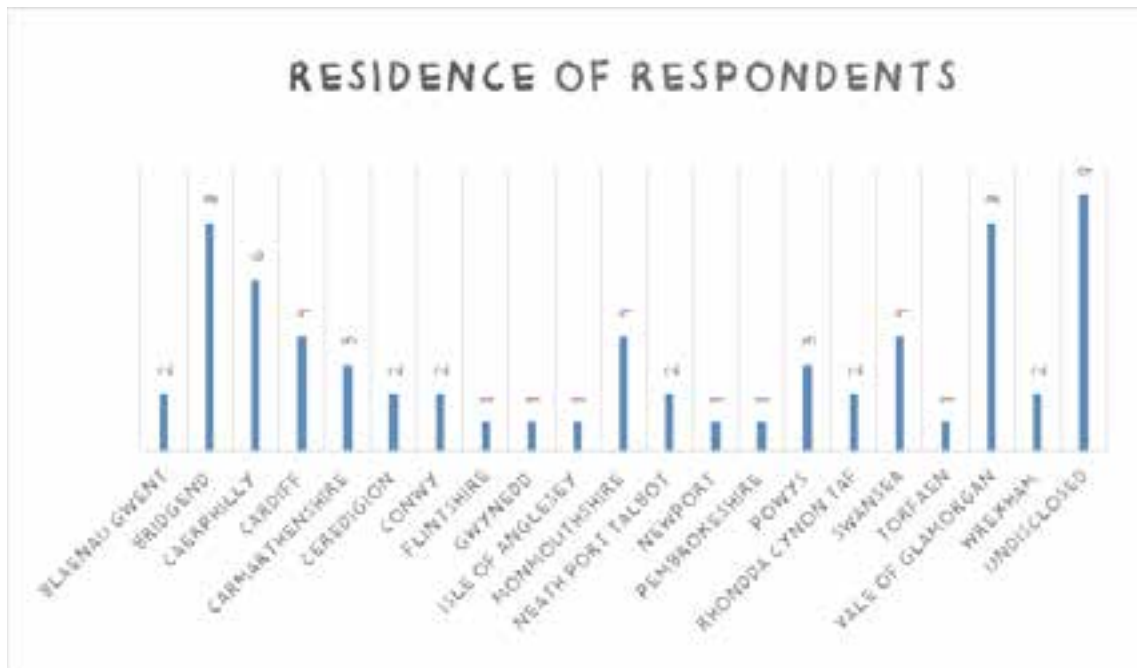


Figure13: Number of respondents residing in each local authority in Wales (women with lived experience)

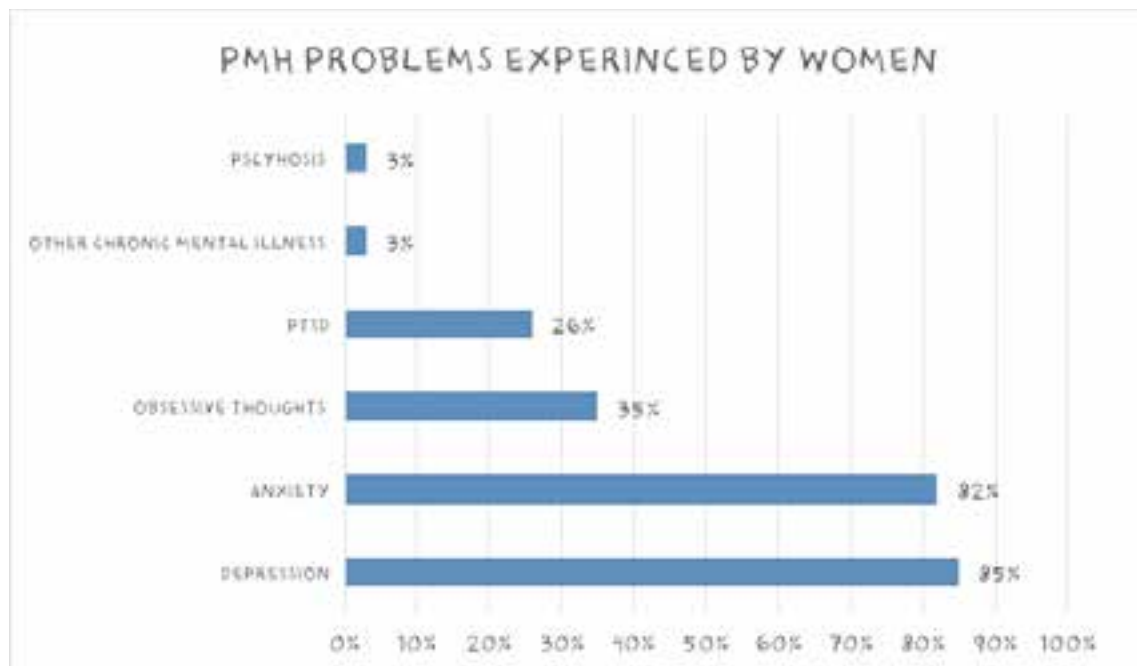


Figure 14: Percentage of perinatal mental health conditions experienced by women

Partners

Six partners of women with lived experience took part in this research. All six respondents identified as White English/Welsh/Scottish/Northern Irish/ British. Five were aged between 25-34 and one aged 35-44. In this study, partners were not asked to specify their gender. Four out of six of the dads/partners experienced mental health problems while their partner was pregnant or in the year after they had a baby. This included:

- Depression
- Anxiety
- Obsessive thoughts
- PTSD

One dad/partner experienced mental health problems for the first time in the perinatal period, and three of the dads/partners had a history of mental health problems which resurfaced while their partner was pregnant or in the year after they had a baby.

Health professionals

45 health professionals took part in this research. Most of the respondents were midwives (N= 16, 36 per cent) working within midwifery teams (N=17, 38 per cent) (see Table 7 and 8). Most respondents were experienced in their current role, with the majority (N=19, 43 per cent) having over 10 years' experience.

| Role | Frequency | Percent |
|----------------------------|-----------|---------|
| Midwife | 16 | 36% |
| Health Visitor | 10 | 22% |
| Social Worker | 1 | 2% |
| Mental Health Nurse | 3 | 6% |
| Perinatal Nurse Specialist | 5 | 11% |
| Perinatal Psychiatrist | 2 | 4% |
| Psychologist | 2 | 4% |
| Other | 4 | 9% |
| Undisclosed | 1 | 2% |

Table 7: Respondents by job role (health professionals)

| Team | Frequency | Percent |
|---|-----------|---------|
| Midwifery | 17 | 38% |
| Health Visiting | 10 | 22% |
| Generic Mental Health Team | 4 | 9% |
| Specialist Perinatal Mental Health Team | 10 | 22% |
| Other | 3 | 6% |

Table 8: Respondents by team (health professionals)

Third sector professionals

Six surveys and two interviews were completed by professionals working in third sector organisations in Wales. A number of additional individuals who worked for organisations which provide perinatal mental health services were also contacted via email for further information about service provision.

Data analysis

The qualitative data collected through the interviews and the open survey questions was analysed using cross-sectional thematic analysis. This analytical strategy involved identifying recurring themes, concepts, topics, or relationships across the data sets (Braun and Clarke, 2006). A phased approach to analysis was conducted, which included:

- Immersion in the data through verbatim transcription and repeated reading of the data sets
- Generating initial codes using inductive²⁵ and deductive²⁶ approaches
- Analysing codes to search for overarching themes
- Refining themes
- The labelling and description of final themes

The computer software package, N-Vivo was used to assist with the coding of data. Manual coding was also conducted on the qualitative data. Due to the relatively small sample sizes, the quantitative data from the three surveys was analysed using simple descriptive statistics only to summarise the basic features of the data (O'Leary, 2004). In the presentation of the quantitative data the percentages have been rounded to the nearest percent, and therefore may not add up to 100.

²⁵An inductive approach draws out themes which are linked to the data itself, it is data driven (Patton 1990) and an analysis of such is 'a process of coding the data without trying to fit into a pre-existing coding frame, or the researcher's analytical preconceptions (Braun and Clarke, 2006:12).

²⁶A deductive approach uses a set of predetermined codes or areas that may be drawn from existing theory of specific areas of interest to the project (Gale et al., 2013).

Ethics

This research was approved by the NSPCC Research Ethics Committee in April 2017. All research within the NSPCC is guided by a comprehensive ethics policy based on the ESRC Framework for Research Ethics and the Government Social Research Unit professional guidance. The NSPCC's ethical research policy is guided by five principles of ethical practice, including:

- Voluntary participation based on valid informed consent
- Enabling participation where possible and avoiding the systematic exclusion of particular sections of society
- Avoidance of personal and social harm to participants and researchers
- Non-disclosure of identity and personal information
- Ethical application and conduct of research methods

This study was carefully designed in collaboration with the project partners and the project advisory group to ensure that it adhered to strict ethical practice. All participants were fully informed of the research parameters and methods through project information flyers, information sheets and consent forms. All interview participants also had the opportunity to view, amend and withdraw any data within the interview transcripts that they no longer wished to include in the study. The identity of participants was kept anonymous using generic pseudonyms.

Limitations

Findings from this study need to be placed in the context of the following limitations.

These include issues with the samples recruited, such as small numbers of participants and unrepresentative population samples, meaning that the findings are not representative of the population of participants and generalisations could not be drawn from the findings. Due to small sample sizes, it was not possible to carry out detailed statistical analysis on the data. Descriptive statistical analysis can only be used to provide simple summaries about the sample and the measures. The sample also did not include general practitioners, general adult psychiatrists and family members, such as parents, grandparents, aunt and uncles. The inclusion of these groups would have added important and additional insight into this study. Due to the changing nature of the third sector, the desktop mapping exercise may not have captured all third sector organisations delivering perinatal mental health services in Wales. These limitations mean that this study is exploratory in nature. It has highlighted some important findings that can drive forward policy and practice changes in relation to perinatal mental health care in Wales, but it is important that additional research is conducted to build upon the findings of this project.

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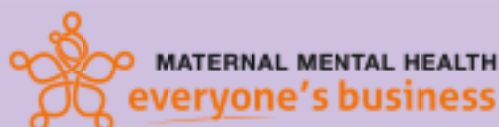
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