

9 July 2020

Submission to the Royal Commission into Victoria's Mental Health System regarding parents who face a prenatal diagnosis of a congenital anomaly

Parents who receive an unexpected prenatal diagnosis of a congenital anomaly face a rollercoaster of emotions. They experience distress, at times trauma, and are at greater risk of developing mental illness. Despite the prevalence of congenital anomalies, parents often struggle to find the information and psychosocial support they need to help move through this time, and research to guide support is currently very limited. The lack of timely, appropriate support heightens the risk to the mental health and wellbeing of expectant parents. While some parents make the heartbreaking decision to end their wanted pregnancy, others continue their altered pregnancies. Stressors and mental ill-health experienced by parents at this time may also have negative, long-term impacts on the baby's neurodevelopment and postnatal outcomes.

*Through the Unexpected*¹ is a newly formed organisation intending to register as a health promotion charity. Our objective is to reduce and where possible prevent psychological distress and subsequent mental health conditions related to receiving a suspected or confirmed prenatal diagnosis of a congenital anomaly, by addressing gaps in research, policy and practice and ensuring that parents are informed, supported and empowered. Our board of directors have a wide range of expertise within health care leadership, strategy, research, law, advocacy, finance, mental health, obstetric sonography and nursing, and some directors have lived experience of receiving a prenatal diagnosis of a congenital anomaly.

Through the Unexpected acknowledges the Royal Commission into Victoria's Mental Health System is nearing completion but was moved to make this submission after noting that no other submissions, nor the Commission's Interim Report, appear to have addressed this issue, which falls within the following terms of reference:

- How to most effectively prevent mental illness and suicide, and support people to recover from mental illness, early in life, early in illness and early in episode, through Victoria's mental health system, and in close partnership with other services.
- How to deliver the best mental health outcomes and improve access to and the navigation of Victoria's mental health system for people of all ages.

This submission was prepared by two *Through the Unexpected* directors who both have lived experience of receiving a prenatal diagnosis of a congenital anomaly as well as relevant professional qualifications and experience.

¹ <http://throughtheunexpected.org>

Key recommendations

The Royal Commission should **acknowledge**:

1. The significant psychosocial impact and consequences for parents who receive a suspected or confirmed prenatal diagnosis of a congenital anomaly, which are compounded by silence and stigma.
2. The unmet psychosocial needs of parents who move through a prenatal diagnosis, leading to preventable mental health conditions.
3. The potential negative impact of unmet parental psychosocial needs on the developing baby of a continued pregnancy.

The Royal Commission should make specific **recommendations** to:

1. Address the current gaps in research, policy and practice relating to communication about a suspected or confirmed prenatal diagnosis of a congenital anomaly and to support for parents who receive such news.
2. Develop and fund targeted, evidence-informed and coordinated psychosocial supports and information services, and ensure they are available on an equitable basis across the state, so that all parents facing a suspected or confirmed prenatal diagnosis of a congenital anomaly are informed, supported and empowered.
3. Remove the silence and stigma around congenital anomalies.

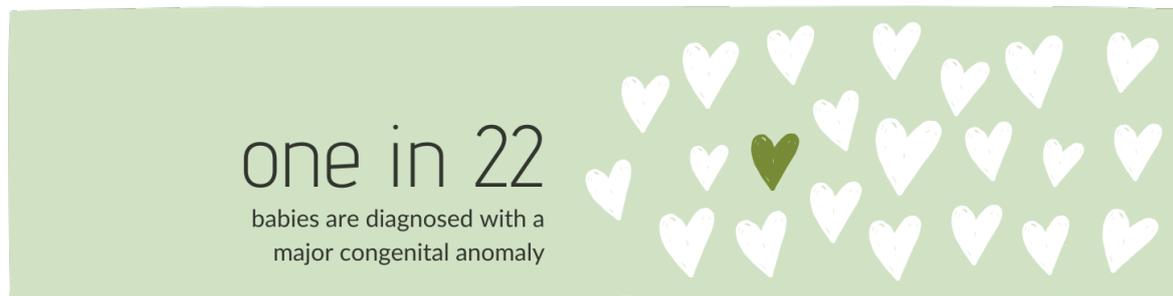
We also note and endorse the following recommendations made by Perinatal Anxiety & Depression Australia (PANDA) in its submission to the Royal Commission,² and add some qualifications to ensure the specific needs of parents facing a prenatal diagnosis of a congenital anomaly are not overlooked.

PANDA's recommendations	Qualifications
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.	Awareness campaigns should also highlight the prevalence of prenatal findings of congenital anomalies and seek to reduce fear and stigma around them.
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.	Sonographers, genetic counsellors, maternal-fetal medicine providers, midwives, obstetricians, general practitioners and others who may identify or deliver news regarding congenital anomalies should also accept their role in supporting perinatal mental health and receive additional training and support.

² SUB.0002.0030.0055_0007, July 2019.

<p>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.</p>	<p>Given the increased experience of suicidal ideation following a prenatal diagnosis, reporting systems should capture whether a suicide during pregnancy or in the year following birth is associated with a diagnosis of congenital anomaly, and this should be a priority area for research.</p>
<p>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.</p>	
<p>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.</p>	
<p>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.</p>	
<p>Maternity systems and services should be reorganised to prioritise and recognise mental health as a key determinant of maternal and infant outcomes.</p>	<p>This is particularly important in the context of prenatal diagnosis, where the developing baby's congenital anomaly may put them at greater risk of negative neurodevelopmental outcomes.</p>
<p>Responsibility for coordinating the Government's response to perinatal mental illness should be clearly identified.</p>	
<p>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.</p>	<p>We strongly endorse this and note the risk of paternalism and pregnancy care providers' personal views and values inappropriately impacting on their communication with and support for parents facing a prenatal diagnosis of a congenital anomaly.</p>

Congenital anomalies are common, and the consequences of prenatal diagnosis are not fully understood



In Victoria, one in 22 pregnancies are complicated by a major congenital anomaly.³ A major congenital anomaly is a difference in the health, development or genetics of a baby which may be associated with a changed developmental path or significant medical intervention. These differences may be identified at any point throughout the pregnancy. Congenital anomalies are one of the top three leading causes of death in the perinatal, neonatal, child and adolescent periods.⁴

The increased availability, accuracy and uptake of prenatal screening and diagnostic tools will increase the number of parents who receive a prenatal diagnosis of a congenital anomaly each year. While prenatal genomic testing may bring further information to parents, it also holds the potential for unintentional harm and anxiety.⁵ Bioethicists suggest that prenatal diagnosis alters the experience of pregnancy and, while technology such as microarray can be beneficial, it can also interfere with parents' autonomous reproductive choices, particularly when variants of unknown significance are identified.⁶ While technology, screening and diagnostic processes continue to advance, research into the experience of receiving a prenatal diagnosis, and the psychosocial needs of parents at this time, remains limited.⁷ Parents who don't receive timely and appropriate information and support following a prenatal diagnosis are likely to experience more significant and enduring mental health consequences and may be more likely to feel rushed into making significant, irreversible decisions which they are not prepared for.

Parents who face a prenatal diagnosis experience significant distress and subsequent mental health conditions

The perinatal period is a risk to any parent's mental health: PANDA's submission to the Royal Commission cited various studies to conclude that 'at least one in every five women will likely

³ Consultative Council on Obstetric and Paediatric Mortality and Morbidity, *Victorian Congenital Anomalies Register. Congenital Anomalies in Victoria 2015 - 2016*. 2018, Safer Care Victoria: Melbourne, Australia.

⁴ Consultative Council on Obstetric and Paediatric Mortality and Morbidity, *Victoria's Mothers, Babies and Children 2018*. 2019.

⁵ Werner-Lin, A., J.L.M. McCoyd, and B.A. Bernhardt, *Actions and Uncertainty: How Prenatally Diagnosed Variants of Uncertain Significance Become Actionable*. Hastings Center Report, 2019. **49**: p. S61-S71.

⁶ de Jong, A., et al., *Microarrays as a diagnostic tool in prenatal screening strategies: ethical reflection*. Hum Genet, 2014. **133**(2): p. 163-72.

⁷ Hodgson, J. and B.J. McClaren, *Parental experiences after prenatal diagnosis of fetal abnormality*. Seminars in Fetal and Neonatal Medicine, 2018. **23**(2): p. 150-154.

experience anxiety, depression or both during pregnancy and/or the year following birth'.⁸ However, the figure for parents who face a prenatal diagnosis of a congenital anomaly is likely to be significantly higher.

Receiving unexpected news about a congenital anomaly in your baby is shocking, distressing and, as various studies have shown, increases the risk of mental health conditions for parents:⁹

- A study of 165 parents found that 88% of mothers and 83% of fathers experienced prenatal diagnosis as a traumatic event.¹⁰
- One of the largest studies, with 1032 expectant mothers and 788 expectant fathers who had received a prenatal diagnosis and completed a mental health screening assessment, found 23% of women and 14% of men met the clinical cut-off for a major depressive disorder, with 50.3% showing signs of depression.¹¹
- Suicidal ideation was found to be significantly increased among women who received a prenatal diagnosis compared to other pregnant women: of the women who received a prenatal diagnosis, 16% indicated suicidal ideation after the diagnosis, 2% at time point two and 8% at time point three further along the gestation, while only 2% of women in the comparison group indicated suicidal ideation at the initial time point only and no other time points.¹²
- In another study, the full diagnostic criteria for post-traumatic stress disorder was found to be met for 35% of 40 mothers who chose to continue their pregnancies after receiving a prenatal diagnosis.¹³ Furthermore, these mothers were significantly more anxious and depressed than mothers who did not receive a prenatal diagnosis.

⁸ PANDA, *Submission to the Royal Commission into Victoria's Mental Health System* (SUB.0002.0030.0055_0007), July 2019, p 6.

⁹ Hodgson, J. and B.J. McClaren, *Parental experiences after prenatal diagnosis of fetal abnormality*. *Seminars in Fetal and Neonatal Medicine*, 2018. **23**(2): p. 150-154; Horsch, A., C. Brooks, and H. Fletcher, *Maternal coping, appraisals and adjustment following diagnosis of fetal anomaly*. *Prenatal Diagnosis*, 2013. **33**(12): p. 1137-45; Carlsson, T. and E. Mattsson, *Emotional and cognitive experiences during the time of diagnosis and decision-making following a prenatal diagnosis: a qualitative study of males presented with congenital heart defect in the fetus carried by their pregnant partner*. *BMC Pregnancy Childbirth*, 2018. **18**(1): p. 26; Bratt, E.-L., et al., *Parental reactions, distress, and sense of coherence after prenatal versus postnatal diagnosis of complex congenital heart disease*. *Cardiology In The Young*, 2019. **29**(11): p. 1328-1334; Kasparian, N.A., *Heart care before birth: A psychobiological perspective on fetal cardiac diagnosis*. *Progress in Pediatric Cardiology*, 2019. **54**: p. 1-7.

¹⁰ Aite, L., Zaccara, A., Mirante, N., Nahom, A., Trucchi, A., Capolupo, I. and Bagolan, P. *Antenatal diagnosis of congenital anomaly: a really traumatic experience?* *Journal of Perinatology*, 2011. **31**(12): 760-763.

¹¹ Cole, J. C. et al., *Identifying expectant parents at risk for psychological distress in response to a confirmed fetal abnormality*. *Archives of Women's Mental Health*, 2016. **19**(3): 443-453.

¹² Kaasen, A., et al., *Paternal psychological response after ultrasonographic detection of structural fetal anomalies with a comparison to maternal response: a cohort study*. *BMC Pregnancy and Childbirth*, 2013. **13**: p. 147-147.

¹³ Horsch, A., C. Brooks, and H. Fletcher, *Maternal coping, appraisals and adjustment following diagnosis of fetal anomaly*. *Prenatal Diagnosis*, 2013. **33**(12): p. 1137-45.

Inadequately treated prenatal mental health difficulties have significant, potentially long-term impacts – including on the developing baby

PANDA's submission to the Royal Commission described the significant impact of perinatal mental health for parents, babies and families:¹⁴

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, impaired parent-child interactions, and psychological and emotional challenges for children. 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. Parents supporting a partner with perinatal mental illness are at increased risk of developing their own mental health difficulties.

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'.¹⁵ Decades of research has identified that 'maternal prenatal stress can affect fetal brain-behaviour development and influence children's neurobehavioral trajectory, potentially increasing their risk of adverse physical and mental health outcomes'.¹⁶ The *Australian Pregnancy Care Guidelines*, the *Mental Health Care in the Perinatal Period: Australian Care Guidelines* and the Victorian Parliamentary Inquiry into Perinatal Services each discuss the risk that untreated maternal mental health poses to a developing baby. This risk is compounded for babies with a congenital anomaly, as their anomaly may already confer a higher likelihood of neurodevelopmental differences. The Royal Commission's Interim Report acknowledges that people with an intellectual or developmental disability are at increased risk of mental health conditions; while there is currently limited research, at least one researcher has suggested that maternal stress following prenatal diagnosis may be a link worth exploring.¹⁷

Significant gaps in research, policy and practice about communicating with and supporting parents regarding prenatal diagnosis

Despite the prevalence of the situation and the significant consequences at stake, the experience and support needs of parents who receive a suspected or confirmed prenatal diagnosis of a congenital anomaly remain hidden and overlooked in research, policy and practice. For example, the report of the 2018 Victorian Parliamentary Inquiry into Perinatal Services included a section on the cost of mental illness in the perinatal period but did not refer to the mental health needs of parents who experience a prenatal diagnosis, and prenatal diagnosis was not specifically noted in the sections dealing with high-risk pregnancies or mental health, and PANDA's otherwise valuable submission to this Royal Commission did not acknowledge or address the specific mental health needs of parents who face a prenatal diagnosis.

¹⁴ PANDA, *Submission to the Royal Commission into Victoria's Mental Health System* (SUB.0002.0030.0055_0007), July 2019, p 7.

¹⁵ *Ibid*, p 22.

¹⁶ Kasparian, N.A., *Heart care before birth: A psychobiological perspective on fetal cardiac diagnosis*. *Progress in Pediatric Cardiology*, 2019. **54**: p. 4.

¹⁷ *Ibid*.

There is currently limited research regarding how parents experience receiving a suspected or confirmed prenatal diagnosis of a congenital anomaly and how they can best be informed, supported and empowered so as to reduce their distress and other adverse consequences. This means there is a significant knowledge gap regarding effective interventions for psychosocial support for parents who move through a prenatal diagnosis.¹⁸ There is also a dearth of literature about the diverse experiences and support needs of particular cohorts of parents facing a prenatal diagnosis, including those who may be at even greater risk of adverse mental health and other consequences, such as women experiencing family violence, parents within non-heteronormative relationships, parents in rural or regional areas, Aboriginal and Torres Strait Islander parents and parents from other culturally and linguistically diverse backgrounds.

Understanding how to prevent distress and harm in this context is an even greater gap. One study found that, when women were provided with a high level of person-centred support following a prenatal diagnosis (including a consistent team that provided prenatal counselling and undertook mental health assessments, and a specialist psychologist who provided person-centred support around the parents' concerns and worries), anxiety levels reduced over the course of those pregnancies to fall in line with women who had not received a prenatal diagnosis.¹⁹ While further research is needed, this highlights the potential for appropriate communication and support to reduce or even prevent longstanding mental health conditions associated with prenatal diagnosis. However, this level of care is not currently available or provided as standard across Victoria.

As a consequence of this research and knowledge gap, the issue receives limited attention in policies, guidelines and training for professionals working in the field. National, consensus-based recommendations developed by the Human Genetics Society of Australia and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (HGSA/RANZCOG) for care when a 'significant condition' has been detected prenatally recommend providing timely information and the opportunity to undertake counselling about the nature of the anomaly, expected prognosis, the likelihood of reoccurrence and care pathways, along with time and support to decide the future of the pregnancy.²⁰ However, they do not provide specific, practical guidance on how to go about communicating the information and discussing the issues in a supportive and empowering way (and, in the absence of relevant research, they cannot be evidence-informed on this point).

Furthermore, while the HGSA/RANZCOG recommendations state that women should be 'assure[d]' that 'they will be offered counselling and support' whether they choose to continue or end their pregnancy, this support is offered inconsistently and inequitably across Victoria. We note that the *Mental Health Care in the Perinatal Period: Australian Care Guidelines*²¹ do not acknowledge the

¹⁸ Hodgson, J. and B.J. McClaren, *Parental experiences after prenatal diagnosis of fetal abnormality*. Seminars in Fetal and Neonatal Medicine, 2018. **23**(2): p. 150-154.

¹⁹ Kaasen, A., et al., *Paternal psychological response after ultrasonographic detection of structural fetal anomalies with a comparison to maternal response: a cohort study*. BMC Pregnancy And Childbirth, 2013. **13**: p. 147-147.

²⁰ HGSA/RANZCOG Joint Committee on Prenatal Diagnosis and Screening, *Prenatal assessment of fetal structural conditions: C-Obs 60*. 2018.

²¹ Austin M-P, Highet N and the Expert Working Group (2017) *Mental Health Care in the Perinatal Period: Australian Clinical Practice Guideline*. Melbourne: Centre of Perinatal Excellence.

unique needs of, nor provide any guidelines on how to support, parents who receive a suspected or confirmed prenatal diagnosis.

Despite awareness of the significant influence of communication at this emotionally charged time, the majority of professionals who may need to deliver unexpected news of a congenital anomaly to parents have had no training in how to go about this.²² Until recently, there were no specific training options for health professionals or therapists working with parents who receive a suspected or confirmed diagnosis of a congenital anomaly. A single online module has recently been added to the training available through the Centre of Perinatal Excellence (COPE), however this appears to be focused around supporting parents who have had a termination of pregnancy, which means there is still a training and practice gap around supporting parents to become informed and make decisions regarding their pregnancy, and for supporting parents who choose to continue their pregnancy, following a prenatal diagnosis. One of *Through the Unexpected's* directors recently assisted COPE in adding some information to its website about coping with unexpected news during pregnancy,²³ however, this information is aimed at parents.

The lack of specific training and support for health professionals who may be required to give unexpected news to parents in the prenatal period has been suggested to lead to compassion fatigue and burn out,²⁴ which then holds consequences for parents. Clinicians have expressed their interest in further training and support on this issue.²⁵ The Australasian Sonographer's Association submission to the Victorian Parliamentary Inquiry into Perinatal Services noted the need for training and support in relation to the communication of unexpected news regarding a congenital anomaly.²⁶ While the final report of that inquiry included recommendations about training for bereavement and loss,²⁷ no recommendations were made regarding the communication of unexpected findings that were not associated with fetal demise.

Existing psychosocial support and information services for parents facing a prenatal diagnosis in Victoria are limited, uncoordinated and inadequate

In its submission, PANDA noted that:²⁸

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

²² Thomas, S., K. O'Loughlin, and J. Clarke, *Factors that Influence the Communication of Adverse Findings in Obstetrics: A Survey of Current Sonographer Practices in Australia*. Journal of Diagnostic Medical Sonography, 2020. **36**(3): p. 199-209.

²³ <https://www.cope.org.au/expecting-a-baby/staying-well/coping-with-unexpected-news-at-your-ultrasound/>

²⁴ Menezes, M.A., et al., "Taking its toll": the challenges of working in fetal medicine. Birth 2013. **40**(1): p. 52-60.

²⁵ Thomas, S., K. O'Loughlin, and J. Clarke, *Factors that Influence the Communication of Adverse Findings in Obstetrics: A Survey of Current Sonographer Practices in Australia*. Journal of Diagnostic Medical Sonography, 2020. **36**(3): p. 199-209; Menezes, M.A., et al., "Taking its toll": the challenges of working in fetal medicine. Birth 2013. **40**(1): p. 52-60.

²⁶ Australasian Sonography Association. *Submission to the Inquiry into Perinatal Services* (SUB S100), January 2018.

²⁷ Parliament of Victoria, *Inquiry into Perinatal Services: Final report*, June 2018, pg. 138, recs 3.4 and 3.5.

²⁸ PANDA, *Submission to the Royal Commission into Victoria's Mental Health System* (SUB.0002.0030.0055_0007), July 2019, p 8.

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.

It is even more difficult for parents facing a prenatal diagnosis of a congenital anomaly to access appropriate psychosocial support. Within Victoria, multidisciplinary fetal medicine teams are only located within specialist tertiary hospitals in Melbourne; therefore, rural and regional parents receiving a prenatal diagnosis are less likely to receive coordinated or effective supports than metropolitan parents. One *Through the Unexpected* director (who has published a full narrative and analysis of her experience²⁹) can speak of her lived experience on this point:

I was living in a regional area when I learned, at 32 weeks pregnant, that my baby's brain had developed differently. I attended appointments in the city but was not offered genetic counselling or psychosocial support. Despite being a mental health nurse, I significantly struggled in the postnatal period and self-referred to a mother-baby unit, only to be denied admission as my daughter's anomaly was unknown to them and, therefore, brought unknown risk.

Expectant parents who receive a suspected or confirmed prenatal diagnosis need timely access to a range of information and supports to come to terms with the diagnosis, make decisions regarding the management of their pregnancy and protect their mental health. However, while there are a number of otherwise-helpful pregnancy, mental health and diagnosis/disability-specific services and organisations which may provide some assistance, there are limitations to each of these in this context:

- The Pregnancy, Birth and Baby helpline acknowledges that support for prenatal diagnosis is not in their scope and have informed us that they would simply refer callers to Lifeline.
- PANDA does support families affected by prenatal anxiety and depression. We are currently in communication with PANDA to better understand their level of experience in assisting parents who have received a suspected or confirmed prenatal diagnosis and the support they may provide, but note that PANDA's website, which provides information and resources on many topics and risk factors related to perinatal mental health, contains no specific information or resources relating to prenatal diagnosis. Being focused exclusively on mental health, PANDA is not well-placed to inform and support parents who have just received a prenatal diagnosis but are not (yet) experiencing mental ill-health.
- SANDS and Pink Elephants, which support parents through miscarriage, stillbirth and neonatal death, provide information about termination of pregnancy for medical reasons on their websites and offer support to parents during or after such a termination. However, these organisations are not well-placed or appropriate to support parents who have just received information about a congenital anomaly and who have not yet made any decision regarding their pregnancy.

²⁹ Shakes, P. and A. Cashin, *Mental health nursing and the prenatal diagnosis of a congenital anomaly; a narrative of experience*. Journal of Psychiatric and Mental Health Nursing, 2020.

- Parents may be able to gain valuable information and support from diagnosis/disability-specific organisations, including the opportunity to speak with peer workers or other parents who have been in their situation and to find out about supports that may be available to assist them to care for their child. However, this can only occur once the parents have received a definite, specific diagnosis (which may not be possible during pregnancy) and have located a relevant organisation. Evidence suggests that parents are not routinely referred to such groups, which means that crucial information about the lived experience and potential quality of life associated with their baby's condition, which is so important for informing decisions about how they manage their pregnancy and prepare for parenthood, is often not available.³⁰

There are a few other ways that parents may be able to access some mental health support during pregnancy but again, these are either inadequate or not equitably accessible for all Victorians in this situation:

- Mothers may access up to three, 30 minute MBS-rebated pregnancy support counselling sessions. At present, there is no data to suggest that parents are aware of this and can find providers to deliver non-directed support, or about the type of service provided. Furthermore, this support is not available to fathers. It is unlikely that this limited support, even if extended through a Mental Health Care Plan, would be adequate.
- Mothers who meet the eligibility guidelines may receive support through Perinatal Emotional Health Programs (PEHP). While PEHP may support mothers with the most heightened mental health concerns following a prenatal diagnosis, this does not help to prevent mental health conditions from taking hold nor help the many women or all fathers who would not qualify for the programs.
- There are private practitioners who provide support that may span the perinatal and childhood period, enabling continuity of care – an aspect of best practice support that is often disrupted when a prenatal diagnosis has been made. However, these services are private billing and therefore not equitably accessible to all Victorians.

Services or practitioners (particularly those with specialised experience) often have long waitlists, which may be a further barrier to accessing effective support at the time when it is most needed. Many parents are presented with the option to terminate their pregnancy following a suspected or confirmed prenatal diagnosis, and sometimes have very limited time to make this decision due to legal and clinical considerations. Not being able to gain immediate access to an appropriate service means that parents are left to make irreversible decisions of tremendous emotional importance and toll without the supports and information they need. The ramifications and consequences for their mental health in this situation may be catastrophic.

³⁰ Marokakis, S., N.A. Kasparian, and S.E. Kennedy, *Parents' perceptions of counselling following prenatal diagnosis of congenital anomalies of the kidney and urinary tract: a qualitative study*. BJU International, 2017. **119**(3): p. 474-481.

Furthermore, research suggests some parents do not seek help or may even decline mental health-specific services initially. As PANDA notes:³¹

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.

Shame and stigma can be even more powerful barriers for parents who receive a prenatal diagnosis: they may perceive societal shame and stigma in relation to their baby's (suspected) diagnosis and potential disability, as well as in relation to the option to terminate the pregnancy, all of which compounds their own complicated and potentially conflicting feelings. The (perceived) need to prioritise their own, and their baby's, physical health may also prevent parents from seeking psychosocial support at this time or from persevering with support which does not fully meet their needs. It is reasonable to expect that parents who have received a suspected or confirmed prenatal diagnosis would be more likely to access and benefit from a specific support line or service targeted to their unique situation than a general pregnancy or mental health service. However, no such service currently exists.

Action is needed to protect the mental health and wellbeing of expectant parents and their unborn children now

Appropriate communication and support have the potential to significantly reduce the distress that comes with a suspected or confirmed prenatal diagnosis of a congenital anomaly and may even prevent mental health conditions from emerging. However, given the paucity of research, pregnancy care providers and psychosocial support services (where they are available) are unlikely to understand how to most effectively support parents in this uniquely complex situation. While COPE and PANDA are wonderful organisations leading the way within perinatal mental health and support, prenatal diagnosis is not their focus. To protect the mental health and wellbeing of expectant parents and their unborn children, it is imperative that:

- The current gaps in research, policy and practice are highlighted and addressed;
- Targeted, evidence-informed and coordinated supports are funded and made available on an equitable basis across the state; and
- The silence and stigma around congenital anomalies are removed.

If you would like to discuss this submission, please contact *Through the Unexpected's* director, Pieta Shakes: throughtheunexpected@gmail.com

³¹ PANDA, *Submission to the Royal Commission into Victoria's Mental Health System* (SUB.0002.0030.0055_0007), July 2019, p 3.