

Submission  
No 246

## INQUIRY INTO BIRTH TRAUMA

**Organisation:** Through the Unexpected

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## Submission to the Inquiry into Birth Trauma

*Through the Unexpected*<sup>1</sup> 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 and we aim to improve the experience for parents in New South Wales. 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<sup>2</sup>. 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, such as non-invasive prenatal testing (NIPT). Psychosocial support after receiving a high-chance screening finding or a prenatal diagnosis of a fetal anomaly is systemically overlooked, resulting in inequitable or inappropriate service delivery which increases the prevalence of birth trauma.

### Key recommendations:

The Committee should acknowledge:

1. The prenatal diagnosis of a fetal anomaly as a significant risk factor birth-related trauma, whether due to the diagnosis or inappropriate care.
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 and wellbeing in subsequent pregnancies.
4. That best practice 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 appropriate care for parents who receive a prenatal diagnosis to reduce the incidence of trauma.
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 state so that all parents facing a suspected or confirmed prenatal diagnosis of fetal anomaly or variation are informed, supported and empowered.

<sup>1</sup> [www.throughtheunexpected.org.au](http://www.throughtheunexpected.org.au)

<sup>2</sup> <https://www.arc-uk.org/>

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 New South Wales suggests a congenital condition is occurs in 1 in every 32 births<sup>3</sup>. A major congenital anomaly or condition is classified as a structural or genetic anomaly that is associated with morbidity, mortality or disability. Unfortunately, this report only includes up to 2017 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,<sup>4</sup>
- Congenital anomalies are the most common cause of perinatal death.<sup>5</sup>
- 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.<sup>6</sup> This lack of attention on the psychosocial impacts is also reflected by the:
  - single recommendation in the national Clinical Practice Guidelines: Pregnancy Care<sup>7</sup> 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 prognosis<sup>8</sup> 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.<sup>9</sup>
  - 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 a brief mention 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 care for expectant parents who receive a life-limiting or life-threatening fetal anomaly diagnosis.

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<sup>3</sup> NSW Government. (n.d.). *Congenital conditions, NSW 2007-2016*.

<sup>4</sup> Australian Institute of Health and Welfare. (2022). *Congenital anomalies 2016*.

<sup>5</sup> Australian Institute of Health and Welfare. (2002). *Australia's mothers and babies*.

<sup>6</sup> Hodgson, J. & McClaren, B.J. (2018). Parental experiences after prenatal diagnosis of a fetal abnormality. *Seminars in Fetal & Neonatal Medicine*, 23, 150-154.

<sup>7</sup> Australian Government Department of Health. (2020). *Clinical practice guidelines: Pregnancy Care*.

<sup>8</sup> 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.

<sup>9</sup> 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.<sup>10</sup>
- 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 pregnancy<sup>11</sup> and concerns from sonographers about harming parents through inattention to the communication of unexpected news.<sup>12</sup>
- lack of recommendation or attention to the remaining inequities and difficulties in accessing a termination of pregnancy after receiving a prenatal diagnosis of a fetal anomaly within the Senate report of the inquiry into the universal access to reproductive healthcare.<sup>13</sup> The Committee received several submissions that detailed the challenges in accessing trauma-informed reproductive healthcare after a prenatal diagnosis, and despite specific encouragement to prepare a submission from employees in the Department of Health, the submissions related to prenatal diagnosis were not referenced in the report at all. Committees should be aware of the toll of continuing to revisit traumatic experiences in preparing such inquiry submissions, particularly when these remain overlooked.

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

The Terms of Reference for this Inquiry into Birth Trauma specify the inclusion of trauma as a result of inappropriate, disrespectful or abusive treatment before, during and after birth. The ongoing nature to overlook the psychosocial aspects of prenatal screening and diagnosis has perpetuated inequities in access to appropriate care, resulting in many parents receiving inappropriate and potentially disrespectful care.

**"My story is probably nothing as compared to what many other people have gone through. Still, the response, approach and attitude of clinicians are what triggered a long lasting pain."**

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

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<sup>10</sup> Consultation draft guideline: Mental health care in the perinatal period, Australian clinical practice guideline. 2022 revision.

<sup>11</sup> Hodgson et al., Submission S073, Family and Community Development Committee.

<sup>12</sup> Parliament of Victoria: Family and Community Development Committee. (2018). Inquiry into perinatal services: Final report.

<sup>13</sup> Commonwealth of Australia. (2023). *Ending the postcode lottery; Addressing barriers to sexual, maternity and reproductive healthcare in Australia.*

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.<sup>14</sup>
- Suicidal ideation was significantly more prevalent in mothers who received a prenatal diagnosis than mothers with a typically-developing baby.<sup>15</sup>
- 39% of mothers who continued their pregnancies met full diagnostic criteria for PTSD,<sup>16</sup> and 85% experienced ongoing symptoms.<sup>17</sup>
- Anxiety after a prenatal diagnosis was rated as moderate to severe in 1 in 2 women.<sup>18</sup>
- 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.<sup>19</sup>
- A 'high chance' screening result impacts long-term mental health even when the baby does not have an anomaly.<sup>20</sup>
- 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,<sup>21</sup> this lack of support has the potential to heighten trauma.

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<sup>14</sup> Aite, L. et al. (2011). Antenatal diagnosis of congenital anomaly: a really traumatic experience? *Journal of Perinatology*, 31(12), 760-763

<sup>15</sup> 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.

<sup>16</sup> Rychik, J. et al. (2013). Maternal psychological stress after prenatal diagnosis of congenital heart disease. *Journal of Pediatrics*, 162(2), 302-307 e301.

<sup>17</sup> Horsch, A. et al. (2013). Maternal coping, appraisals and adjustment following diagnosis of fetal anomaly. *Prenatal Diagnosis*, 33(12), 1137-1145.

<sup>18</sup> 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.

<sup>19</sup> 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

<sup>20</sup> 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.

<sup>21</sup> Hodgson 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*.

- Anxiety, depression and PTSD symptoms are frequent in the early stages of a pregnancy following a TFMR.<sup>22</sup>

### **Exacerbating factors in delivering and accessing maternity care that impact on birth trauma;**

**Workforce:** 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 training<sup>23</sup> 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 related to trauma informed care and prenatal diagnosis means that the single recommendation in the Clinical Practice Guidelines: Pregnancy Care, to refer to trained professionals, cannot be met resulting in inappropriate care which may increase the incidence of trauma. 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.

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.<sup>24</sup>

Research currently underway has surfaced gaps in training and education and how this results in health and allied health professionals learning the job, which has resulted in many situations where professionals report feeling that the care provided was inadequate or insensitive. Professionals have expressed that these moments continue to weigh upon them for years to come, increasing their own distress, trauma and burnout. Systems that are poorly designed to support health and allied health professionals to work with families, then increase the incidence of traumatic stress and distress for all.

**Models of care:** 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. A prenatal diagnosis may trigger referrals to other providers or metropolitan based maternal fetal medicine clinics or underpin changes to birthing plans, threatening continuity of care. While some women and families

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<sup>22</sup> 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.

<sup>23</sup> 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

<sup>24</sup> 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.

may have access to continuity of care after a prenatal diagnosis, such as that delivered by the PEARLS clinic<sup>25</sup>, this is not universal as it is dependant on location and diagnosis.

**Location related inequalities:** 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. 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.<sup>26</sup>

**Stigma:** Some parents have shared their stories of feeling pushed into further testing, pushed into a termination of pregnancy or feeling judged for undergoing termination. There can be stigma and judgement of parents who continue pregnancy and parents who undergo a termination of pregnancy, this can be perpetuated by health and allied health professionals. In times of acute stress or when recovering from a traumatic experience, parents require highly personalised communication which is sensitive to their situation and does not cause additional harm or trauma.

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 trauma 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. 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 alerting to “high risk”, despite the recommendations in the Pregnancy Care guidelines to avoid this. 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

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<sup>25</sup> Psaila, K. M., Schmied, V., & Heath, S. (2023, Jul 6). Exploring continuity of care for women with prenatal diagnosis of congenital anomaly: A mixed method study. *J Clin Nurs*.

<sup>26</sup> Booker, C. (2022, October 8). When the pain of losing a baby is doubled by a lack of care and support. *The Age*.

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 and trauma to disabled people and their families.

Of note, additionally, disabled people and people who advocate for inclusion and disability rights may find decision making during pregnancy more complicated due to their experiences and values as decision making can prompt moral conflict. Appropriate care provision after a prenatal diagnosis requires recognition of the complexity of thoughts and emotions and the potential for trauma within the decision making itself.

**Lack of informed choice:** Informed choices are threatened within prenatal screening and diagnosis, this is a well understood phenomenon. Expectant parents are often unprepared for unexpected findings, whether through ultrasound or genetic screening. Many parents and professionals view screening as routine or an opportunity to learn the sex of their baby and are not fully informed of the potentials. Upon receiving a high-chance finding or an identified structural anomaly, invasive follow up testing can be planned or booked before ascertaining the parent's perspectives of this. The decision to continue or end a pregnancy can be influenced by the information presented and the perspectives of health professionals. Furthermore, decisions about care within follow up can lack a shared decision making or non-directive approach, as experienced by mothers who have reported to us that choices about lactation or autopsy after a termination were not offered. Best practice holistic care after a prenatal diagnosis would include flexible opportunities to revisit information and decisions, given the significance of distress and disassociation on the ability to process information, ask questions and make decisions.

We thank you for the opportunity to bring attention to the prevalence and contributing factors of acute stress and trauma related to prenatal diagnosis and the care provided. Research suggests that holistic care, sensitive to the distress of parents and which addresses the trauma can indeed improve the experience of prenatal diagnosis and reduce trauma. This inquiry has the potential to promote changes in NSW that ensure that all expectant parents who receive a prenatal diagnosis are informed, supported and empowered through the unexpected. This will result in a reduction of birth-related trauma and allow NSW to lead the way in holistic care for parents who receive a prenatal diagnosis.