PANDA
Perinatal Anxiety & Depression Australia

Submission to The Royal Commission into Victoria's Mental Health System

July 2019

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Introduction

PANDA – Perinatal Anxiety & Depression Australia's interest in this Royal Commission is in relation to the impact of perinatal mental illness, a public health issue of critical importance. If parents at risk of or experiencing perinatal mental illness are not identified and able to access adequate support and treatment, there can be significant and devastating consequences for the entire family unit, with the potential to impact children well into their adult lives.

We know that more than 1 in 5 mothers and 1 in 10 fathers will experience mental illness during pregnancy and the first year of their child's life, and that many will not seek or successfully access the help they need. Stigma and shame act as powerful barriers to help; many of those affected feel isolated and ashamed about their feelings. Stigma relating to mental illness in the perinatal period can be particularly problematic, given social expectation that this is a time characterised by joy and new life, not uncertainty, sadness, or fear.

PANDA works each day to provide support, information and hope to families in Victoria (and across Australia) affected by mental illness. Through amplification of the voices of those with lived experience of perinatal mental illness we strive to help create a society in which perinatal mental health is valued and understood, and where stigma and systemic barriers to help seeking no longer exist.

This submission has been developed in collaboration with our Community Champions and Community Education Volunteers who have experienced perinatal mental illness. The submission is also informed by practice wisdom gained through providing support to families in Victoria since 1983, services to callers to PANDA's National Perinatal Anxiety & Depression Helpline since 2010, and the latest research evidence. The stories shared within this document are our volunteers' experiences, and have been shared with consent to support the Commission's work.

> 'There were many tears... lots of times of doubting myself, seeing myself as worthless, seeing myself as never good enough and wanting to sometimes pack up and leave, or not be on earth anymore. I still have days that I cry, that I can't cope, or I can't handle a situation. I am still seeing a psychologist, and still on medication.
>
> So, to you, in the bathroom crying, not wanting to get out of bed, wishing you were not here anymore, please speak up and get help.
>
> Because although today seems dark and hopeless, I promise you there will be a day that things seem brighter and you will want to be around to see that!'
>
> Community Volunteer

About PANDA

PANDA was established in Victoria in 1983 by two women who had experienced postnatal depression, and wanted to support others in the same situation. Since that time PANDA has continued to grow, and now supports families across Australia impacted by perinatal mental illness. PANDA is committed to raising community awareness of the incidence and impact of perinatal anxiety, depression and postnatal psychosis so that families can understand what is happening to them and seek help early. This national awareness raising work is led by the experience of our Community Champions and Community Education Volunteers (hereafter referred to as Community Volunteers) who share their stories.

Since 2010 PANDA has provided the only specialist National Perinatal Anxiety & Depression Helpline Service, underpinned by clinical evidence and informed by the lived experience of perinatal mental illness. PANDA also runs community and professional education programs in Victoria with funding from the Victorian Government. In addition, PANDA's websites and written resources provide specialised information and support for families and health professionals.

PANDA's unique expertise

As the only provider of a specialist Perinatal Helpline Service, PANDA is well regarded as the national expert in the lived experience of perinatal mental illness. This knowledge places PANDA in a unique position to advocate that Victoria's approach to perinatal mental health must be evidence based, and driven by a strong consumer voice.

Since the establishment of PANDA's Helpline we have had over 120,000 conversations about perinatal mental health with expectant and new parents, their loved ones and health professionals. These conversations provide us with a valuable understanding of the lived experience of perinatal mental illness, including the barriers to accessing and engaging with universal and specialist health services. Our submission is informed by this knowledge, and feedback from our Community Volunteers who have generously shared their own experiences of perinatal mental illness. As a key consumer organisation, PANDA's expertise is frequently sought by governments, researchers, health bodies and policy makers.

PANDA's consumer engagement experience

As a consumer organisation, PANDA is committed to facilitating consumer engagement at every level of the organisation. Peer support volunteers are highly valued members of PANDA's National Perinatal Anxiety & Depression Helpline team, providing peer support, information, and referral services. Our national volunteer program includes more than 280 Community Champions and Community Education Volunteers with lived experience of perinatal mental illness.

PANDA undertakes meaningful consumer engagement in a number of ways. PANDA:

- Includes consumers and carers on our governance board;
- Consults consumers and carers in the development of key policies;
- Includes diverse consumer and carer voices in our advocacy to government, policy-makers and health services;
- Trains consumers and carers to participate in advocacy and consumer participation work with government, policy-makers and health services;
- Promotes consumer and carer co-design approaches and supporting consumer involvement in research partnerships, including co-design of perinatal mental health interventions;
- Draws on diverse consumer and carer voices and stories in developing all communications (for consumer, health professional and public audiences);

- Tests all communications with consumer and carer volunteers as a core part of the production process;
- Draws on learnings from the PANDA Helpline's work with diverse families in communications, training and resources for health professionals and consumers;
- Amplifies diverse consumer and carer voices through traditional and social media;
- Undertakes a range of consumer and carer engagement practices in health professional training from co-design and co-delivery with consumer volunteers, to inclusion of diverse stories, consumer/health professional panels at workshops and conferences, to production of multimedia training resources featuring diverse consumers;
- Trains and supports consumer and carer volunteers to deliver health education sessions to at-risk groups in partnership with health professionals, including information sharing, facilitation of structured discussion activities, purposeful story-sharing and promotion of a range of support options;
- Trains and supports consumer and carer volunteers to provide support to callers to the PANDA Helpline experiencing mild to moderate symptoms, and in recovery;
- Trains and supports consumer and carer volunteers to raise awareness in their communities, including distributing PANDA resources in local community spaces and services, organising awareness raising activities in their communities, promoting key messages through social media, and having purposeful conversations with friends, family and community to raise awareness and reduce stigma related to perinatal mental health issues.

Meaningful consumer engagement is an iterative process, and requires an ongoing commitment of time and resources. PANDA's experience of consumer engagement has demonstrated that these ongoing commitments are necessary for perinatal services to meet the needs of service users.

Collaboration

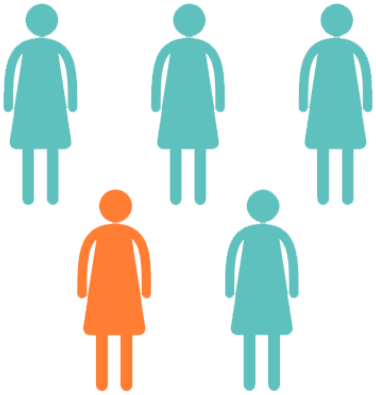
PANDA has a proven record working successfully across a number of health discipline and health service areas, and across state and territory borders. This is evidenced by our professional collaborations, including:

- Parent-Infant Research Institute (PIRI);
- Judith Lumley Centre, La Trobe University;
- Centre of Perinatal Excellence (COPE);
- DJIRRA (Aboriginal community controlled family violence prevention and legal service);
- NHMRC funded research collaborations, including two current projects.

PANDA also collaborates with a number of health professional groups, partnering with health services and local government to provide workforce training and resources. In addition, we provide education and training for a number of non-government organisations and associations. These partnerships include:

- General practitioners;
- Midwives and Maternal, Family, and Child Health nurses;
- Allied health service providers, including psychologists;
- Specialist perinatal mental health professionals, including psychiatrists, mental health nurses, and specialist services including mother baby units;
- Specialist domestic and family violence services.

Perinatal mental illness



‘I experienced terrible anxiety during my first pregnancy, which was never discussed. The birth of our first child was traumatic, it was never followed up on or discussed. And then after our second child was born anxiety was very present yet there was no one I felt I could turn to or ask for help. The stigma of feeling I was "failing" was overwhelming.’

Community Volunteer

The perinatal period is a time of increased risk for mental illness. A range of mental health difficulties occur in the perinatal period; mental disorders are one of the most common morbidities women experience during pregnancy and the year following birth[1]. Disorders across the diagnostic spectrum can occur, however until recently attention in research and practice has remained on postnatal depression, with far less focus on mental health during pregnancy and the importance of other disorders such as anxiety[2]. This is beginning to change, with increasing evidence to demonstrate significant morbidity relating to other mental health disorders in the perinatal period[1]. This historical focus on maternal mental health and postnatal depression still impact health care practices and community understanding of perinatal mental illness today[3,4].

Prevalence of perinatal mental illness

Estimates regarding the incidence and prevalence of perinatal mood disorders differ due to methodological and population variations between studies[5–7]. Regardless, there is wide acceptance that parent’s mental health during pregnancy and the first year of a child’s life is a key public health issue.

Research undertaken in Australia and other high income countries has identified that approximately 15-22% of women experience depression during pregnancy and/or following the birth of their baby[8–10]. While less research has focused on perinatal anxiety, it is understood to be at least as common as depression, if not more so[11,12]. A number of women will experience both anxiety and depression[8,13]. Therefore, at least one in every five women will likely experience anxiety, depression, or both during pregnancy and/or the year following birth.

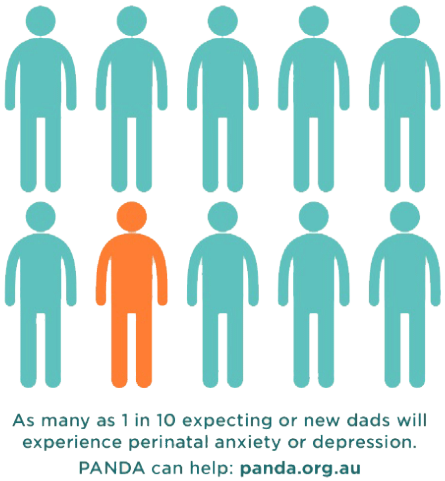
During the perinatal period women may also experience less common but important mental health disorders, including Post Traumatic Stress Disorder (PTSD), personality disorders[1], bipolar disorder, and schizophrenia. The perinatal period is associated with an increased risk of severe mental illness such as bipolar disorder and affective psychosis[14].

Postnatal psychosis

It is estimated that 1-2 of every 1,000 new Mums will experience postnatal psychosis. Onset is often acute with rapid deterioration in the early days and weeks following birth, with most women requiring care in an inpatient mental health facility. More than half of the women who develop postpartum psychosis have no history that suggests they were at high risk of the illness[14].

Mental health of fathers

> 'It was once I was home that things began to fall apart. My partner was beyond stressed having had to manage his older children, the house, the property and work as well as his own shock and trauma from the birth. He now recognises that he was suffering depression, anxiety and the ongoing stress of the trauma.'
>
> Community Volunteer



There is increasing acknowledgement of the importance of father's mental health, including the impact poor paternal mental health can have on physical, emotional, and developmental child outcomes[15,16]. It is estimated that one in 10 fathers will experience anxiety and/or depression in the perinatal period[17,18].

Risk factors

The perinatal period can be a period of vulnerability for women's mental health, although some women are more likely to experience perinatal mental illness than others. Key risk factors include a lack of partner support; inadequate social support[19,20]; history of abuse or domestic violence[19,21]; a personal history of mental illness[13,19]; low self-esteem; and past or current pregnancy complications[19,22].

Although not all of these factors are modifiable, early identification of risk factors presents opportunities to ensure additional supports are in place to help protect the woman's and her family's mental health during pregnancy and the early years of their child's life.

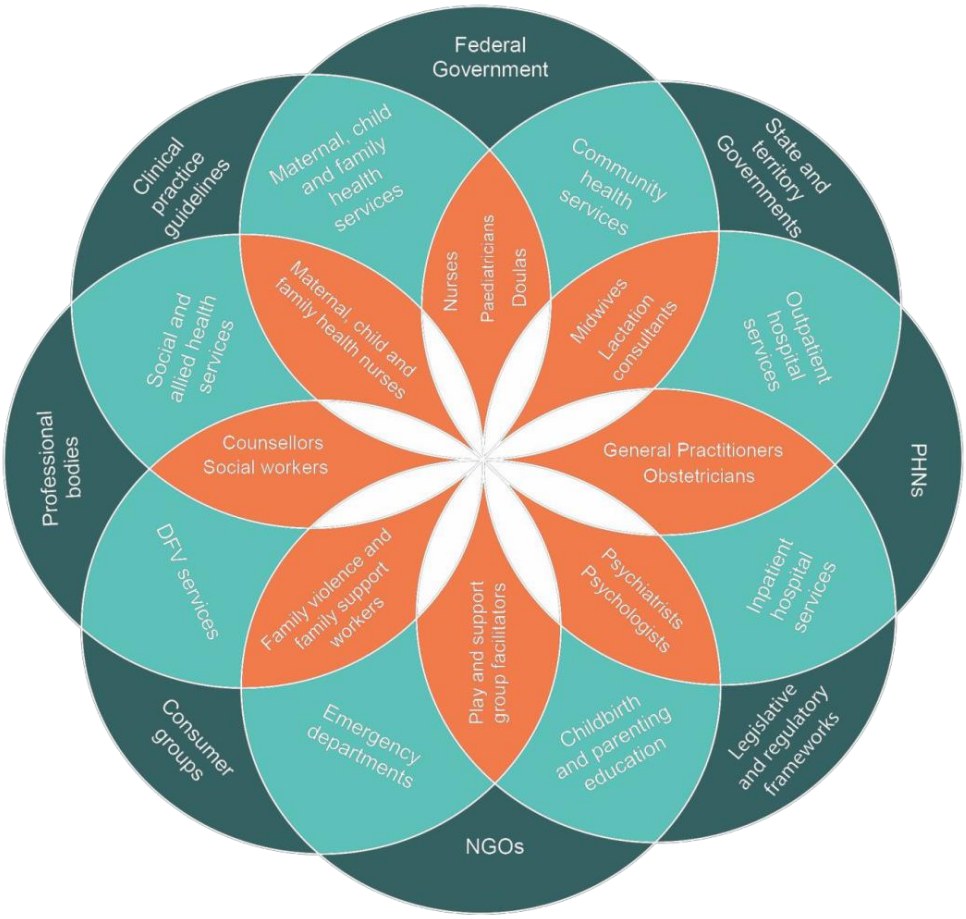
Impact

If untreated, perinatal mental illness has clear potential to impact the family's health across generations. Perinatal anxiety and depression have been associated with an increased chance of premature birth and low birthweight[23], impaired parent-child interactions, and psychological and emotional challenges for children[7,24]. Women can experience thoughts of self-harm or suicide; sadly, suicide is the leading cause of maternal death in Australia during pregnancy and the year following birth[25–28]. Parents supporting a partner with perinatal mental illness are at increased risk of developing their own mental health difficulties[17].

Perinatal mental health service delivery, policy, and funding landscape

One of the greatest challenges for perinatal mental health in Victoria is that it exists at the intersections between the maternity, early family, and mental health systems. Perinatal mental health is the responsibility of all health and social professionals who care for families within these systems. This presents both an opportunity and a challenge; the opportunity to ensure a diverse range of health professionals are actively supporting a family's mental health, and the challenge of ensuring systems traditionally geared to physical health are adequately re-framed to meet the mental health needs of parents.

Figure 1: Perinatal mental health service delivery, policy, and funding landscape



Responses to the Commission's Questions

1. What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

> 'Raising awareness and reducing stigma about perinatal mental illness needs to be a priority too, because I believe these two factors stop people seeking help even if they know they may feel mentally unwell'
>
> Community Volunteer

There is poor community understanding of perinatal mental health and illness, particularly regarding perinatal anxiety, the incidence of mental illness during pregnancy, and perinatal mental illness in men[3]. A historical focus on mental illness following birth, particularly depression, still impacts public awareness, and may also help to explain why women with perinatal anxiety seem less likely to seek help than women with depression[4].

Becoming a parent is one of the most significant life transitions someone can experience. There is a social expectation that the perinatal period is a time characterised by joy, new life, and happiness, not fear, sadness, or loss. These expectations, shame and stigma, and fear of being seen as a 'bad parent' can work as powerful barriers to early identification and appropriate care.

In this time of great change symptoms of perinatal mental illness are often confused with 'normal' experiences of parenting. The lack of awareness of the incidence and impact of perinatal mental illness amongst expecting and new parents can contribute to delays in seeking help. We know that early intervention is the key to reducing symptoms and helping those affected to recover.

Illustration by Melissa Vallence

Raising understanding of mental health in the perinatal period

While we need an overall increase in awareness of perinatal mental illness, PANDA has identified a need for specific focus on three key areas:

- Increased understanding that mental illness occurs during pregnancy, not only following birth
- Heightened awareness that anxiety is at least as common as depression in the perinatal period
- Awareness that fathers and non-birth parents can also experience depression and anxiety in the perinatal period

Significant improvements in attitudes relating to perinatal mental illness including reducing stigma will only occur with increased community awareness and system wide commitment to perinatal mental health.

Community Awareness of Perinatal Mental Illness

In 2016 PANDA undertook research into community awareness of perinatal mental illness[3]. This research built on work completed by beyondblue in 2009. While the beyondblue research focussed on awareness of antenatal and postnatal depression we also explored community understanding of perinatal anxiety and awareness of perinatal mental health difficulties in expecting and new fathers.

The research demonstrated that 52% of Australians identified depression as a key health issue in the year after birth. This increased from 45% in the 2009 study. However, when asked about key health issues during pregnancy, only 5% identified depression or anxiety as a key issue. Interestingly, 34% were able to identify gestational diabetes as a key health issue, even though it is less common than antenatal anxiety and depression.

When prompted just 39% of respondents indicated they were aware that some women experience anxiety during pregnancy and after birth. Further, 60% of the Australian community are unaware that perinatal anxiety and depression can be experienced by men.

Effective Awareness Raising

Universal community anxiety and depression awareness campaigns do not reach parents in the perinatal period. Awareness raising efforts need to specifically target the unique reality of the perinatal period to help expecting and new parents identify when symptoms go beyond the normal challenges of pregnancy and parenting.

Stories about the real experiences of those affected by perinatal mental illness are an essential component of awareness raising; to both connect parents to the messages and break down stigma about mental illness at this crucial time. PANDA's websites panda.org.au and howisdadagoing.org.au both contain stories from PANDA's Community Volunteers. The popularity of these stories is evidenced through feedback and high numbers of page visits. Some of our Community Volunteers have reported that while they did not access PANDA's Helpline Service, they instead spent many hours reading the stories to help them know that they were not alone and that they could get better.

Perinatal Mental Health Checklist

In November 2018 PANDA launched a new online perinatal mental health checklist for expecting and new parents and carers. This comprehensive checklist (30 questions addressing physical and behavioural changes, thoughts and feelings, and relationships) has been completed by more than 18,000 people since it was launched just under five months ago. The checklist is a powerful awareness raising tool, and produces a personalised summary report that indicates whether the symptoms being experienced by the user or their loved one could be a reason to seek help.

Perinatal Anxiety & Depression (PANDA) Awareness Week

PANDA works all year round to raise awareness through traditional and social media drawing on the generous stories provided by our Community Volunteers. This works culminates in the annual Perinatal Anxiety & Depression Awareness (PANDA) Week in November. PANDA established this week in 2005 to increase awareness of perinatal mental illness and to reduce stigma. Since then PANDA has been using the awareness week to speak out about supporting the mental and emotional wellbeing of expecting and new parents, including raising awareness about the signs to look for and where to go to seek support. While the reach of this campaign increases each year our efforts are limited by a lack of funding for this work.

Key Recommendation

There is a need for a government supported consumer informed perinatal mental health awareness campaign highlighting antenatal mental health, perinatal anxiety, and partner perinatal mental health.

2. What is already working well and what can be done to better prevent mental illness and to support people to get early treatment and support?

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

> 'I was suffering extreme anxiety with a newborn to the point of losing 15 kilograms in 3 weeks – I only gained 7 in my pregnancy. I could hardly eat and felt sick all the time. I felt as if I could not be alone with my daughter or do anything by myself… I had to advocate for myself, whilst my mother and husband helped me care for my daughter 24/7. I knew I didn't feel right… I knew I needed more intervention. I ended up doing my own search for [Mother Baby Units] and made my own referral. My GP had to be convinced by my husband that I needed it. I ended up being admitted for 5 weeks. It was the best thing we could have done. I just wish it had been done sooner, with less leg work from me. I wish someone had been my advocate. It's only because of my line of work, my education and skills, and my history of mental illness, that I was able to strongly advocate for myself, despite my mental state at the time.'
>
> Community Volunteer

Victoria has led the way in some important support for perinatal mental health. We have more inpatient mother baby beds than any other Australian state or territory, demonstrating a clear commitment to the mental health of women and their babies. There are a range of excellent and committed health professionals supporting families across Victoria; PANDA is in daily contact with a range of family and mental health practitioners as well as community support groups.

Victoria has long implemented policies supporting universal screening for mental illness in the perinatal period, particularly following the introduction of the National Perinatal Depression Initiative[29]. The report recent Victorian Parliamentary Inquiry in Perinatal Services further supports universal screening for anxiety and depression in the perinatal period.

These policies are intended to ensure every woman is screened for symptoms of anxiety and depression during pregnancy and following birth, using tools such as the Edinburgh Postnatal Depression Scale (EPDS) and Antenatal Risk Questionnaire (ANRQ)[30]. Screening intends to reduce morbidity resulting from perinatal mental illness by ensuring women who are at risk of, or are experiencing, perinatal anxiety and depression are identified and receive appropriate assessment, referral, treatment and follow up support. Screening programs alone, however, do not improve mental health outcomes for women[31,32]; screening programs are only effective when they are properly embedded within a system of referral and support[32,33].

Despite clear policy guidance, screening has been inconsistently implemented. Research indicates less than half of all women with perinatal depression are identified as such, and of those recognised less than half are adequately treated[34]. This is a stark indication that the issue is not one of policy, but of implementation at a service delivery level. Much faith is held in the 'best practice' administration of screening tools both antenatally and postnatally, yet insufficient consideration is given to workforce development to ensure health professionals are ready to have difficult conversations, know how to

explore sensitive and complex issues and feel confident responding when concerns are raised. This gap in confidence and skill set might be one explanation as to why so many parents experiencing perinatal anxiety and depression are not identified by care providers.

Maternal and child health nurse education

Over the past four years PANDA has received funding through the Department of Education to provide professional development and support for maternal and child health nurses to improve their capacity to effectively identify and refer parents at risk of or experiencing perinatal mental illness. It appears from our Helpline data that women residing in Victoria are more likely than those residing in other states to have shared how they have been feeling with their Maternal and Child Health Nurse. Although this is promising, the number of women who have told their care providers how they are feeling still remains worryingly low:

Table 1: Who callers have told about how they've been feeling

State of residence	Midwife	GP	MCH Nurse
Victoria	2%	15%	8%
New South Wales	3%	16%	3%
Queensland	4%	15%	3%

> 'I was deeply traumatised following the birth of my first child. In the days and weeks following I experienced PTSD symptoms [including] regular flashbacks and severe anxiety. When I asked for help from the visiting midwife or whether I could receive [debriefing] or counselling from the hospital, she told me that was not a service they offered and I needed to sort it out myself. I then supressed those feelings and over the following 9 months spiralled further and further into postnatal depression before calling PANDA for help on the verge of total breakdown. How different might my experience have been if that midwife had simply said 'yes, we can do that and yes we can support your mental health needs.'
>
> Community Volunteer

Experiences of seeking help

The experiences of PANDA Community Volunteers illustrate the difficulties regularly faced in getting support for perinatal mental illness. Many parents report multiple help-seeking attempts before they were finally able to get the help they needed. Some are lucky because they have seen a health care provider, such as a midwife or a GP, who is skilled in perinatal mental health and has been able to meet their needs. Others have not received adequate care, but have been able to access the help they need through perseverance and even self-referral to acute mental health services. These experiences bring to life the reality that a significant number of parents experiencing perinatal mental illness do not receive the help they need.

Helpline Service Knowledge

The stories shared with PANDA on a daily basis tell us that health services caring for women, babies, and their families in the perinatal period are overtly focused on physical health, with far less emphasis placed on mental health. This has a detrimental impact on the chance of prevention and early identification measures being successful. Access to early identification and appropriate supports and treatment should be universal, and not rely on parents advocating for themselves.

Callers to PANDA's Helpline are asked how long they have been experiencing symptoms before picking up the phone for help. Consistent with research findings regarding barriers to care, most callers have been unwell for more than a month before they contact PANDA. Worryingly, 11.5% of callers have been experienced symptoms for more than a year before finally accessing the help they need.

Table 2: Timing of help-seeking

< 4 weeks	41.5%
1 - 6 months	38.0%
6 - 12 months	9.0%
> 12 months	11.5%

Over 65% of Helpline callers report anxiety symptoms including engaging in significant avoidant behaviours related to the care of their baby. A mother who is unaware of the symptoms of anxiety is likely to think her anger, agitation, distress and irritability are personal flaws and indicators that she is ill-equipped to be a parent rather than a sign of anxiety. These are often persistent thoughts and it is not uncommon for callers to the Helpline Service to state *'my partner and baby would be better off without me'.*

'I presented with postnatal anxiety the day my daughter was born. No one asked how I was doing mentally after my planned caesarean birth. I left the hospital after day 2 because I felt suffocated and out of control - still, no one asked how I was doing mentally. My baby suffered horrific colic and was not sleeping, still, my maternal health nurse did not ask how I was coping mentally and just kept badgering me to make sure my baby had good sleep. I knew I was losing the battle so I went to a doctor and she said "oh, all good! Just take antidepressants- most people in your suburb are on them!"... the doctor didn't really hear me when I told her how much I wasn't coping. So I went back to another doctor and broke down in front of her. She was the first professional person to understand me. She gave me different antidepressants and suggested I see a psychiatrist who specialises in postnatal depression… the psychiatrist saved my life. He listened to me, he understood me and he helped me. I was lucky. I kept pushing and I kept seeking. I was also lucky enough to live near good resources.'

Community Volunteer

Key Recommendation

All midwives and maternal and child health nurses have a vital role to play in supporting perinatal mental health.

Fulfilling this potential requires additional training and support which values mental health and increases capacity to effectively screen and respond to perinatal mental illness in line with National guidelines.

3. What is already working well and what can be done better to prevent suicide?

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

> 'I experienced severe postnatal depression and anxiety following the birth of my son in 2016. Despite recognising it early and reaching out myself to get the help I needed, it still took too long for me to get the right level of help and by then I was both suicidal and had lost hope. Unfortunately the health care professionals weren't aware that there was a mother baby unit that I was able to access, nor that I needed that level of care, until I was critically ill. Once my son and I attended the unit I quickly received incredible care and support, ensuring I was able to return home within a few months.
>
> The mother baby unit saved my life.'
>
> Community Volunteer

Recording suicide in the perinatal period

Suicide is the leading cause of maternal death in Australia[25–28]. This is despite the fact that most women are in frequent contact with health professionals during pregnancy and early parenthood. Deaths during pregnancy and the first year after birth have reduced over time, but psychosocial deaths have sadly increased[25]. Part of the reason for this may be related to improved data collection; although it is still estimated that up to 50% of all late maternal deaths, those occurring between 42 and 356 days after birth, are not identified as such[28]. In this respect, it is possible that even more women die by suicide in the perinatal period than is currently recorded. There is an opportunity to improve recording of maternal suicide in the perinatal period so that we can better understand and respond to this tragic outcome of perinatal mental illness.

Very little is known about suicide at this time in women's lives. What we do know indicates that women appear more likely to use violent means of suicide than they do at other times of life, such as gunshot or jumping from a high place[28,35]. Use of these methods, although uncharacteristic of female suicide at other times, have been identified in both Australian and international research[36].

Key Recommendations

Reporting systems and processes should ensure deaths from suicide during pregnancy and the year following birth are identified and reported as such.

Further research is required to better understand the phenomenon of suicidality in the perinatal period, including factors protective against suicidal behaviours.

4. What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

The perinatal period is a time when most women and families are in frequent contact with health professionals, presenting regular opportunities to identify and care for those at risk of or experiencing perinatal mental illness. Referral and access to appropriate resources, including consumer informed information and treatment, should occur as needed throughout pregnancy and the first year of baby's life.

Barriers to identification and care

Although one in five women will experience anxiety and/or depression in the perinatal period, up to three quarters of women with perinatal mental illness will not be identified by their care providers[37,38].

There are a number of interpersonal and systemic barriers to parents being identified and receiving adequate care for perinatal mental illness. The design of maternity and maternal and child health systems and services has historically been driven by the physical health rather than mental health needs of women and babies. This design focus acts as an important systemic barrier to perinatal mental health care. Although the over emphasis on physical health outcomes is beginning to shift, the design of health systems has remained largely unchanged. Efforts to improve health professionals' skills and confidence relating to perinatal mental health need to be supported by efforts to improve health system design so that the mental health needs of parents and infants can be more easily met.

It is not uncommon for health professionals to report a lack of confidence in addressing issues relating to perinatal mental health. At present there is no universal mandatory perinatal mental health training for midwives, obstetricians or maternal and child health nurses working in Victoria. It is crucial that all health professionals caring for families in the perinatal period have the necessary skills, confidence, and referral knowledge to meet the needs of parents with perinatal mental illness, including how to appropriately manage suicidality. The health workforce requires additional consumer centred training and support in order to meet Victoria's perinatal mental health needs.

Barriers to specialist perinatal mental health care

It is important that parents experiencing moderate-severe mental illness have access to specialist perinatal mental health services and professionals who are aware of and responsive to the challenges and circumstances unique to the perinatal period. Non-specialised health professionals may provide advice that is not appropriate for the perinatal period. Unfortunately, families experience a number of barriers to accessing specialist health professionals. This can include extended wait time of weeks to even months, and significant out of pocket costs. These barriers are further compounded for particular populations, particularly those who live in regional and rural parts of Victoria, where there may be literally no one with perinatal expertise available to them.

'Looking back, a lot of red flags for mental illness - anxious person, difficult end stages of pregnancy, traumatic birth resulting in general anaesthetic [caesarean birth], breastfeeding issues. If appropriately trained mental health professionals were involved in perinatal care, they could have better identified my risk factors and put an appropriate care plan in place. Any checks with health professionals felt forced, uncomfortable and like they were "tick and flick"… they had to ask because there was a sheet of paper that told them to'

Community Volunteer

Key Recommendations

The key opportunity for improved perinatal mental health rests with the perinatal health professionals who care for every family in Victoria, including midwives, obstetricians, GPs, and maternal and child health nurses.

Efforts to improve health professionals' capacity to address perinatal mental illness need to be supported by innovation in the redesign of maternity and maternal child health systems and services.

5. What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

> When my daughter was 3 and half, we moved to Australia. I was 14 weeks pregnant. Despite the grief of having left behind family and friends, I was happy and excited about our new life. After my son was born, I had a lot of pain in my lower back. I could hardly walk….
>
> My husband stayed home for the first week, but then I was all on my own with my baby. From that time, I remember the contrast between the calm at home while my baby sleeps – he sleeps so well, how lucky I am! – and the inner storm of emotions and thoughts that constantly come and go, those that I don't share with anybody. There is nobody to share how I'm feeling, anyway. For the first time I really miss my friends, they would have come to visit me, to chat, to laugh together, to hold my baby, to give me a break. I feel so isolated!
>
> Community Volunteer

Supporting our diverse community

We know that families from minority communities, including those who are culturally and linguistically diverse (CALD), Aboriginal and Torres Strait Islander, and LGBTIQ+ face additional risks for perinatal anxiety and depression, and barriers to accessing safe, appropriate services. It is crucial that services supporting families in the perinatal period are responsive to this, with the ability to individualise care and support in response to these factors.

Culturally and linguistically diverse families

Each day through PANDA's Helpline Service we talk with families with different cultural and language backgrounds. From this experience we know that perinatal anxiety and depression can be exacerbated by different cultural expectations about being a new parent. We regularly talk to parents who are struggling to blend their values about being a parent in Australia with those of their own parents.

Whilst extended families often want to support a new parent through the experience of bringing a new baby into the world, sometimes this can cause tension and distress for the new parents as they negotiate their personal need to adjust to being a parent with the ideas of others around them. This can create difficulties between the new parents. We also talk to parents who are struggling because their families do not understand that mental illness is a 'real illness'.

Supporting Aboriginal and Torres Strait Islander families

It is important that health professionals and services acknowledge the historic and ongoing impacts of colonisation, dispossession and of the policies and practices that resulted in the Stolen Generations. These impacts include both intergenerational trauma and barriers to engagement with mainstream services that greatly increase the risk and impact of perinatal anxiety and depression for Aboriginal and Torres Strait Islander families. We frequently have conversations with families who have struggled to access safe and appropriate support for their mental health in the perinatal period. This is particularly difficult for Aboriginal and Torres Strait families who commonly express fear of child removal, informed by reality that Aboriginal and Torres Strait Islander children are almost 10 times more likely to be in out of home care than non-Aboriginal and Torres Strait Islander children[39].

Diverse family formations

Increasingly, children are growing up in diverse family formations, including sole parent, step-parent, blended, foster, extended and kinship families. Sole parents by choice are also an increasing population, especially following reforms that removed discrimination in access to fertility services for single people. It is important that health professionals and services are respectful of and responsive to this diversity.

LGBTIQ+ parented families

LGBTIQ (lesbian, gay, bisexual, trans*, intersex and queer) parented families in themselves are diverse in their family forms and ways of creating families. While there are many that have two mothers or two fathers, there are also many that include bisexual, trans*, gender diverse, non-binary, queer or intersex people in parenting roles parents or co-parents.

In addition to the range of risk factors for perinatal mental illness, both LGBTIQ parents and sole parents by choice face minority stress – that is, the impact of both interpersonal prejudice and institutionalised discrimination. Callers from these communities often share with PANDA counsellors a range of experiences of exclusion, judgement and prejudice from families of origin, their local communities and care providers, including maternity services, child and family health services, new parent group, GPs and even mental health clinicians.

Key Recommendation

Significant investment is required to ensure services are able to respond to family diversity, including having the knowledge and flexibility to individualise care to meet the unique mental health needs of each family.

6. What are the needs of family members and carers and what can be done better to support them?

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

'I went to a highly regarded, experienced psychologist last year who literally chuckled condescendingly as he told me that men don't experience postnatal depression'

Community Volunteer

Supporting partners as carers

It is crucial that parents supporting a partner with perinatal mental illness are also supported themselves. Parents can find themselves acting as a carer for a very unwell partner, trying to navigate an unfamiliar mental health system (often for the first time), caring for their children, and processing their own transition to parenthood. To maximise infant welfare the entire family unit needs to be supported, not just the parent who has been identified as acutely unwell.

It is also important to recognise that parent's supporting a partner with perinatal mental illness are at increased risk of a perinatal mental illness themselves[17]. In the absence of universal services providing routine care and support to partners there is a risk of perinatal anxiety and depression in non-birth parents being unrecognised and untreated. Health services and professionals caring for a parent with perinatal mental illness should routinely consider provision of information and referral for their partner.

PANDA's Helpline counsellors often 'care for the carer', by providing them with assistance to navigate the mental health system, and offering support in their own journey to parenthood. This is an easily accessible, free early intervention to reduce the possibility of a decline in the partner's mental health.

Fathers mental health

Fathers stepping into the role of primary care giver in the postnatal period, whether by choice or due to their partner's mental illness, tell us they find it difficult to access the systems designed for mothers and babies. They report that they are not equally valued as key stakeholders in their baby's wellbeing and not welcomed by maternity and child health systems. The way services are named, such as *maternal* and child health centres, can also act as powerful barriers to fathers accessing care and support.

Parental mental health is crucial for infant mental health

There is increasing recognition that poor parental mental health can have significant and long term negative impacts on physical, emotional, and developmental outcomes for children[7,15,16]. It is therefore important that the mental health of all family members is recognised as interconnected, and that all members of a family, including older children, receive mental health information and support.

Key Recommendation

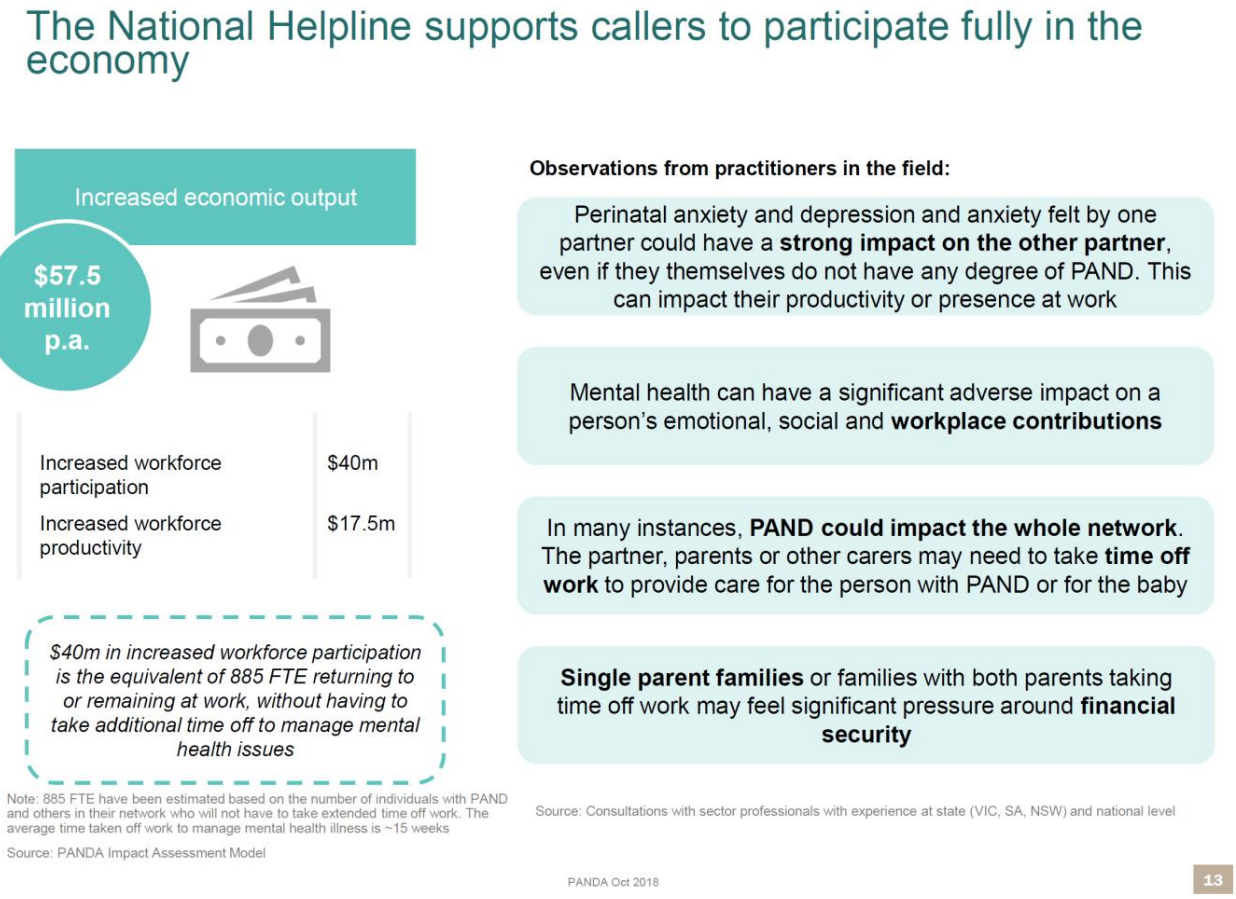
Health systems and professionals can better address the needs of families and carers by acknowledging and responding to the impact perinatal mental illness has on the entire family unit, including partners and children.

8. What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

Any intervention to improve perinatal mental health has clear immediate economic benefits for parents, and improves children's potential future social and economic participation.

In 2018 PANDA commissioned an Impact Assessment of our National Perinatal Anxiety & Depression Helpline. The intention of the report was to gain a better understanding of the impact the Helpline makes in the lives of those experiencing perinatal anxiety and depression, their family and networks, and the broader economy.



Workplace support

Workplaces can play an important role in supporting their employees' mental health during pregnancy and the transition to parenthood. This is particularly important given poor community understanding of perinatal mental illness[3], and that up to three quarters of women with perinatal mental illness are not identified by their care providers[37,38]. Parents are often in regular contact with their employers during this period, negotiating provisions such as parental leave, and changes to work hours. This presents an opportunity for employers to provide information regarding mental health in the perinatal period, and how parents can access additional support if it is needed.

9. Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

An effective perinatal mental health system starts with high quality maternity services, in which:

- Women and families are cared for by compassionate and skilled health professionals with a sound understanding of perinatal mental health and illness;
- Care providers and systems are flexible and responsive to individual parent and family needs;
- Maternity and family services have been successfully re-framed to value and emphasise emotional, mental, and physical health equally;
- Parents at increased risk of perinatal mental illness, including those with a mental health history or social isolation, are identified in pregnancy and care providers are able to put additional supports in place to reduce the chance of mental health decline;
- Parents experiencing mental health decline are identified early by their care providers, receive appropriate referrals, and receive ongoing proactive support and care;
- Specialised perinatal mental health services, including Mother Baby Units, are available as required;
- Key barriers to care, including discrimination, poverty, and geographical location have been addressed.

In preparation for this submission, we asked our Community Volunteers what their ideal perinatal mental health system would look like:

'Holistic – my experience was compounded by the lack of family support other than my husband who returned to work. For many women the role of the parents is non-existent, leaving women to manage in isolation'

'It would actively support all women during pregnancy and post birth by ensuring ongoing assessment of mental health as a standard procedure. Through this there would be education for the whole family around stigma and symptoms of perinatal mental illness. Women at high risk would receive the right intervention at the right time…'

'Open discussion from the start… checks done throughout pregnancy… given information to seek support and options available… more awareness and communication between all health professionals involved to give continuity of care'

'One that asks the mother during every stage of the process if she is doing ok or does she need support for her mental health in any way. There is way too much focus on the physical by health providers and minimal (if any) on the mental side. From the beginning post birth, debriefing should be standard…'

Key Recommendation

Maternity systems and services should be reorganised to prioritise and recognise mental health as a key determinant of maternal and infant outcomes.

10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

Any changes to the mental health system should consider centralised departmental coordination of perinatal mental health, and commit to building on the government's existing commitment to consumer engagement in the design, implementation, and evaluation of perinatal services and supports.

The Victorian Government currently has no central approach to planning, early identification, treatment, support and promotion of perinatal mental health. This is evidenced in the sporadic and at times poor uptake of research evidence and clinical practice guidelines, lack of coordination and cooperation across the state. Coordination is crucial to develop a clear understanding of the impact of perinatal mental illness, foster cooperation and support best practice.

There is an opportunity to plan across departments, health services and disciplines to support better perinatal mental health outcomes and therefore better health outcomes for the children of parents affected by this illness. There is a need to increase understanding of best practice perinatal mental health systems and services and encourage cooperative approaches to service planning and provision.

11. Is there anything else you would like to share with the Royal Commission?

Please note – due to PANDA's specific focus our response to this question relates only to perinatal mental health.

PANDA would like to acknowledge the significant commitment to mental health this Royal Commission demonstrates, and thank the Victorian Government for the opportunity to contribute to the Commission. We acknowledge the Commission's commitment to consumer engagement.

Consumer engagement

We take this opportunity to encourage the Commission to prioritise effective and meaningful consumer engagement in its recommendations for the future of Victoria's mental health system.

There is increasing global acknowledgement of the importance of involving consumers* in the development of health policy and priorities, as well as the design, implementation, and evaluation of health services and supports[40]. In order for health care to be safe and of high-quality, it needs to be consumer centred. Research evidence demonstrates that consumer centred care can improve health outcomes, and engaging in consumer partnerships has become an important part of mental health service accreditation in Australia[41,42]. Meaningful collaboration between consumers, health practitioners, policy makers, and governments can help to ensure health services and supports are accessible and effective, and improve consumer experiences[43].

Current practices in consumer engagement

At present, consumer engagement in perinatal mental health is limited at best. Many projects and research studies are undertaken without adequate consumer contributions – some do not have any form of consumer engagement. There is no coordinated system which facilitates consumer engagement in perinatal mental health planning and policy development, service design and evaluation, or research, meaning the decision whether and to what extent to involve consumers is made on a case by case basis.

Meaningful consumer engagement is a skilled and iterative process. It requires that people and organisations have access to quality training and ongoing support to facilitate consumer engagement, and resources to ensure consumers are supported and paid for their time. Without these resources and systems, meaningful consumer engagement will not be possible.

Transformative potential

Effective consumer engagement has the potential to transform perinatal mental health. Key opportunities include:

- Providing meaningful opportunities for parents to share their experiences of perinatal mental illness;
- Ensuring health planners, providers, policy makers and researchers involved in perinatal mental health are aware of and prioritise what matters to parents;
- Designing and delivering consumer centred health services;
- Improving the appropriateness, relevance, and scalability of research projects;
- Ensuring undergraduate and postgraduate education and ongoing professional development for health professionals is consumer focused.

'I am proud now to be part of PANDA and to stand gently in front of other new parents and share with them my story and give them a map of what some people experience in the perinatal period so that they don't feel the pain and shame as I once did. Talking about my experience with the other volunteers at PANDA has been a key part of my recovery and I highly recommend peer support as part of any mental health system.'

Community Volunteer

Key Recommendation

Outcomes from the Commission should ensure the Victorian perinatal mental health system has consumers at the heart of everything it does, including design, implementation, and evaluation of health professional education, health service provision, treatment and support.

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