



## **Opening statement to the Inquiry into universal access to reproductive healthcare – Tuesday 28 February public hearing**

**Down Syndrome Australia’s submission focused on prenatal screening and the fact that many prospective parents may not be making informed choices about prenatal testing.**

### **Informed Consent**

The context and manner in which prenatal screening is presented to prospective parents, including the language used, has the potential to enable or compromise free and fully informed choice. The principles of Informed Consent should be applied to all screening and diagnostic testing.

Screening is a choice, further diagnostic testing is a choice, what to do with the results is a choice. Yet it is often presented as standard “pregnancy journey”.

Healthcare professionals should focus on supporting parents through their decision making process based on the individual values of those prospective parents in a non-directive manner. This is not occurring and there is the need for more and better training, easier access to non-directive counselling and referral pathways to organisations such as Down Syndrome Australia and its State and Territory members.

### **Communication of results**

Healthcare professionals should carefully consider how news of a high chance screening result or diagnostic result is shared with prospective parents. The exact wording used by health care professionals to convey screening or diagnostic results is often recalled by prospective parents many years later. This psychosocial impact, regardless of outcome, should not be dismissed.

It is important that people are aware that a high chance screening result is not a diagnosis (yet over 90% of prospective parents terminate based on a high chance screening result).

### **Exiting guidelines**

RANZCOG and DoH Antenatal guidelines exist but not are being delivered consistently in practice and don’t consider all of the aspects of informed decision making.

### **Negative community attitudes**

Outdated information and negative attitudes to disability in general, mean that many people have incorrect views on what it means to raise a child with Down syndrome in 2023.



Furthermore, the inherent values that underly screening result in language that is values based (the use of terminology such as “High risk” etc). These values often lead to the pressure for more testing and/or termination, and the use of outdated or biased information.

This underlying difference in values has the potential to cause significant harm to people with disabilities and their families. People with Down syndrome and their families have to constantly face the stigma, the community react and are impacted by this and this contributes to the negative perception in the community.

### **Access for PwDS to sexual and reproductive healthcare**

Finally, unrelated to prenatal screening there is a need to improve the access that people with Down syndrome have to sexual and reproductive healthcare. They need to be able to access healthcare including routine screening, contraception, menstrual management on the same basis as everyone else. That is with full access and with informed consent. They need to be involved in decisions regarding their health – sterilisation, menstrual management, contraception etc.