




Speech By
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MEMBER FOR COOPER

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ASSISTED REPRODUCTIVE TECHNOLOGY BILL

 **Ms BUSH** (Cooper—ALP) (12.17 pm): I rise to make a contribution to the Assisted Reproductive Technology Bill. I want to start by making a couple of opening statements. I want to recognise that Queensland's fertility sector is broadly efficient, professional, caring and safe. Around 15,000 to 20,000 cycles of IVF are completed every year in Queensland, and fewer than one per cent of those result in a complaint so we have a broadly safe and efficient sector.

I want to recognise the service providers who work in fertility services, including those who are in my electorate who met with me around the bill. They offer people the chance of having or expanding their family when they otherwise may not be able to, including ourselves. Our youngest, Albie, was conceived through IVF. She is a beautiful miracle baby and we would not have her without that service. Even the days that are tough—and there are tough days—I savour because the alternative is so much worse. I do want to recognise all those people who work in that really important sector we have in Queensland.

That said, it is clear that when things go wrong—when samples are misused, when people are not fully informed or when consent is not given—the gravity of those mistakes is lifelong and life changing. I want to also recognise those advocates whose experiences have contributed to this bill. It was clear from reading the submissions, listening to people who presented to the committee and reading the report of the Office of the Health Ombudsman, which I did, that reform was clearly needed.

In terms of the background to the bill, following the stories raised with her and in the public, the Minister for Health directed the OHO to complete a section 81 investigation into assisted reproductive technology in Queensland across 24 providers registered with RTAC. The initial scope of that investigation looked at issues of noncompliance or adverse events associated with the handling of gametes and embryos, including the collection, labelling, storage and transportation; the screening of gametes and embryos used in Queensland; record keeping and provision of information; maximum donation and distribution within Australia; whether adequate information is made available to consumers to allow them to provide informed consent when choosing ART treatment; issues related to the quality of donated sperm and the impacts that that has on the choices for ART treatment; the use of sex selection in accordance with the National Health and Medical Research Council guidelines; and issues associated with the discarding of gametes and/or embryos which is the genetic or biological material.

The OHO's investigation identified significant systemic issues relating to the provision of ART services here in Queensland, including the gaps and risks in the current self-regulatory regime. The OHO found there was, in fact, justification for legislation to regulate ART providers in Queensland and to strengthen the safeguards of consumers, donors and donor-conceived people, and this bill is a response to that.

The bill will establish a framework to regulate assisted reproductive technology providers and services and will establish a donor conception information register in Queensland. The legislation will ensure the wellbeing and interests of people receiving fertility treatments are central to the delivery of assisted reproductive technology services, and that the welfare and interests of people born as a result of these services are of paramount importance.

This bill deals with key themes in the OHO report. I will speak to two. In relation to the theme of appropriate collection, storage, identification and distribution of gametes and embryos, the OHO, in their report, commended the ART providers who were fulsome in their investigation and participated in site visits. It was this ability to gather information that led to the recommendations that were outlined.

While the occurrence of gamete misidentification and mix-up is incredibly small, the gravity of this type of event is large. One of the case studies provided during their investigation was the following—

A couple undertook ART treatment from a provider resulting in three children. The couple intended for all three children to be biologically related using a single sperm donor of their choice. Following private genetic testing undertaken by the couple, they learned that their two younger children were not biologically related to the oldest child, although the two younger children are full siblings. One of the younger children also has significant disabilities which may have been inherited from the unintended sperm donor.

I reiterate that the OHO found that this was uncommon, but the case study illustrates and justifies how important robust record keeping and systems are to minimise this risk.

The bill adopts a key recommendation from the Health Ombudsman by establishing a licensing framework to ensure robust oversight of providers. Providers will be required to obtain a licence to operate in Queensland, and it will be an offence to operate without one. The bill encourages transparency from the sector and requires licensed providers to give written notice of certain events within prescribed timeframes. Queensland Health will operate the licensing regime. They will have powers to investigate, and will also have the ability to issue an improvement notice where it is necessary for a provider to rectify a particular matter to prevent or to minimise a risk to the health, safety or welfare of patients or people born as a result of those services. Queensland Health will also have the power to suspend or cancel a provider's licence. Inspectors will be appointed under this bill to investigate, monitor and enforce compliance with the act and will have powers to enter premises, inspect and seize things and require production of information. The penalties will be serious. Noncompliance of this requirement will be an offence.

The second theme I will speak to is the establishment of a donor registry for Queensland. Most, if not all, submissions received illustrated the impact that not knowing your genetic history and not knowing your biological truth has a profound impact on donor-conceived children in particular. I want to share elements of a statement provided to the committee anonymously. It reads—

I only become aware that I was conceived using donor sperm three weeks prior to my 38th birthday. I asked my mum if Dad was my biological father. She admitted that he was not and explained I was conceived using donor sperm.

The next day I looked at my face in the mirror and was at a loss as to who I was looking at. The experience was harrowing and not one I would wish on anyone. I now understand that this experience has a term, genetic bewilderment.

This bill requires providers to collect and keep information about gamete providers, including donors, and people who undergo procedures, for at least 99 years. The bill also makes it an offence to destroy records. It is imperative that services are preserving and recording Queenslanders' genetic origins and that they take their role as custodians in that very seriously.

The bill will establish the donor conception information register in the Registry of Births, Deaths and Marriages. The establishment of the register was considered and recommended by the parliamentary Legal Affairs and Safety Committee, that I was on in this term of government, following our inquiry into matters relating to donor conception information. We heard then and we have heard again through this parliamentary committee process from donor-conceived people and their families that access to information about a donor is often fundamental in informing their identity and that the inability to do that contributes to ongoing mental health and familial consequences.

We also heard, as a committee, of the life-changing positive impacts that it has for donor-conceived families when they are able to put those pieces together. One of the submitters advised us that—

Hearing the three-page letter from my donor was one of the most beautiful experiences of my life. As he described his life, it was as if he was describing my life and interests and it provided clarity for where so many of my talents came from. The letter also explained that I had a donor-conceived (DC) brother and sister, both born in the same year as me, and they helped write the letter also. I instantly had 3 new family members! What an amazing day.

It is for these reasons that our former committee recommended the establishment of a retrospective register so that all donor-conceived people can be provided with the right to access identifying information about a donor, regardless of when they were born. Whilst it is raised with us, and

we have acknowledged, that the establishment of a retrospective register impacts on the right to privacy of donors, the right of donor-conceived people to know their genetic origins outweighs that competing right to privacy.

As the minister remarked in her introductory speech, making the register operate retrospectively creates information access equality for all donor-conceived people, regardless of when a donor-conceived person was born, and ensures all donor-conceived people are treated equally before the law.

This bill demonstrates the Queensland government's commitment to improving health care for families and for women and that that forms part of our landmark Queensland Women and Girls' Health Strategy. I commend the bill to the House.