

### A TALE OF THREE INQUIRIES<sup>1</sup> BY STEPHEN PAGE<sup>2</sup>

#### WHICH THREE INQUIRIES?

The first inquiry was the Queensland Parliamentary inquiry into access by donor conceived persons to information about their gamete donors.

The second inquiry was the review, *Building Belonging*, by the Queensland Human Rights Commission into the *Anti-Discrimination Act 1991* (Qld).

The third inquiry is the Senate inquiry as to universal access to reproductive healthcare, for which submissions are open until 15 December.

#### THE QUEENSLAND PARLIAMENT INQUIRY

#### SO WHAT'S NEXT IN QUEENSLAND?

It's likely that there will be laws setting up a central registry run by the Registrar of Births, Deaths and Marriages, and with retrospective anonymity removed.

It's unlikely that there will be an ART Act in Queensland, other than to set up a central registry, and related steps.

I'll go through step by step how the inquiry came into being, and what it concluded.

#### THE MEDIA RELEASE

On 24 February 2022 the Attorney-General, Shannon Fentiman sent out this media release:

"The rights of donor-conceived Queenslanders to access genetic information about their donors to manage their health and personal wellbeing will be considered by the Queensland Parliament.

Attorney-General and Minister for Justice Shannon Fentiman said that she had today asked Parliament to refer the important matter to the legal affairs and safety committee for enquiry.

'Conception using donated sperm, eggs or embryos has given countless Queensland couples and individuals the precious gift of starting or extending their family,' Minister Fentiman said. 'For those people who are donor-conceived, it is important that they can access information

<sup>&</sup>lt;sup>1</sup> Apologies to Dickens

<sup>&</sup>lt;sup>2</sup> Stephen Page is a dad through surrogacy. His daughter was born through surrogacy and egg donation. He is a principal of Page Provan, Family and Fertility Lawyers, Brisbane. Since 1988 Stephen has advised in thousands of ART cases. Since 1996 he has been a Queensland Law Society Accredited Family Law Specialist. Since 2012 he has been an international representative on the American Bar Association ART Committee. Since 2017 he has been a Fellow of the International Academy of Family Lawyers and of the Academy of Adoption Assisted Reproduction Attorneys. He is a Director of Access Australia's Infertility Network Limited and of the Fertility Society of Australia and New Zealand Limited.



'For those people who are donor-conceived, it is important that they can access information about their genetic identity to better understand their origins and to manage their health appropriately.'

'That's why the Legal Affairs and Safety Committee will examine this issue carefully, and to determine whether a statutory register of donor-conception information should be established in Queensland.'

'The Committee will consider the extent to which identifying information about donors should be given to donor-conceived persons, while also taking donors' rights to privacy into consideration.'

Under the Terms of Reference, the Committee will consider the experiences of donor- conceived people in accessing information under the current Queensland framework, as well as the views of donors and industry stakeholders, and governance and realty frameworks operating in other Australian jurisdictions.

Minister Fentiman said in addition to donor-conceived people, the Committee would also consider the ability of their parents and siblings to access information.

'Another important issue will be how identifying information about donors can be collected and disclosed for donations made on the condition of anonymity,' Minister Fentiman said.

'Clearly there is a balance to be struck between donors' rights to privacy and donor- conceived peoples' right to information.'

'However, I believe all Queensland children should grow up knowing their origins, have access to their genetic information they need to manage their health, wellbeing and sense of identity.'

'I look forward to seeing the Committee's recommendations.'

The Parliamentary inquiry into access donor conception information expected to report its findings by 31 August 2022."

#### THE TERMS OF REFERENCE

On that day the Legislative Assembly agreed:

"That the Legal Affairs and Safety Committee (the committee) inquire into a report to the Legislative Assembly by 31 August 2022 on:

- 1. Issues relating to access to donor conception information, including:
  - (a) rights of donor-conceived persons, including to know their genetic origins;



- (b) extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors;
- (c) access to historical clinical records and implications of retrospectivity activity;
- (d) access to support and counselling for donor-conceived persons and donors;
- (e)whether a register should be established; and
- (f) benefits, risks and implications on donor conception practices arising from any recommendations.
- 2. That the committee consider.
  - (a) views and experiences of donor-conceived people, donors and industry stakeholders of the current framework;
  - (b) current governance/regulatory frameworks, including registers established interstate;
  - (c) options to manage collection, storage and disclosure of identifying and non-identifying information about donors, donor-conceived persons and relatives;
  - (d) whether and how to collect and disclose identifying information about donors where a donation was made on the condition of anonymity, including matters relating to consent;
  - (e) whether any models should include information from private donor arrangements;
  - (f) costs of any proposal including to establish and maintain any register and options for efficiencies, including a user-pays model;
  - (g) whether regulating donor conception practices and assisted reproductive technology should also be considered as part of establishing a donor conception register; and
  - (h) human rights engaged under the Human Rights Act 2019."

#### THE INQUIRY

The Committee is an all party committee, in which the Government does not have a majority. Its report was unanimous.

Membership of the Committee is:

Member	Party
Peter Russo, Toohey, chair	ALP



Laura Gerber, Currumbin, deputy chair	LNP
Sandy Bolton, Noosa	Independent
Jonty Bush, Cooper	ALP
Jason Hunt, Caloundra	ALP
Jon Krause, Scenic Rim	LNP

There were 71 submissions including from academics, donor-conceived adults, donors, mothers of children who have been adopted, the NHMRC, the AMA, Queensland Fertility Counsellors<sup>3</sup>, QFG, Women's Legal Service Queensland and me<sup>4</sup>, among others.

Among the other witnesses, Narelle Dickinson and I were both privileged to give evidence to the Inquiry.

When I gave evidence, I was surprised about the lack of knowledge by the committee members. This was clearly a topic with which they were not familiar and had not come across in their own lives. They clearly had not had the opportunity at that stage to fully absorb the written submissions. They did not know, for example, about how the NHMRC *Ethical Guidelines* worked when it came to donation and were unaware that in effect open identity donation, as practised in Queensland and throughout Australia, had been the norm since 2004.

The committee asked lots of questions and were, as expected, polite and respectful.

A majority of submitters<sup>5</sup> called for the stripping away of retrospective anonymity. QFG was opposed to stripping back anonymity.

There was criticism from some submitters that because Queensland did not have an ART Act therefore there was inadequate regulation in Queensland. Both QFG and I called for there not to be an ART Act in Queensland.

#### I said6:

"I would be opposed to the enactment in Queensland of an Assisted Reproductive Treatment Act. One should be concerned about creeping regulation. Our IVF clinics are currently well regarded internationally. The requirement for them to publish their outcomes to both the Australian and New Zealand Assisted Reproductive Database (ANZARD) and www.yourivfsuccess.com.au through the lens of transparency helps keeps them that way.

In my view, IVF clinics in Queensland work efficiently and in clear compliance with the Ethical Guidelines. I do not sit on the board of any of the clinics. My experience in dealing with clinics inNew South Wales, Victoria, and Western Australia (and to a lesser extent South Australia) is that adding State requirements on top of the Ethical Guidelines adds to cost and complexity. Costsare

<sup>&</sup>lt;sup>3</sup> Narelle Dickinson, Elise Atkinson, Fiona Stark, Fiona McDonald, Donna Griffiths, Jeanne Strahan, Barbara Wood, Nicole Wimmer, Susan Prince, Jodie Housman, Tess Law and Alix Gibson, all of whom are members of ANZICA.

<sup>4</sup> https://documents.parliament.qld.gov.au/com/LASC-C96E/I-7780/submissions/00000013.pdf.

<sup>5</sup> Including me.

Submission 13, found at https://documents.parliament.qld.gov.au/com/LASC-C96E/I- 7780/submissions/00000013.pdf , pp55-56.



compounded for those clinics that operate across State borders which our three biggest clinics do, namely, Virtus Health, City Fertility and Monash IVF.

The view has been expressed from time to time in other quarters that having corporate ownership of IVF clinics is a bad thing. The implication is that the clinics are driven solely by profit. IVF clinics have always been driven by profit, whether they are doctor owned or not. In my view, having corporate ownership is not necessarily a bad thing, and in many ways is a good thing, because of the need to innovate, to ensure consistent quality over several sites, to be responsive to the requirements of consumers, and to be compliant with legal and compliance requirements—especially when operating in several States.

Invariably, an increase in cost will be passed on to the consumer. Ideally, there should be a national model of regulation of IVF clinics. Sadly, it is likely not to be any time soon. In the meantime, the default model of regulation of IVF clinics is the Ethical Guidelines. In my view they are a more than adequate means of regulation, and should remain the prime means of regulation of IVF clinics in Queensland.

Queensland fertility doctors have at times been sharply critical of interstate models, which have increased costs and compliance requirements, reduced flexibility, and reduced options for patients. In my view the doctors are right, as was the Lavarch Committee and the Government in response- that the Ethical Guidelines set out clear requirements that IVF clinics must follow."

#### QFG said in its submission<sup>7</sup>:

"QFG has been providing donor services since 1983. In the last five years alone, QFG has managed approximately six thousand sperm, egg and embryo donor cycles. The outcome of each cycle has been reported to the Australian and New Zealand Assisted Reproduction Database (ANZARD), published annually in the Assisted Reproductive Technology in Australia and New Zealand and benchmarked nationally on the Your IVF Success website, both readily accessible public resources. This framework provides an unprecedented degree of regulation, transparency, and accountability unparalleled in any health service in Australia. As such, QFG highlights the risk that state-based legislation of reproductive health care and medical services may jeopardise the access to such services by Queenslanders, as clearly illustrated by the discriminatory draconian legislation mandating police checks for couples accessing fertility services in Victoria until 2020... QFG is concerned that the establishment of further legislative constraints, would limit the acceptability of the process to donors, increase complexity and costs for recipients and increase health risks to donor-conceived individuals. Australian fertility clinics have already established robust, contemporary processes to manage donors in a safe, transparent and publicly accountable framework."

Not surprisingly, QFG gave a mea culpa as to past practices:

"Medicine, like any other profession, has evolved over time and some practices have historically occurred that, by the current standard, may now not be considered appropriate. Such actions must be seen in the historical associated-cultural context and were taken in the best interest of



the donor, the recipient, the donor offspring and their families at the time. Nonetheless, QFG does not support the legislated release of identifying information on donors prior to 2004, as donors provided and recipients accepted gametes on the understanding that their identities would remain confidential. If the commitment of patient confidentiality was to be overwritten by any new legislation, without evidence that the presumptions of benefit are shown to be erroneous, there could be widespread consequences to the healthcare community by undermining the trust implicit in the confidentiality of any patient-doctor or other therapeutic relationship.

In the context of historical donor anonymity, fertility clinics are optimally positioned to facilitate linkage between donors and donor-conceived persons through voluntary linkage programs and support networks. However, not all donor-conceived persons will be able to be linked and QFG acknowledges the challenges and difficulties experienced by some donor-conceived persons in such circumstance. However, QFG recognises that the changes implemented almost two decades ago will protect the current generation of donor-conceived individuals. Fertility clinics have and will continue to support affected donor-conceived individuals, donors and recipients through linkage programs, counselling and support networks."

#### **RECOMMENDATIONS**

The Chair of the Committee, Peter Russo MP said, in introducing the report8:

"The journey to becoming a parent is different for everyone, and for those who do struggle to conceive, creating a family can come with difficulty and heartache. Assisted reproductive technology (ART) is an increasingly popular option, and it is therefore timely that the Queensland Government consider the unique needs of those who are conceived through this process.

This report presents a summary of the Legal Affairs and Safety Committee's examination of the enquiry into matters relating to donor conception information.

Children born through donor conception often have the same desire and need to know their genetic history as any other person. However, Queensland's legislative arrangements do not currently reflect these needs.

Consequently, the committee heard of donor-conceived people continually searching the faces of strangers looking for genetic similarity. We heard of people being refused records and information and of people conducting comprehensive searches through social media trying to connect with biological family. We heard from people who were so uncertain of their genetic history that they were apprehensive to embark on relationships themselves.

The recommendations in this report will make it possible for donor-conceived people to be provided with important information – including medical information – about their donor, and information about donor siblings.

Ethe report can be found at: https://documents.parliament.qld.gov.au/tableoffice/tabledpapers/2022/5722T1242-74D8.pdf



As one submitter stated: 'Not having knowledge of one's genetic origins is like having the first chapter missing from one's life story'. Whilst we recognise that the recommendations in this report cannot entirely correct this, our aim is that they go some way to restoring those early chapters. There was some concern regarding the retrospective application of legislation in this area. It is important to note that DNA testing has changed the landscape, and people are able to access this information now, but without adequate support.

Ultimately, at the heart of this issue lies the central legal and ethical dilemma: does a person's right to know their genetic history outweigh a person's right to privacy? The committee has found that it does.

This was an important inquiry to have, and to be part of. On behalf of the Committee, I thank those individuals and committees and organisations who made written submissions on this important issue, and to those who provided in-person testimony to the committee ..."

The Committee made eight recommendations:

#### Recommendation 1: rights of donor-conceived persons, including to know their genetic origins

The committee recommends that all donor-conceived persons be legislatively provided with the right to know the identity of their donor when they reach the age of 18, regardless of when they were born.

Recommendation 2: extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors.

The committee recommends that:

- identifying information about donors, including their medical history, be made available on request to all donor-conceived persons when they reach the age of 18
- information about the gender and year of birth of donor-conceived persons born from their donation be made available on request to all donors
- information about the gender and year of birth of donor-conceived siblings be made available on request to donor-conceived persons
- requests from donors for contact with donor-conceived persons be facilitated subject to the consent of the donor-conceived person
- requests from donor-conceived persons who contact with their donor be facilitated subject to the consent of the donor
- requests from donor-conceived persons who contact with their donor siblings be facilitated subject to the consent of both parties.

#### Recommendation 3: access to historical clinical records and implications of retrospectivity

The committee recommends that the Queensland Government introduces legislation to:



- prohibit the deliberate destruction of historical donor records
- require clinics involved now and historically with donor conception to retrieve, check and submit all donor information to a central register within a reasonable timeframe
- provide that birth certificates or donor-conceived persons be annotated to note the fact of donor conception
- provide the birth certificates of donor-conceived persons already born be amended to note the fact of donor conception.

### Recommendation 4: access to support and counselling for donor-conceived persons, recipient parents and donors

The committee recommends that:

- the Queensland Government considers funding counselling and support services for donorconceived persons, recipient parents and donors to facilitate positive outcomes from recommendations in this report, utilising services with relevant and lived experience
- such counselling and support services should be independent of the fertility industry.

#### Recommendation 5: whether a register should be established

The committee recommends, as a matter of urgency, that:

- a central donor conception register be established within the Registry of Births, Deaths and Marriages
- this register be mandatory in relation to donor conception achieved within a fertility clinic
- this register be available voluntarily to those who have pursued donor conception in private arrangements
- the Queensland Government undertake investigation to determine how to:
- encourage participants in private donor conception arrangements to lodge donor conception information on the central donor conception register; and
- ensure the information is accurate.
- the staff who operate this register to actively contact previously anonymous donors about relevant changes to the law and available support services, and permit them to lodge contact preferences
- the Queensland Government works with states and territories to investigate the linking of donor conception registers across jurisdictions and any potential implications

### Recommendation 6: benefits, risks and implications on donor conception practices arising from any recommendations

The committee recommends that all past, current and future donors be fully informed of relevant changes to the law and that they will be identifiable to those born from their donation.



#### Comment as to recommendation 1 - the right to know genetic origins

The Committee saw it as fundamental that each of us should know our genetic origins, no matter when the donation occurred.

Submissions to the Committee included9:

"Jigsaw Queensland noted the impacts on a donor-conceived person of not knowing their origins and suggested that privacy provisions are becoming redundant:

We do not believe, however, that the right to privacy extends to the right of a person to withhold from another person information vital to that person's own private identity—knowledge of their origins or knowledge of their children. Not having knowledge of one's personal origins is like having the first chapters missing from one's life story. Knowledge of one's personal history is so central to human identity that everyone ought to have a right to knowledge of their personal origins and the circumstances of theirbirth. Indeed, privacy provisions have been made somewhat redundant by the availability and popularity of commercial DNA kits.

Stephen Page agreed that 'anonymity with genetic donation is dead' due to the following reasons:

- use of DNA databases which hold information enabling individuals to track down their genetic history
- IVF clinics often provide photos of their prospective donors and a Google search can often identify the donor
- social media photographs can identify lookalike children.

Professor Katharine Gelber, a recipient parent with a donor-conceived child, also commented that 'anonymity is disappearing informally and any promises once made to donors to preserve their anonymity can no longer be upheld', explaining: DNA testing makes it more than likely that a donor conceived person can discover the identity of their donor. This means anonymity is no longer an option. It is far preferable for disclosure to occur through a government authority, alongside appropriate counselling and support services, and based on accurate records, than for it to happen informally. This is the reality of donor conception today.

Donor Conceived Australia also addressed the use of DNA testing: In regard to privacy and anonymity of donors, some of whom retrospectively signed up as anonymous donors, there is no need to continue to offer them anonymity as the easy to access direct-to-consumer DNA testing market has done away with any level of anonymity.

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Even if they have not tested themselves, most DCP [donor-conceived people] are able to work at finding their donor with the help of "Search Angels" - professional genealogists - who often volunteer their time to help families connect. Donor Conceived Australia is of the view that this information would be much better to be provided by a government organisation that can provide support and counselling at the same time, rather than a multinational corporation or a volunteer genealogist.

Sarah Clay provided the committee with her personal perspective on DNA databases: My biological father first found out about his children by ancestry.com. Without going through that pathway, I would not know my status or my child's medical history—not looking at the benefit of relationships. So much has changed from the eighties, when people agreed to anonymous donation. We cannot pretend that 40 years has not passed and science has not improved; human rights have developed and changed."

#### The Committee noted:

"Most donor submitters expressed the view that donor-conceived people should be provided with identifying information about their donors." 10

Further in relation to privacy, a number of submitters argued that the advent of new technology, including DNA testing and the use of social media, now makes it difficult to maintain donor anonymity. The committee notes the experience of some donor-conceived people are advised that there is a risk to the wellbeing of a donor-conceived person if they uses these technologies and either discover their previously unknown donor conception status or start the process of making contact with donor relatives without support.

Attitudes towards donor conception expectations around anonymity have changed over time. Evidence and the experiences of donor-conceived people indicate that a person not knowing their genetic origin may negatively impact on their sense of identity and wellbeing and that early disclosure of donor conception status is important to their formation of identity.



The committee heard evidence that having access to the medical history of donors is important, not only for a donor-conceived person's own health management and awareness of any predisposition to develop genetic diseases, but also for any children they may have. In this regard, the committee recommends all donor-conceived persons have the legislated right to know their identity of their donor from the age of 18, no matter when they were born. The committee also recommends identifying information about donors, including the medical history, should be made available on request to all donor-conceived persons when they reach the age of 18."

The Committee also noted that it was important to know about the gender and year of birth of any donor siblings on request:

"This would mitigate the risk of forming consanguinous relationships unknowingly and address some of the fear or hesitancy that donor-conceived people may hold about forming relationships in general."

#### RETROSPECTIVITY

Clearly the Committee recommended a Victorian style approach so that there is transparency of genetic origin. The Committee noted<sup>11</sup>:

"The independent Queensland fertility counsellors, social workers and psychologists supported establishing processes which would facilitate access to historical clinical records, and acknowledge that this may require retrospective application of legislation to arrangements which were made in the past under the assumption of anonymity."

The Information Commissioner stated12:

"Should a retrospective model be proposed to support the right to know identity and medical information, safeguards will be important to protect the privacy of individuals, even if their personal information is communicated to another without their consent."

Associate Professor Anusch Yazdani, then with QFG, explained why QFG's position on a legislative requirement for releasing pre-2004 identifying donor information is not supported and the difficulties with providing identifying information of donors who donated decades ago<sup>13</sup>:

"We do not support a blanket legislative release of identifying information for donors prior to 2004 as those arrangements occurred within a medical consultation, understanding that those identities would remain confidential. This is a problem for all of us, including for QFG.

QFG does not participate in any private donor arrangements, and we cannot provide any information on this, but I do highlight the risks that are inherent in terms of donor arrangements

<sup>&</sup>lt;sup>11</sup> At p.33.

<sup>&</sup>lt;sup>12</sup> At p.37.

<sup>&</sup>lt;sup>13</sup> At p.37.



in this situation. Medicine, like any other profession, has evolved over time. While by current standards some of these practices may not be okay, such actions have to be seen within their historical context, particularly that those actions would have been taken by those individuals in an effort to assist the conception of those people they helped.

We absolutely recognise the importance of the information that donors want. If you asked me now today if you wanted to know who a donor is, I can give you that information in two minutes – on non-identifying information I could tell you who the person is and what their family history is – and within a day I can give you all of the identifying information, but for historical records that is a completely different situation. That is nothing to do with the unit or its structure; it's something to do with the way that medicine was practised 40 years ago, and that is all it is."

#### QFG stated14:

"QFG recognises that the changes implemented almost two decades ago will protect the current generation of donor-conceived individuals. Fertility clinics have and will continue to support affected donor-conceived individuals, donors and recipients through linkage programs, counselling and support networks."

#### Donor Conception Australia stated<sup>15</sup>:

"The current NHMRC guidelines ... do not work in practice to protect the rights of donor-conceived people since they are not enforceable as they are only guidelines. The ART industry is for-profit and largely unregulated. Additionally the interests of clinics may be at odds with the interests of the people that they are creating. Given this lack of oversight and/or accountability, clear legislation is crucial to protect the best interests of donor-conceived people."

#### The Committee stated16:

"Currently the NHMRC Guidelines allow for donor-conceived persons to be provided identifying information about their donor upon reaching the age of 18, or if they are younger than 18 and determined to be sufficiently mature. The NHMRC Guidelines also set the minimum conditions of use of gametes collected before 2004, before which time many donations across Australia were provided on the condition of donor anonymity.

The committee considered the views of submitters in relation to donor-conceived persons having access to historical clinical records, including that the historical context of anonymous donations has created a situation where identifying donor information is available to some donor-conceived people but not others depending on when they were born. Some submitters contended this was discriminatory and that retrospective legislation shall be introduced to afford all donor-conceived people equality regardless of when and where they were conceived.

The NHMRC Guidelines stipulate that clinics must ensure all existing information about parties

<sup>14</sup> At p.37.

<sup>&</sup>lt;sup>15</sup> At p.38.

<sup>&</sup>lt;sup>16</sup> At pp 41-42.



involved in donor conception programs prior to the introduction of the 2004 edition of the NHMRC Guidelines is maintained appropriately. However, the committee heard evidence from submitters that this information was not always available from clinics upon request. Some submitters considered it important that clinics be required by law to protect their historical records, check them for accuracy and submit them to central register, with some submitters stating that a register should be established and managed by a Government agency, rather than fertility clinics. The committee supports legislation to prohibit the deliberate destruction of historical donor records and require clinics involved now and historically with donor conception to retrieve, check and submit all the donor information to a central register within a reasonable timeframe.

The committee also considered the matter of noting donor conception status on birth certificates. The committee heard evidence that early knowledge of being donor- conceived is important to the formation of identity for donor-conceived persons and contributes to their wellbeing. Without a requirement to note donor conception on a birth certificate, a person may not be aware of their donor conception status and therefore also unaware of their genetic origin. However, with this information, a donor-conceived person is able to request identifying information about their donor and non-identifying information about any donor siblings once they reach the age of 18. In addition, a donor-conceived person would also be able to pursue contact with consent. In this regard, the committee supports the introduction of legislation to provide the birth certificates of donor-conceived persons be annotated to note the fact of donor conception and that the birth certificates of donor-conceived persons already born be amended to note the fact of donor conception."

#### INDEPENDENT COUNSELLING

There is general support from submitters for independent counselling and support services to be provided. Sarah Dingle explained what independent counselling meant17:

"Donor-conceived people should be entitled to **independent support and counselling**. What that means is counselling provided by individuals **who are not in the party of any fertility clinic, nor have come from the fertility industry**. The conflict of interest is insurmountable." [emphasis in original].

Cate Smith was of the view that the Queensland Government should cover costs relating to this, 'with the potential for also collecting a special levy from IVF clinics' A levy as proposed may be unconstitutionall9, but that doesn't prevent the State of Queensland charging some other fee for service.

I certainly understand the point of counsellors being independent. I have a concern that if there are counsellors who have no expertise in the area who have been funded by the State to provide counselling, that this may cause more damage to donor-conceived adults than counselling provided by those perceived to be associated with the fertility industry.

I don't have any difficulty with counsellors providing this counselling not being employees or affiliated with a particular IVF clinic.



Of all the recommendations, this recommendation caused me the most concern. After the release of the report, fellow FSANZ board member and fertility counsellor, Narelle Dickinson and I wrote to the Attorney-General, calling for this counselling to be provided by preferably ANZICA counsellors who are not affiliated with clinics.

#### WHO IS TO PROVIDE THE CENTRAL REGISTER?

There was general consensus that it should be provided by the Registrar of Births, Deaths and Marriages. In my submission, this included that the register would be cheap and efficient and would be much more preferable to than if it were run by Queensland Health. The Committee was of the view that BDM should run the register.

#### PRIVATE DONOR ARRANGEMENTS

I told the committee that it was almost impossible to regulate these given that in effect it would be intruding in peoples' bedrooms. In recent times we have seen:

- "Joe Donor", from the US but who visited Australia, who has proudly created 100 children but had annual health checks<sup>20</sup>.
- Alan Phan<sup>21</sup>, in 2020 aged 40, the donor and dad from Brisbane who had donated through several clinics, hit the cap and then kept donating privately, creating 23 children in one year.
   The publication of the story resulted in at least two clinics discarded his donated sperm or embryos created form them- no doubt to the great anguish of the recipients.
- John Lindsay Mayger<sup>22</sup>, in 2020 aged 72, who had commenced donating in 1978, who was still
  donating for lesbian couples, having been rejected by clinics years before. His efforts resulted
  in at least 21 children, but believes that there are up to 50. He said: "Some people fish, some
  golf... I masturbate."
- Adam Hooper, whose Instagram avatar is @spermdonationworld, and who runs Facebook group Sperm Donation Australia, with 1500 members, has created 20 donor- conceived children and was recently on baby making tours of Queensland<sup>23</sup> and New Zealand<sup>24</sup>. He estimates that 900 children have been born courtesy of his efforts through his group.

With the rise of the internet, regulating these private donations is almost impossible, complicated by whether, following the High Court decision in Masson v Parsons [2019] HCA 21, the donor would be recognised as a parent or a child. In addition, through at least one of the donor websites, donors are able to distinguish between whether they were AI (artificial insemination) or NI (natural insemination – i.e. sex). Current case law in Australia is to the effect that when a child is conceived by sex in Australia, the man is the father<sup>25</sup>. It is unclear whether that will remain the position, given Masson, which stated that one of the facts that are relevant as to determine whether someone is a parent is the intention to parent (or presumably, conversely, the intention not to parent).

<sup>&</sup>lt;sup>20</sup> https://www.9news.com.au/national/60-minutes-joe-donor-sperm-ivf-pregnancy-children/bb45b667-9494- 4684-8295-64945eb8f3b8.

<sup>&</sup>lt;sup>21</sup> https://www.kidspot.com.au/birth/conception/ivf/australias-most-prolific-sperm-donor-has-fathered-23- children-in-a-year/news-story/4d163b3b0e64c8aeda1a96d25d af35b2.

<sup>&</sup>lt;sup>22</sup> https://www.dailymail.co.uk/news/article-9087093/Meet-Australias-oldest-sperm-donor-fathered-50- kids.html .

<sup>&</sup>lt;sup>23</sup> https://www.kidspot.com.au/news/serial-sperm-donor-adam-hooper-going-on-babymaking-tour-of- queensland/news-story/b7465a4c01a2b3451e73f7072defedff .

<sup>&</sup>lt;sup>24</sup> https://ivfdonationworld.com/sperm-donation-new-zealand/, https://www.newstalkzb.co.nz/on-air/heather-du-plessis-allan-drive/audio/adam-hooper-australian-sperm-donor-on-his-nationwide-new-zealand-donation-tour/.

<sup>&</sup>lt;sup>25</sup> ND & BM [2003] FamCA 469.



There has been a case in Canada where the man (who had conceived a child through sex) was found to be a donor<sup>26</sup>. In a South African case<sup>27</sup>, the mother alleged that the man of a child conceived through sex was a donor, but the court found that he was a parent, in part because his intention was to parent.

As Justice Thackray stated in the Baby Gammy case<sup>28</sup>, decided before Masson made plain that intention is a relevant consideration:

"If intention was to be determinative of paternity, what would happen where the intentions of the sperm donor and the birth mother differ?...

In my view, the law in this area is already sufficiently fraught for it to be highly undesirable to introduce the contestable element of "intention". One need only look at the time and money expended on this litigation to see how difficult it can be to establish intention."

I said to the Committee that it was important that intended parents are able to make wise choices and that information from the Government may be able to assist them.

I said that there were private donors entering into private donation agreements which I had drafted. Some of these were through clinics and some were not. I said that it was optimal if those in private donor arrangements were able to opt into a central register. They can't be compelled to do so.

I supported the idea of a central register. From the donor-conceived adult's point of view, if they believed that they have been conceived through donation, but they don't know through which clinic, then it could be a lottery of trying clinic after clinic before learning through which clinic they were conceived.

A central register will make that process a lot easier. Whilst the donor-conceived adult can still go through the clinic directly (as is mandated under the NHMRC Ethical Guidelines), instead they can go straight to the State central register, not knowing which clinic that they might have gone to, but still be able to find their records.

It seemed obvious to me that the Stated based central registers should operate much like a one-stop shop, so that if a donor-conceived adult makes an application in Queensland for example, that this is linked with the databases with the central registers that currently exist in New South Wales, South Australia and Victoria and one would expect soon, a fit for purpose register in Western Australia. While it doesn't cover the entire country (with a national register being preferable it is better than a series of State based unlinked registers).

I said to the Committee<sup>29</sup>:

"I would hope that there would be legislative and administrative measures enabling a Queensland central register to connect with those interstate, so that a donor-conceived adult can search in one place and have all of the records available to them. Queensland IVF clinics

<sup>&</sup>lt;sup>26</sup> M.R.R. v J.M., 2017 ONSC 2655.

<sup>&</sup>lt;sup>27</sup> R v S (11830/2016) [2018] ZAKZDHC 23; 2018 (5) SA 308 (KZD).

<sup>&</sup>lt;sup>28</sup> Farnell & Chanbua [2016] FCWA 17 at [382] and [384].

<sup>&</sup>lt;sup>29</sup> https://documents.parliament.qld.gov.au/com/LASC-C96E/I- 7780/Public%20hearing%2013%20may%202022.pdf , p.11.



have gone from secret squirrel type of model, where children have not been told where they have come from, to mandated transparency. Queensland now leads the world, in my view, with the quality of IVF and donor transparency, but retrospective transparency in a state central register would be even better."

I'm glad that the committee endorsed this approach.

#### WHAT'S NEXT?

What the committee has not done is draft legislation. That is commonly seen to be the role of Government.

The outcome from that committee was no surprise. In essence, the Attorney-General Shannon Fentiman called for this committee presumably so that these issues could be discussed and in particular, the thorny issue of retrospectivity considered carefully. By the issues being delat with unanimously by a bipartisan committee, it is much less likely that the Government's Bill will be determined on party lines.

However, when South Australia reviewed its donor conception laws, unlike Victoria and unlike this committee's recommendations, it did not recommend retrospectivity.

One should expect that the Government's response will be to have a central register, run by the Registrar of Births, Deaths and Marriages and that hopefully it will be able to be linked with central registers interstate.

I am of the view that we should be proud of the Queensland Registry of Births, Deaths and Marriages. It is the most efficient in the country. It is also user-pays, being cost neutral on the taxpayer.

To give an illustration, when a parentage order is made in Queensland and New South Wales, there is a vast gap in how fast the birth register is updated to reflect that the intended parents are now the parents who should be named on the birth register instead of the surrogate and her partner. In New South Wales, the Supreme Court sends a copy of its order within a few days of the order being made to the Registry – which then takes six weeks to process (subject to Covid delays).

In Queensland, the Childrens Court makes the order. Within a couple of days that order is available. Either online or via a paper form, the intended parents notify the Registrar of Births, Deaths and Marriages. Typically, the Registrar will issue the new birth certificate in two business days. In my own case, I was lucky that it happened within about three hours of my providing the form in person to the Registry.

There will be a particular challenge for QFG in particular in providing old records – because many of those records are reportedly not accurate.

We remain to see who is to provide the counselling.



I hope that the Government does not draft the legislation in isolation, but engages with various stakeholders in the drafting process, so that the legislation is workable.

I was fortunate recently to be a member of the Northern Territory Government's joint surrogacy working group. I say fortunate because clearly I am not a Territorian. I am a Queenslander. I am also not a member of the Northern Territory public service. However, I have expertise in the area. There were also several representatives from the local IVF clinic. There was a range of stakeholders across the Northern Territory Government from the Departments of Health, Attorney-General and other agencies.

That process was intense, but in my view has ended up with better legislation than if that process were not engaged in.

#### THE QUESTION OF WHO IS A DONOR

It might seem arcane, but the definition of who is a donor is essential to get right when considering creating a donor registry. Three examples are clear from interstate that lack of clarity about who is a donor has led to difficulty later.

Quite simply:

- An intended parent under a surrogacy arrangement should not be considered to be a donor.
- A person from whose gametes were retrieved posthumously should not be considered to be a donor.

#### **New South Wales**

The Ministry of Health in New South Wales administers the central register as well as administering the Assisted Reproductive Technology Act 2007 (NSW), which sets out the requirements for New South Wales clinics to be licensed (in addition to RTAC accreditation). In June I travelled to Sydney to make representations to the Ministry on behalf of Surrogacy Australia<sup>30</sup>. The Ministry had taken the view that a gamete provider for the purposes of the central registry included a genetic parent under a surrogacy arrangement – because the surrogate was the recipient. The Ministry has taken the view that because a parentage order may never be made, in effect, an intended parent was a donor to the surrogate. Never mind that if there is a surrogacy arrangement, clinics in New South Wales must advise the central register of any birth, and intended parents with the surrogacy arrangement must notify the central register prior to applying for a parentage order.

Any appeal to reason that an intended parent was not a donor to a surrogate of the intended parents' genetic material was met with the clear, absolutely firm, stance that the intended parent was a gamete provider and was a donor to a surrogate. The reasoning was along the lines that the surrogate was a parent as a matter of law, and that the surrogacy arrangement was not legally binding. It did not matter, except in one outlier case (where it seems the IVF occurred outside Australia) that a NSW surrogate had ever declined to proceed with a surrogacy arrangement.

<sup>30</sup> For which I act pro bono.



#### Victoria

Some years ago, Victorian Assisted Reproductive Treatment Authority took the view that intended genetic parents through surrogacy was a donor within the meaning of the Assisted Reproductive Treatment Act 2008 (Vic) and ought to be treated accordingly. There was uproar from the clinics. Legal advice given to various clinics was contrary to that of VARTA, i.e., the view taken was that the genetic intended parents under a surrogacy arrangement were not donors. There was a very uncomfortable meeting between VARTA and the various clinics. Following the Gorton Review into ART and surrogacy in Victoria, there have been amendments to the Assisted Reproductive Treatment Act 2008 (Vic.) to clarify that an intended parent through surrogacy is not a donor for the purposes of the central register. This change is set out in section 16(3):

- "(3) To avoid doubt, a reference in subsection (2) to a person who donated gametes used to create the embryo includes a reference to a person who produced gametes used to create the embryo, unless the treatment procedure is to be carried out on—
  - (a) the person who produced the gametes or that person's partner; or
  - (b) a surrogate mother under a surrogacy arrangement, in relation to which the person who produced the gametes is an intended parent."

#### Western Australia

In both Victoria and Western Australia, the import and export of donor gametes and embryos must be approved by the regulator, either VARTA or the Reproductive Technology Council.

I took the view that under the *Human Reproductive Technology Act 1991* (WA) donor did not include gametes to be used (or retrieved) posthumously from a man on behalf of his widow.

In GLS v Russell-Weisz [2018] WASC 79, the lawyers for the former de facto partner of a man who committed suicide were unsure about whether the man was a donor. Accordingly, they wrote to the RTC to see whether approval was required, whilst submitting to the RTC that permission of the RTC was not required because by definition he was not a donor!

Not surprisingly, the RTC said that the man was a donor and that the answer to the request for consent was "no".

It took the Supreme Court to conclude that the man was not a donor and that RTC approval was not required.

Nobody should have to spend that amount of money in running a case, or have that stress involved.

#### **AVOIDING REPEATING A MISTAKE MADE IN VICTORIA**

Victoria is the first, and currently only, jurisdiction in the world to enact complete transparency on donor transactions retrospectively. It did so after a donor-conceived woman was unable to find her genetic origins.



The conception of each of us is unique to us, much like fingerprints. Most of us are conceived naturally, and take it for granted as to the identity of our parents. For some of us, who are conceived through donation, those of us may never know where we came from. In my view, it is a fundamental human right to know. The Victorian lead on this to remove anonymity is to be welcomed, although it is a fine balancing act, given that donors and parents were told that secrecy was essential or assured.

I have acted for donors who have already found out that a child or adult who has been conceived and born from their gametes has been able to identify them. This, at times, has been quite concerning. When Victoria effected the change so that there was retrospective transparency, VARTA wrote to all the donor-conceived adults to tell them the news<sup>31</sup>. Before sending out those letters, it seems no thought was given to telling their parents first. Many of their parents had not been transparent with their children about where they had come from. Rather than writing to the parents first and therefore preparing the parents for what was to come, the parents were just as surprised as the children when their children confronted them about the truth.

I hope that if Queensland legislates for transparency retrospectively, that the Register of Births, Deaths and Marriages writes to the parents first and the children second, giving the parents the opportunity to explain to their children about why they hadn't been told that they had been conceived through gamete donation.

#### A FINAL WORD ABOUT TRANSPARENCY

It is essential in my view, given the fundamental human right of where each of us has come from, for parents to be utterly transparent with their children about how they were conceived, doing so in an age-appropriate manner. A colleague from New Zealand explained it that the sooner the child is told, then rather than having to make a full explanation later, it is just part of the landscape – because the child already knows.

Fertility counsellors, as my clients attest, tell those who attend upon them about this need for transparency, sometimes at length.

When these sermons as to transparency are given to lesbian couples or gay couples, or indeed single cis-men who intend to be parents through surrogacy, the result is quite amusing. To put it bluntly, the child will discover sooner or later that they could not have been conceived naturally and that gamete donation was necessarily part of their makeup. I hope that when fertility counsellors talk to these clients that this obvious fact is understood. For some intended parents, it feels as though the statements about transparency are patronising.

My daughter Elizabeth is now aged 3. When she was aged 18 months and attended a childcare centre of 165 families, our family was the only one composed of a same-sex couple. At the age of 18 months, Elizabeth realised that her family was different to every other family at that centre. She realised that she was the only one who had two dads (or two mums). It was at that point, at age 18 months, that Elizabeth decided to name my husband Mitchell and me. He became dad and I became daddy – and they have been our names ever since.

<sup>31</sup> I was advised by the staff at several clinics.



It was said in the Family Court as long ago as 1995 when considering the wishes of children<sup>32</sup>:

"There appears to have been a tendency for adults to underestimate the wisdom of children and their ability to make sound choices about their future welfare. It must be recognised that children know their parents' attributes and failings better than any outsider and in most cases they alone have direct experience of the environment which each offers."

#### TO CONCLUDE AS TO THE QUEENSLAND PARLIAMENT INQUIRY

There will be another layer of regulation in Queensland that will accompany the setting up of the central register, in addition to RTAC requirements. However, the committee accepted that there does not need to be an *Assisted Reproduction Treatment Act in Queensland* – something which I opposed – so hopefully, the level of regulation will help keep costs down for Queenslanders but enable donor-conceived adults to find out where they came from.

Time will tell.

#### **BUILDING BELONGING**

The Queensland Human Rights Commission has reviewed the Anti-Discrimination Act 1991 (Qld), in its report *Building Belonging*<sup>33</sup>. In its sights was section 45A, which purports to allow discrimination in ART based on sexuality or relationship status. In my view s.45A would fall foul of s.22 of the *Sex Discrimination Act 1984* (Cth) which says that there should not be discrimination in the provision of services based on the other person's sex, sexual orientation, gender identity, intersex status, marital or relationship status, pregnancy or potential pregnancy, or breastfeeding. Two cases, both concerning ART, have decided that when State legislation is contrary to this provision (though relating to married or single women), section 22 prevails<sup>34</sup>.

The Commission has recommended the repeal of the section. It said<sup>35</sup>:

"The exception was inserted in 2002 when relationship status and sexuality were added to the protected attributes in the Act, and allowed clinicians to lawfully refuse services based on 'clinical and ethical standards.'

Since then, society's attitudes have changed as shown by the passing of marriage equality laws. The largest fertility service provider in Queensland [QFG] actively advertises to and provides services for same-sex couples and single parents.

In the Discussion Paper, we asked whether there were any reasons why the Act should not apply to providing assisted reproductive technology services (such as artificial insemination, IVF, and other treatment). We received 18 submissions on this topic, and all said that the provision should be removed, because:

<sup>&</sup>lt;sup>32</sup> H & W [1995] FamCA 30 at [71] per Baker J.

 $<sup>^{\</sup>rm 33}$  https://www.qhrc.qld.gov.au/about-us/law-reform .

<sup>&</sup>lt;sup>34</sup> Pearce v SA Health Commission (1996) 66 SASR 486; McBain v Victoria [2000] FCA 1009.

<sup>&</sup>lt;sup>35</sup> Pp 606-609



- Assisted reproductive services, like other health services, should be available to anyone who
  needs them regardless of their relationship status or sexual orientation.
- The exception implies that single parents and non- heterosexual couples are not worthy
  of assistance to become parents and perhaps should not become parents at all, which
  is contrary to all research in this area, and inconsistent with the introduction of marriage
  equality.
- Fertility service providers in Queensland do not exclude people based on their sexuality or relationship status and some target their services to the LGBTQ+ community, which shows that the law is not reflecting practice.

The Queensland Council for LGBTI Health sought community views about access to assisted reproductive technology services, and one survey participant described a discriminatory comment when accessing these services:

My wife was told she needed a good man.

However, because of the current exception this type of discrimination may not be unlawful.

#### INCONSISTENCY WITH FEDERAL LAWS

Submissions highlighted that service providers are currently required to comply with the federal Sex Discrimination Act, which has protected people from sexual orientation discrimination since 2013.

Three submissions considered that, based on their understanding of existing case law, the exception may not stand up to a challenge based on section 109 of the Australian Constitution, which says that, 'When a law of a State is inconsistent with a law of the Commonwealth, the latter shall prevail, and the former shall, to the extent of the inconsistency, be invalid.

In McBain v Victoria, the Federal Court found that an exception in the now repealed Infertility Treatment Act 1995 (Vic), which permitted refusal of infertility treatment because of marital status, was inconsistent with the Sex Discrimination Act, and therefore inoperative under section 109 of the Constitution.

#### **HUMAN RIGHTS CONSIDERATIONS**

The assisted reproductive technology services exception limits human rights protected by the Human Rights Act including the:

- right to equality before the law<sup>36</sup>
- right to access health services without discrimination<sup>37</sup>
- right to protection of families (the fundamental group unit of society) and children.<sup>38</sup>

<sup>&</sup>lt;sup>36</sup> Human Rights Act 2019 (Qld) s 15(3).

<sup>&</sup>lt;sup>37</sup> Human Rights Act 2019 (Qld) s 37(1).

<sup>38</sup> Human Rights Act 2019 (Qld) s 26. As we discuss in further detail in chapter 7 – family, carer and kinship responsibilities, international human rights law has broadly interpreted the concept of 'family'.



While human rights may be subject to reasonable limitations,<sup>39</sup> the Review did not identify any justification for such a significant limitation on human rights, and we consider the provision may be incompatible with the Human Rights Act.

#### THE REVIEW'S POSITION

The Review considers that:

- there is no justification to retain the assisted reproductive technology services provision because it.
- · is redundant
- · does not meet current community standards
- may be invalid under the Constitution
- may be incompatible with the Human Rights Act."

#### THE SENATE INQUIRY

On 28 September 2022, the Senate referred an inquiry into the universal access to reproductive healthcare to the Senate Community Affairs References Committee for inquiry and report by 31 March 2023<sup>40</sup>.

Submissions are due 15 December 2022.

#### **TERMS OF REFERENCE**

The terms of reference are:

Barriers to achieving 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', with particular reference to:

- a. cost and accessibility of contraceptives, including:
  - i. PBS coverage and TGA approval processes for contraceptives,
  - ii. awareness and availability of long-acting reversible contraceptive and male contraceptive options, and
  - iii. options to improve access to contraceptives, including over the counter access, longer prescriptions, and pharmacist interventions;
- b. cost and accessibility of reproductive healthcare, including pregnancy care and termination services across Australia, particularly in regional and remote areas;

<sup>39</sup> Human Rights Act 2019 (Qld) s 13.

<sup>40</sup> https://www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Community\_Affairs/ReproductiveHealthc are



- c. 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;
- d. best practice approaches to sexual and reproductive healthcare, including trauma- informed and culturally appropriate service delivery;
- e. sexual and reproductive health literacy;
- f. experiences of people with a disability accessing sexual and reproductive healthcare;
- g. experiences of transgender people, non-binary people, and people with variations of sex characteristics accessing sexual and reproductive healthcare;
- h. availability of reproductive health leave for employees; and
- i. any other related matter.

In the context of assisted reproductive treatment, some obvious points that are relevant are:

1. While Medicare rebates are available for assisted reproductive services, they are not available for surrogacy. They have remained that way since 1990, when Medicare for ART was introduced, and surrogacy was banned in much of the country. Time has moved on, but the exclusion has remained. Item 5.2.6 of the Health Insurance (General Medical Services Table) Regulations 2021 (Cth) provides:

"Items 13200 to 13221 do not apply to a service provided in relation to a patient's pregnancy, or intended pregnancy, that is, at the time of the service, the subject of an agreement, or arrangement, under which the patient makes provision for transfer to another person of the guardianship of, or custodial rights to, a child born as a result of the pregnancy."

I have recently written to the Health Minister Mark Butler calling for the removal of the exclusion. If the exclusion is removed, the cost to the Commonwealth, on current figures, is about \$900,000 a year. A copy of my letter is attached.

- 2. The legislative scheme seen under those regulations, the Research Involving Human Embryos Act 2002 (Cth) and the Prohibition of Human Cloning for Reproduction Act 2002 (Cth), and related State and ACT legislation is focused on a woman becoming pregnant or having treatment. It does not take into account transgender, non-binary or intersex people. Nor does it take into account the legitimate desires of single men or gay couples to create embryos. By way of example, section 12 of the Prohibition of Human Cloning for Reproduction Act 2002 (Cth) provides:
  - "(1) A person commits an offence if the person intentionally creates a human embryo by a process of the fertilisation of a human egg by a human sperm outside the body of a woman, unless either or both of the following apply:



- (a) the person's intention in creating the embryo is to attempt to achieve pregnancy in a particular woman;
- (b) the creation of the embryo by the person is permitted under section 28B of the Research Involving Human Embryos Act 2002 (carrying out activities authorised by mitochondrial donation licences).

Penalty: Imprisonment for 15 years.

(2) Despite subsection 13.3(3) of the Criminal Code, a defendant does not bear an evidential burden in relation to any matter in subsection (1) of this section."

Section 8 of the equivalent Queensland Act, the Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Act 2003 (Qld) provides:

"(1) A person commits an offence if the person intentionally creates a human embryo by a process of the fertilisation of a human egg by a human sperm outside the body of a woman, unless the person's intention in creating the embryo is to attempt to achieve pregnancy in a particular woman.

Maximum penalty-15 years imprisonment.

(2) A defendant does not bear the burden of proving any matter in subsection (1) ."

One clinic has taken the clear view that for intended parents to create embryos today but not to have an identified surrogate (the particular woman) means that the clinic and its staff would be committing the offences.

- 3. There have remained barriers in practice for transgender, non-binary and intersex intended parents becoming parents through ART<sup>41</sup>, as seen for example in the Building Belonging report.

  4. There remain extraordinary barriers to overcome for intended parents through donation and surrogacy- as to the availability of gametes, availability of surrogates, the need to go overseas for surrogacy<sup>42</sup>, accessibility in some parts of Australia as a matter of law<sup>43</sup>, and cost. For a local surrogacy journey, the ballpark is \$70,000. Going to somewhere like Canada, the ballpark cost of the journey end to end is \$140,000. Avoiding potential criminalization of the overseas egg donation and surrogacy journey is much like walking through a legal minefield.
- 5. Those who are recipients of donation or are intended parents through surrogacy are defined as disabled under the 2017 ICMART international consensus definition of infertility<sup>44</sup>:

In its recent review of the Anti-Discrimination Act 1991 (Qld), the Qld Human Rights Commission in its report, Building Belonging, the Commission recommends the abolition of section 45A, which purports to allow discrimination in the provision of artificial reproductive treatment based on sexuality or relationship status.

<sup>&</sup>lt;sup>42</sup> In rough terms, for every child born in Australia via surrogacy, four are born overseas.

<sup>&</sup>lt;sup>43</sup> ACT: couples only, and surrogate must be in a couple relationship, Northern Territory: no law to allow surrogacy to commence. Hopefully the Surrogacy Act 2022 (NT) commences at the latest by March 2023; Tasmania: everyone must reside there, Victoria: traditional surrogacy cannot occur in a clinic, Western Australia: single men and gay couples do not have access to surrogacy. The position of transgender, non-binary and intersex access to surrogacy is unclear. Even for those eligible, the gamete donor must be known and be a party to the surrogacy arrangement.

 $<sup>^{44}\,</sup>https://www.icmartivf.org/glossary/i-m/$  .



"A disease characterized by the failure to establish a clinical pregnancy after 12 months of regular, unprotected sexual intercourse or due to an impairment of a person's capacity to reproduce either as an individual or with his/her partner. Fertility interventions may be initiated in less than 1 year based on medical, sexual and reproductive history, age, physical findings and diagnostic testing. Infertility is a disease, which generates disability as an impairment of function." (emphasis added)

The definition came about this way<sup>45</sup>:

"In 2015, Barbara Collura, the president and C.E.O. of the U.S. infertility- advocacy group *RESOLVE*, travelled to Geneva to take part in a series of discussions, led by the International Committee Monitoring Assisted Reproductive Technologies, over the definition of infertility. In 2009, the World Health Organization (W.H.O.) defined infertility as "a disease of the reproductive system"; its definition held that infertility could be diagnosed after a year or more of "regular unprotected sexual intercourse" had failed to produce a pregnancy. But, by 2015, there was broad agreement that this language, with its reliance on heterosexual sex as a reference point, excluded many of the people who currently seek fertility treatment, including queer and single patients. The delegates—most of whom represented professional medical bodies, such as the American Society for Reproductive Medicine, the African Fertility Society, and the International Federation of Gynecology and Obstetrics—hoped to redefine infertility in a new, more inclusive way.

"There were several hours of discussion, of wordsmithing," Collura said. Eventually, they settled on an expansion of the 2009 W.H.O. definition. The new language explained that infertility could also be diagnosed based on "an impairment of a person's capacity to reproduce either as an individual or with his/her partner."

In essence, anyone who needs ART to reproduce is by this definition infertile. Some of them will be disabled within the meaning of the Disability Discrimination Act 1992 (Cth) and equivalent State and Territory legislation. Some won't. A woman who does not have functioning ovaries will. Two healthy men in a gay relationship won't. Disability is defined under section 4 of the DDA as:

" "disability", in relation to a person, means:

- (a) total or partial loss of the person's bodily or mental functions; or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or

<sup>45</sup> https://www.newyorker.com/culture/annals-of-inquiry/the-case-for-social-infertility .



- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

and includes a disability that:

- (h) presently exists; or
- (i) previously existed but no longer exists; or
- (j) may exist in the future (including because of a genetic predisposition to that disability); or
- (k) is imputed to a person.

To avoid doubt, a disability that is otherwise covered by this definition includes behaviour that is a symptom or manifestation of the disability."

6. Paid parenting leave is not guaranteed for those who are parents through surrogacy. In NSW, for example, parents through surrogacy who are NSW public servants can only obtain that leave if they obtain a parentage order from the Supreme Court of NSW. Too bad if they cannot get an order in NSW because they have undertaken their surrogacy journey interstate, or in an overseas altruistic jurisdiction such as Canada<sup>46</sup>.

7. While the Commonwealth pays out more than \$250 million a year for ART services through Medicare, intended parents through surrogacy are restricted under State and Territory laws (if they are in the ACT, Victoria or WA), so that the implantation must occur in that jurisdiction. Freedom of choice, being the ability to choose a doctor interstate, is not available to them.

#### AND FINALLY, THE BOOK!

A quick plug! My book, When Not If: Surrogacy for Australians, is almost here. I expect that it will be launched by the end of the month:

- I start with my professional journey with surrogacy, then my personal journey with infertility and then with our very difficult surrogacy journey.
- I then cover all the topics of interest- laws in each State, statistics, jargon schmargon, and so on and on- and finish with proposals for reform. As the old ad said: "What has it got? The lot, that's what." The book is full of practical tips and case studies to illustrate points.



My first surrogacy client was in 1988, upon the enactment of the Surrogate Parenthood Act 1988 (Qld), which criminalised all forms of surrogacy in Queensland- traditional, gestational, commercial and altruistic- whether in Queensland or anywhere else, if undertaken by Queensland residents.

By my best estimate I have now advised in about 1800 surrogacy journeys for clients in all parts of Australia and at last count 36 countries overseas. It has been a glorious ride, including in 2014 being interviewed by the world's media about the Baby Gammy case- and I want to share the news with others!

I never imagined being a fertility lawyer- but here I am, with the wonderful vocation of helping people have babies. What a thrill and honour!

#### **Stephen Page**

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