

14 December 2022

Submission to the Inquiry into Universal Access to Reproductive Healthcare

*Through the Unexpected*¹ is a health promotion charity founded to improve the psychosocial outcomes of parents who receive the news that their unborn baby has a difference in their health, development or genetics. We are the only organisation in Australia that exists with the specific focus on improving psychosocial outcomes for parents who receive any type of prenatal diagnosis and walk any path through the unexpected. As a volunteer led charity, we do not yet have the capacity or funding to provide direct parent services, unlike the UK government funded service, Antenatal Results and Choices. Instead, our activities function to build the capability of existing organisations and health and allied health professionals to provide trauma-informed, parent-centred care to parents who receive a prenatal diagnosis. We also advocate for recognition and reduction of the striking gaps in psychosocial support for parents who receive a prenatal diagnosis of a fetal anomaly or variation.

In Australia, hopeful and expectant parents have access to government funded antenatal screening and can pay for additional screening tests. We understand there are barriers to universal access to antenatal screening and information for making informed decisions about antenatal screening, yet our organisation focuses on the aftermath of screening. As such, in this submission we focus attention on the access to reproductive healthcare when a high chance screening result or a confirmed genetic or structural fetal anomaly is identified during pregnancy.

Key recommendations:

The Committee should **acknowledge**:

1. The significant psychosocial impact and consequences for parents who receive a suspected or confirmed prenatal diagnosis of a fetal anomaly or variation, 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.
4. That best practice reproductive healthcare must include attention to the psychosocial aspects of prenatal diagnosis.

The Committee should make specific **recommendations** to:

1. Address the current gaps in research, policy and practice standards relating to the psychosocial aspects of prenatal diagnosis.
2. Develop and fund targeted, evidence-informed and coordinated psychosocial support and information services, and ensure they are available on an equitable basis across the country so that all parents facing a suspected or confirmed prenatal diagnosis of fetal anomaly or variation are informed, supported and empowered.

¹ www.throughtheunexpected.org.au

3. Remove the silence and stigma around congenital anomalies.

The incidence of parents receiving a high-chance screening finding or a prenatal diagnosis is currently unknown. State and territory based congenital anomaly registers do not record high chance findings and mandatory reporting of confirmed anomalies is typically only required from 20 weeks gestation. The most recent available report from Victoria suggests that 1 in 22 babies has a major congenital anomaly. A major anomaly is classified as a structural or genetic anomaly that is associated with morbidity, mortality or disability. Unfortunately, this report is from 2015-16 period as there is a lag in reporting, similar to the reporting by the Australian Institute of Health and Welfare in which 2016 was the most recent year reported.

Despite the significant limitations of these reports, we know that;

- Over 8,900 (3%) of babies born in 2016 had a congenital anomaly which had significant medical, social or cosmetic outcomes,²
- Congenital anomalies are the most common cause of perinatal death.³
- Antenatal screening technology has advanced faster and gained more attention and funding than the psychosocial implications and supports for parents who receive a high chance screening finding or a prenatal diagnosis.⁴ This lack of attention on the psychosocial impacts is also reflected by the:
 - single recommendation in the national Clinical Practice Guidelines: Pregnancy Care⁵ to refer women to trained professionals for counselling and ongoing support. This recommendation fails to provide specificity about psychosocial support, as prenatal counselling is information giving about the diagnosis and expected prognosis⁶ rather than therapeutic counselling. Furthermore, the guidelines recommend a service and booklet that is no longer available.
 - lack of consideration of the psychosocial impacts in the economic analyses related to antenatal screening.⁷
 - initial draft of the Stillbirth Clinical Care Standards did not include fetal anomalies in the tabled risks of stillbirth or recommend support for parents who receive a prenatal diagnosis of a life-limiting anomaly. We are pleased to report the final Standard did include prenatal diagnosis and understand our formal response may have contributed to this change. Nonetheless, there remains no specific recommendations about psychosocial support or key indicators related to the psychosocial aspects of prenatal diagnosis.

² Australian Institute of Health and Welfare. (2022). *Congenital anomalies 2016*.

³ Australian Institute of Health and Welfare. (2002). *Australia's mothers and babies*.

⁴ Hodgson, J. & McClaren, B.J. (2018). Parental experiences after prenatal diagnosis of a fetal abnormality. *Seminars in Fetal & Neonatal Medicine*, 23, 150-154.

⁵ Australian Government Department of Health. (2020). Clinical practice guidelines: Pregnancy Care.

⁶ Kratovil, A.L. & Julion, W.A. (2017). Health-care provider communication with expectant parents during a prenatal diagnosis: an integrative review. *Journal of Perinatology*, 37, 2-12.

⁷ Australian Government Department of Health. (2018). *Clinical practice guidelines: Pregnancy care, economic analyses*.

- no data capture and reporting of psychosocial outcomes of women and families who have receive unexpected news.
- no funding to include the impact of prenatal diagnosis in the update of the Mental Health Care in the Perinatal Period guidelines, as identified on Page 1.⁸
- lack of recommendations and action despite submissions to *the Victorian Inquiry into Perinatal Services* which highlighted the lack of relevant, accurate information to base important decisions, lack of appropriate support for those who receive a prenatal diagnosis of a life-limiting condition and continue pregnancy, inadequate care provision at the time of undergoing a termination of pregnancy⁹ and concerns from sonographers about harming parents through inattention to the communication of unexpected news.¹⁰

This overlooked nature of the psychosocial consequences of antenatal screening and diagnosis presents a significant barrier to universal access to sensitive, parent-centred and trauma-informed healthcare that addresses the psychosocial needs of parents who receive a high-chance screening finding or prenatal diagnosis.

Specifically, this inquiry seeks to address barriers to achieving the priorities under the National Women's Health Strategy for 'universal access to sexual and reproductive health information, treatment and services that offer options to women to empower choice and control in decision-making about their bodies'.

The National Women's Health Strategy¹¹ does not specifically reference women who receive a prenatal diagnosis – again highlighting the overlooked nature of this experience. However, this area of significant need and emerging priority will need to be intentionally and comprehensively addressed to achieve the *Priority area 1 – Maternal, sexual and reproductive health* aligning with actions that *promote access to resources and information; address community awareness of under recognised reproductive conditions and risk factors; remove barriers to equitable access to timely, appropriate and affordable care for all women including culturally and linguistically sensitive and safe care; and strengthen access pathways to reproductive health services across the country.*

Cost and accessibility of reproductive healthcare, including pregnancy care and termination services across Australia, particularly in regional and remote areas;

Specialist fetal medicine clinics are located in metropolitan areas across Australia. Women from regional and remote areas are required to travel to clinics for appointments. While there may be

⁸ Consultation draft guideline: Mental health care in the perinatal period, Australian clinical practice guideline. 2022 revision.

⁹ Hodgson et al., Submission S073, Family and Community Development Committee.

¹⁰ Parliament of Victoria: Family and Community Development Committee. (2018). Inquiry into perinatal services: Final report.

¹¹ Commonwealth of Australia as represented by the Department of Health. (2018). *National women's health strategy 2020-2030*.

options to adopt virtual care models, there is a need for further research regarding women's perspectives and experiences due to evident concerns and barriers.¹²

From communication with parents who have received a prenatal diagnosis, we know that there are striking differences in care based on your location. There are also challenges with access to termination within some public hospitals with religious affiliations. Receiving a prenatal diagnosis can cause shock and distress, with emerging research suggesting the news can also trigger a dissociative response. Despite this acute stress, women and their families may be expected to travel long distances for healthcare, or to locate different services that provide the full spectrum of reproductive healthcare. This need can significantly increase distress, isolation and trauma.¹³

Workforce development options for increasing access to reproductive healthcare services, including GP training, credentialing and models of care led by nurses and allied health professionals;

At present, there is no specific multidisciplinary training for addressing the psychosocial needs of parents who have received a prenatal diagnosis of a fetal anomaly or variation. The varied experiences and pathways of parents who receive a prenatal diagnosis are not universally explored in entry-to-practice midwifery training¹⁴ and are likely to be overlooked in training of other professions. Prenatal diagnosis is not included within the short training modules which professionals complete before access to the MBS *non-directive pregnancy counselling* item number.

This lack of specific training means that the single recommendation in the Clinical Practice Guidelines: Pregnancy Care, to refer to trained professionals, cannot be met universally. The lack of specific training or credentialing increases the risk of harm and the risk for the psychosocial support needs of parents to be overlooked. This is an urgent priority given the continually expanding screening technologies.

Through the Unexpected secured limited non-government funding to codesign and deliver evidence-informed online training that begins to address this striking gap.

Best practice approaches to sexual and reproductive healthcare, including trauma-informed and culturally appropriate service delivery;

Best practice reproductive healthcare in relation to prenatal screening and diagnosis would ensure that parents had access to trauma-informed and ongoing support during and beyond the prenatal diagnosis. There is no universal access to this type of healthcare.

¹² Potenza et al. (2021). Business as usual during COVID-19 pandemic? Reflections on state-wide trends in maternity telehealth consultations during lockdown in Victoria and New South Wales. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 61(6), 982-985.

¹³ Booker, C. (2022, October 8). When the pain of losing a baby is doubled by a lack of care and support. *The Age*.

¹⁴ Browning, N.K & Henry, A. (2020). Supporting families after the diagnosis of a life-limiting foetal condition: How are Australian student midwives being prepared? *Journal of Paediatrics and Child Health*, 56(1). 55-135

As previously noted, there is a lack of attention to the psychosocial support in current guidelines and standards.

After a high chance result is identified by genetic screening, many parents receive a phone call with the results and are offered an appointment for invasive testing. Some parents have shared their stories of feeling pushed into further testing.

After the identification of a structural anomaly through ultrasound, the care provided is also not universal. Some parents are notified of the anomaly by the sonographer or ultrasound practitioner at the time, some are informed by the overseeing radiologist, and some leave their ultrasound appointments unaware of the findings. The Australasian Society of Ultrasound in Medicine (ASUM) produced guidelines about parent-centred communication in obstetric ultrasound, however, there remain many barriers to the implementation of these guidelines. Ultrasound services in Australia do not have universal policies and procedures in relation to the communication of unexpected findings and there are different interpretations of who should and should not inform parents.¹⁵ The consequence is disjointed care and no minimum standards of care that parents can expect, some parents are provided exceptional care while others are not.

After the identification of a suspected anomaly, many parents are referred to fetal medicine clinics which are located in metropolitan areas only. Fetal medicine clinics are multidisciplinary and aim to provide time limited reproductive healthcare that centres on diagnosis, prognostication and the reproductive options. In-progress research suggests that some providers in fetal medicine understand their scope of practice to be specifically focused on the fetal anomaly rather than the psychosocial outcomes of the parents. We are also aware of other providers in fetal medicine who place a high priority on the wellbeing of parents and provide exceptional care, however even in this setting, care can be time limited, and for many parents will be a single appointment for many parents.

Research continually highlights the acute and enduring psychosocial challenges experienced by parents who have received a prenatal diagnosis of a fetal anomaly or variation, such as;

- 88% of mothers and 83% of fathers experienced prenatal diagnosis as a traumatic event.¹⁶
- Suicidal ideation was significantly more prevalent in mothers who received a prenatal diagnosis than mothers with a typically-developing baby.¹⁷
- 39% of mothers who continued their pregnancies met full diagnostic criteria for PTSD,¹⁸ and 85% experienced ongoing symptoms.¹⁹

¹⁵ Thomas, S. et al. (2017). Sonographers' communication in obstetrics: Challenges to their professional role and practice in Australia. *Australasian Journal of Ultrasound in Medicine*, 23, 129-139.

¹⁶ Aite, L. et al. (2011). Antenatal diagnosis of congenital anomaly: a really traumatic experience? *Journal of Perinatology*, 31(12), 760-763

¹⁷ Kaasen, A. et al. (2017). Maternal psychological responses during pregnancy after ultrasonographic detection of structural fetal anomalies: A prospective longitudinal observational study. *PLoS One*, 12(3), e0174412.

¹⁸ Rychik, J. et al. (2013). Maternal psychological stress after prenatal diagnosis of congenital heart disease. *Journal of Pediatrics*, 162(2), 302-307 e301.

¹⁹ Horsch, A. et al. (2013). Maternal coping, appraisals and adjustment following diagnosis of fetal anomaly. *Prenatal Diagnosis*, 33(12), 1137-1145.

- Anxiety after a prenatal diagnosis was rated as moderate to severe in 1 in 2 women.²⁰
- At 6 weeks and 6 months postpartum, parents who received a prenatal diagnosis reported significantly increased psychological distress compared to parents who received a postnatal diagnosis.²¹
- A 'high chance' screening result impacts long-term mental health even when the baby does not have an anomaly.²²
- An Australian based study about the experience of decision-making after a prenatal diagnosis found that many of the 102 parents interviewed felt unsupported immediately after receiving the unexpected news.²³
- Anxiety, depression and PTSD symptoms are frequent in the early stages of a pregnancy following a TFMR.²⁴

While many fetal medicine clinics may have mental health professionals in the wider team, referral or engagement with these professionals is typically an optional extra which requires parental request. Many parents do not specifically recognise their acute mental health challenges at the time, which can be understood within the context of acute stress, shock and distress. Along with limited recognition in an acute state of distress, barriers to accessing mental health branded supports may relate to the conceptualisation and awareness of perinatal mental health support, where there is a large focus on perinatal anxiety and depression and a gross lack of representation and normalisation of the emotional turmoil of prenatal diagnosis. Parents may wonder how a mental health professional may help them through a prenatal diagnosis or the relevance of approaches used. Prenatal diagnosis did not present in any of the official stories or awareness days of the recent 2022 Perinatal Mental Health Week campaign.

The lack of perinatal mental health service recognition of parents who receive a prenatal diagnosis may relate to the assumption that parents receive psychosocial support through fetal medicine and their current care providers. While parents receive prenatal counselling, this type of counselling is largely information giving rather than emotional support or therapeutic counselling, as mentioned. Genetic counselling aims to bridge this gap, however some parents do not see a genetic counsellor, or it can be session limited and recent discussions have surfaced the limited attention to trauma-informed practice within genetic counselling training or the nuances between the prenatal space versus other areas of genetic counselling practice.

²⁰ Fontoura, F. C. et al. (2018). Anxiety of mothers of newborns with congenital malformations in the pre- and postnatal periods. *Revista Latino-Americana De Enfermagem*, 26, e3080-e3080.

²¹ Skari, H. et al. (2006). Prenatal diagnosis of congenital malformations and parental psychological distress—a prospective longitudinal cohort study. *Prenatal Diagnosis*, 26(11), 1001-1009

²² Kristjansdottir, H., & Gottfredsdottir, H. (2014). Making sense of the situation: women's reflection of positive fetal screening 11-21 months after giving birth. *Midwifery*, 30(6), 643-649.

²³ Hidgson J. et al. (2016). Experiences of prenatal diagnosis and decision-making about termination of pregnancy A qualitative study. *Australian and New Zealand Journal of Obstetrics and Gynaecology*.

²⁴ Beauquier-Maccotta, B. et al. (2022). Prenatal attachment, anxiety and grief during subsequent pregnancy after medical termination of pregnancy. Attachment to which child? *Journal of Gynecology Obstetrics and Human Reproduction*, 51, 102353.

After a prenatal diagnosis and during prenatal counselling, parents are often given the option to continue or end their pregnancy. The care at this time influences decision-making and psychosocial outcomes, yet there is no universal access to non-directive pregnancy counselling where the focus is on supporting parents through decision-making drawing upon their individual values, understanding and conceptions of family and quality of life. Very few parents access this type of support, limited to those who may already be linked with therapists or who have capacity to locate and afford such support. There are two relevant MSB supported options to reduce the fee for parents, however both are limited in relation to access for distress related to prenatal diagnosis. Better Access eligibility is limited to the specified *categories of mental health behavioural disorders* of the Diagnostic and Management Guidelines for Mental Disorders in Primary Care. None of the included diagnoses fit well with acute distress related to unexpected news in pregnancy and some parents may not wish for specific mental disorders to be on their medical record. The other MBS option, for *non-directive pregnancy counselling* is underutilised and was intended and marketed for unplanned pregnancy counselling. Furthermore, attempting to find therapists to deliver this service is challenging as many do not advertise such option. Reaching out to provider can be very difficult when decision making, because of the unknown of the type of response that will be received, the discussed challenge of the recognition of the need and benefit, the sheer impact of distress on executive functioning and the urgency.

Therefore, parents who receive a prenatal diagnosis through antenatal screening do not have universal access to trauma-informed information and services.

There are vital support services for parents who have undergone a TFMR, including Red Nose, SANDS and The Pink Elephants. There is also a consumer led service in Queensland delivering practical supports to parents who receive a poor fetal diagnosis or have pregnancy complications, Harrison's Little Wings. These services provide essential supports to particular groups of parents who receive a prenatal diagnosis, mainly providing support after bereavement. The signposting or referral to these supports is not currently universal.

There is a lack of universal access to information and services for parents who continue their pregnancies, particularly the less known anomalies or those that will not be treated through surgery in infancy. The identification of an anomaly means significant changes to the pregnancy even for parents who continue their pregnancy. These changes often mean the loss of continuity of care, loss of maternity care, a medicalised focus on pregnancy and birth, loss of control and decision-making, loss of birthing plans and hopes, birthing in different locations that may be far from home and the potential for more interventions in birth. On a personal level, the pregnancy can also be changed, and some parents may struggle to bond, may find challenges in preparing for baby and typical pregnancy milestones can become triggers.

The decision to continue a pregnancy can typically end fetal medicine care involvement. There are no universal services to support parents' psychosocial health during this time moving towards birth. Parents can be isolated during this time, while still experiencing many triggering factors and carrying lots of uncertainty. There are no guidelines or standards to guide best practice support for this group of parents, thus increasing the risk of poor psychosocial health outcomes. This gap in services poses a risk to the baby. There is a growing body of literature that suggests there are consequences to the ongoing distress after a prenatal diagnosis, suggesting changes in fetal brain development, postnatal

outcomes and developmental trajectory of babies within continued pregnancies. Best practice reproductive healthcare must include psychosocial support for parents who receive a prenatal diagnosis, without this, antenatal screening programs pose risks to women and families.

There is also a likely gap in culturally sensitive practice, assumed by the significant lack of research in this area. There is no literature to unpack the experiences and needs of Aboriginal and Torres Strait Islander families who receive a prenatal diagnosis or other marginalised groups of women in Australia.

Experiences of people with a disability accessing sexual and reproductive healthcare;

The current lack of training and guidelines about sensitive and person-centred information and support related to prenatal screening and diagnosis increases the risk of harm to people with a disability or health condition. Medical and health professionals are trained to view differences as deficit and risk. Screening programs focus on identifying this difference and altering to the “risk” of difference. The availability of screening and termination at any stage of gestation after identification of a major anomaly, while essential for person-centred care and reproductive options, also serves to perpetuate the underlying assumption that difference should be avoided and a fetus with an anomaly. Unfortunately, these underlying values can result in care that harms people, particularly disabled people and those with differences and conditions.

The inherent values that underline screening then consequently result in language and terminology that is value-based. Screening reports show hazard symbols and use words altering to “high risk”. This language is also carried over into care both in the antenatal and postnatal space, and has been shown to have a detrimental impact on psychosocial outcomes of parents. The underlying values that some practitioners hold can result in the pressure to make certain decisions, such as to terminate a fetus with a particular anomaly. This pressure is identified in global research, within Australian surveys and our organisation has had direct contact with parents who have felt pressured into invasive testing or termination. Furthermore, the underlying values may mean that parents are provided with incorrect, outdated or limited information of which to use to empower their choice and control in decision-making. For example, many parents wish to be connected to peers and patient support organisations after a prenatal diagnosis, however, many do not receive this.

People affected by a disability, personally or familial, often have a strong understanding of the impact that the society has in relation to their health and wellbeing, the Social Model of Disability. Thus, there can be a very different conceptualisation of disability and quality of life between providers and parents. This difference may contribute to the well documented discordance between the information and support that parents seek after receiving a prenatal diagnosis, and the information and support provided.

The underlying difference in values has the potential to cause significant harm to disabled people and their families.

Availability of reproductive health leave for employees; and

Pregnancy typically includes many appointments. Parents who have received a prenatal diagnosis often have an increased number of appointments to attend, some which will require significant

travel to metropolitan located fetal medicine clinics. For many, these appointments can also trigger stress and trauma related symptoms such as panic attacks, sleeplessness and general anxiety. As noted, many women experienced significant daily distress, particularly while decision-making and well-meaning, typical pregnancy related comments from work colleagues can thrust parents into distress. Hence, it is understandable that for many, returning to work following a diagnosis can be very difficult.

Despite this difficulty, we are yet to identify workplace reproductive leave policies that specifically note prenatal diagnosis. There have been some wonderful changes which have gained significant media attention, related to the inclusion of leave for loss or for fertility treatment. However, neither of these additions cover the period after prenatal diagnosis.

The added complexity parents face is the stigma related to their choices. Parents can feel and be judged for their decisions, and there is both stigma related to termination, and related to continuing a pregnancy with a baby with a congenital anomaly. Parents who receive a prenatal diagnosis often already hold concerns about their ability to return to work if their baby requires significant care after birth, thus the potential responses from employers would present barriers to sharing their circumstances with employers. This leaves parents in an inequitable predicament to use other types of leave, if available and if approved.

We thank you for the opportunity to bring attention to the inequitable access to holistic reproductive healthcare that informs, supports and empowers women and their families through a prenatal diagnosis.

**If you would like to discuss this submission, please contact Pieta Shakes- Executive Director:
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