Western Australian Review of:
Human Reproductive Technology Act (1991)
and
Surrogacy Act (2008)

Prepared by Damian Adams as an individual submission

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PhD candidate, B.Biotech (Hons)

Damian Adams
[redacted]

(address is to remain confidential)

Aspects pertaining to the implementation of the Human Reproductive Technology Act (HRT Act 1991), and Surrogacy Act (2008), including the practice of donor conception (which includes surrogacy) within Western Australia at present, will be discussed particularly in relation to the child's welfare. When analysing these practices and their outcomes the most important factor to consider is the child. The HRT Act refers to the welfare of the child as follows; "that the prospective welfare of any child to be born consequent upon a procedure to which this Act relates is properly taken into consideration;" (Section 4(1)(d)(iv)); and "consideration has been given to the welfare and interests (ii) any child likely to be born as a result of the procedure," (Section 23(1)(e)). The Surrogacy Act in terms of child welfare refers to; "In deciding whether to make a particular decision concerning a parentage order or proposed parentage order about a child, the court must regard the best interests of the child as the paramount consideration" (Section 13(1)); "The plan needed to satisfy the court as section 21(2)(f) requires may deal with any matter relating to the child, and has to — (b) promote the child's long-term welfare;" (Section 22(1)(b)); and "When the court makes a parentage order it may make any consequential or ancillary order it thinks fit in the interests of justice or for the welfare and in the best interests of the child whose parentage would be affected" (Section 23).

It is clear from these sections of both Acts that the welfare of the child is an important component of both pieces of legislation. In addressing this aspect the voices of those most affected must be heard and that is the voices of the offspring conceived with these technologies themselves. They are the ones left to live with the consequences of other people's actions and decisions. Decisions that were made on their behalf, ones which they were not a party to, nor had any control over. These decisions have the potential to adversely affect their psychological and physical well-being. Current and previous models implemented which have in many instances caused pain and trauma to offspring have resulted from the paternalism of the medical big business fertility industry catering to the desires of adults while at times neglecting the needs and welfare of the children they are creating. The consequences of these practices are not only restricted to the current generation of offspring but have the potential to be felt in and passed on to future generations that will be born to donor conceived (and surrogacy) people. As such there is a duty of care to a far greater proportion of the population than just the figures of donor conceived and surrogacy people would lead one to believe.

Damian Adams is an adult donor conceived offspring who was conceived during the early stages of the clinical practice in South Australia. He is a published medical research scientist with numerous articles in peer reviewed journals including articles on donor conception. He has presented at conferences on the subject of the ethical practice of donor conception and the perinatal outcomes of the practice. He is currently undertaking PhD studies at Flinders University investigating the welfare and outcomes for donor conceived people. He has also been an invited speaker at conferences and symposiums on donor conception, has been regularly sought after for media interviews and has provided evidence for federal and state inquiries on donor conception in Australia. Additionally he has also provided evidence for court proceedings in Canada on this subject. As a father himself, he has a unique insight into the ramifications that have and are currently being made on behalf of the Donated Generation.

Damian has previously had several phone conversations with Professor Sonia Allan on the topic of donor conception and legislative change in Australia. Damian is willing and available for further comment and discussion.

As an overarching recommendation for the HRT Act and Surrogacy Act, key components that pertain to the welfare of the child should follow the example set by the Victorian Assisted Reproductive Treatment Amendment Act (2016) of the Assisted Reproductive Treatment Act (2008), and the recommendations from the South Australian review of the Assisted Reproductive Technology Act (2010). This is essential to move towards nationally consistent legislation. Various terms of reference will be addressed hereafter.

Terms of Reference

The Review of the Human Reproductive Technology Act 1991 (HRT Act) to consider such matters as appear to be relevant to the operation and effectiveness of this Act including:

• Research and experimentation on gametes, eggs in the process of fertilisation and embryos. In particular consider the current disparity between the HRT Act and relevant Commonwealth legislation and need to adopt nationally consistent legislation regarding excess assisted reproductive technology (ART) embryo research and prohibited practices.

As Commonwealth legislation over-rides State legislation it would be nonsensical for the two to be in conflict. Therefore the HRT Act should follow Cwlth legislation. However, the HRT Act has the ability to clarify components of Cwlth legislation where the latter may be unclear.

• Genetic testing of embryos, saviour siblings, mitochondrial donation and gene editing technology.

Pre-implantation Genetic Diagnosis (PGD) provides a powerful tool to ensure that any embryos and subsequent children created do not suffer from the same genetic abnormalities that perhaps other embryos and foetuses that a couple may have previously had. In instances whereby a couple may be predisposed to having children with a genetic abnormality, or perhaps even a fatal one, PGD has enormous potential to prevent heartbreak for the parents. Problematically, from an ethical perspective, for those conditions that are not fatal during the embryonic stage (for example trisomy 21 – Down syndrome), it creates a situation in which the life of a person with such a condition is not deemed to be worthy of living to the same extent as a person who does not have any conditions. We in effect create a dichotomy in which to avoid the heartache of parents, we have created a form of eugenics and are reducing the number of people in our society who are born with disabilities. I do not have an answer for this ethical dilemma, suffice to say that those people with disabilities which can also include things such as hereditary deafness, add value and richness to our society which would be missing if they were all selectively screened out at the embryo stage. Furthermore, if we take the corollary approach and take the position that parents should be able to use PGD as they see fit, should deaf parents be able to use PGD to ensure that any child they have is also deaf as a couple wanted to do in the UK?[1] Should parents be able to use PGD to ensure that their child has a specific disability?

In relation to saviour siblings I will repost my response to this question from an interview I gave to The Advertiser (Adelaide):
"It would be difficult for the child to not feel as though their existence was purely a result of being a saviour," he said. "The welfare of the child should always be paramount."[2]

To expand on that concept, if a child is being created with the express intent of being a saviour sibling, then their primary reason for coming into being is to be as body parts for their already existing sibling. This has the potential to be extremely traumatic psychologically for the child. This is not only in terms of existing as a saviour but also if surgery or other procedures are required at a later stage, that they will be pressured into agreeing to the procedure (for example donating a kidney), and therefore may not be able to give informed consent without duress. Additionally there is the potential for it being a source of great pain physically if the child has to undergo a surgical procedure. With the potential for such psychological and physical trauma it is difficult to conclude that being a saviour sibling is in the best welfare interests of the child being created.

Mitochondrial donation while currently allowed in various jurisdictions around the world is still not fully understood. There have been serious concerns raised by leading researchers in this field about the efficacy of the procedure. For example Yamada et al., (2016),[3] and Kang et al. (2016),[4] found that there is the potential for genetic drift to occur leading to the embryo having the original genetics that the replacement therapy was trying to remove.

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[1] https://www.theguardian.com/science/2008/mar/09/genetics.medicalresearch

[2] http://www.adelaidenow.com.au/news/south-australia/perfect-siblings-to-save-dying-children/news-story/615cc79f239dae2133c54de9061a56cb?sv=d5c775a123bb7082b5fa5fb25190c337

[3] Yamada M, Emmanuele V, Sanchez-Quintero MJ, et al. Genetic Drift Can Compromise Mitochondrial Replacement by Nuclear Transfer in Human Oocytes. Cell Stem Cell. 2016 Jun 2;18(6):749-54.

[4] Kang E, Wu J, Gutierrez NM, et al. Mitochondrial replacement in human oocytes carrying pathogenic mitochondrial DNA mutations. Nature. 2016 Dec 8;540(7632):270-275.

Subsequently the use of mitochondrial replacement therapies raises considerable concerns and is not at the stage where it can be used safely. Others have argued that PGD is a viable alternative to mitochondrial donation.[5]

Considering that mitochondrial donation through oocyte donation (an oocyte is required to obtain the donor mitochondria) is invasive and potentially life-threatening through the possibility of ovarian hyperstimulation syndrome (OHSS) occurring; then the use of PGD to avoid mitochondrial disease is a better alternative in that it does not involve the use of a third party whose own welfare could be adversely affected.

Gene editing technologies such as CRISPR still have a long way to go before they could be safely used in humans. Currently there are still far too many off-site mutations occurring,[6] which could lead to dire consequences for the fetus. We also have no idea how our edits may affect the germ-line and long term health of subsequent generations.

The NIH's National Human Genome Research Institute states "Researchers and ethicists who have written and spoken about genome editing, such as those present at the International Summit on Human Gene Editing, generally agree that until germline genome editing is deemed safe through research, it should not be used for clinical reproductive purposes; the risk cannot be justified by the potential benefit."[7]

I am in complete agreement with this position. If the leading researchers and ethicists in the world are stating that it should not be currently done, then Western Australia certainly should not be diverting from their advice.

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[5] Smeets HJ, Sallevelt SC, Dreesen JC, de Die-Smulders CE, de Coo IF. Preventing the transmission of mitochondrial DNA disorders using prenatal or preimplantation genetic diagnosis. Ann N Y Acad Sci. 2015 Sep;1350:29-36.

[6] Zhang XH, Tee LY, Wang XG, Huang QS, Yang SH. Off-target Effects in CRISPR/Cas9-mediated Genome Engineering. Mol Ther Nucleic Acids. 2015 Nov 17;4:e264.

[7] https://www.genome.gov/27569225/what-are-the-ethical-concerns-about-genome-editing/

- ***Posthumous collection, storage and use of gametes and embryos, including the consent required, conditions for use, and any impact on other legislation such as the Human Tissue and Transplant Act 1982, Artificial Conception Act 1985, Births Deaths and Marriages Registration Act 1998, Administration Act 1903 and Family Provision Act 1972.***

The following is an article I wrote regarding posthumous use of gametes for the Sydney Morning Herald in 2011.

"Simplistically, creating a child between a loving couple is an expression of their love. By extrapolation, when a partner passes away before conception, but had gametes stored, the creation of that child posthumously is still an expression of that love. Sounds like a happy ending from an adult-centric perspective. What if we analyse the situation from a child-centric perspective?

What occurs as a result of posthumous conception is a deliberate and pre-planned deprivation of a meaningful relationship that that child should have had. Such situations do occur, such as when one of the parents dies, or abandons the child and parental responsibilities. As a society we recognise the loss incurred to that child as a result. However, by sanctioning and condoning posthumous conception we are making a statement that this loss is acceptable provided it was intentionally induced.

Research data from donor-conceived people in loving homes (after all, they were wanted, too, and their parents also went to extreme lengths) shows a significant proportion still want to know, meet and have a relationship with their donor (see studies as referenced in Adams 2013).[8] It is clear that their progenitor has meaning to them. Not only is it a matter of kinship but also of identity. Without having one of the mirrors of themselves that they see in their genetic parents, there is the potential they will have trouble forming their identity.

Sociological data shows that children growing up in fatherless or motherless households have myriad problems such as increased promiscuity, teenage pregnancy, imprisonment, substance abuse and poorer educational outcomes. This is not to say that these things will occur, rather that they occur at higher incidences than in the two-parent scenario. This does not take into account how the child may feel about being created from a deceased person.

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[8] Adams DH. Conceptualising a child-centric paradigm: do we have freedom of choice in donor conception reproduction? J Bioeth Inq. 2013 Oct;10(3):369-81.

Some donor-conceived people already report feeling like an experiment and having trouble dealing with their artificial conception.

In a world where adults seem able to obtain anything they want, is it ethically sound to presume our desire and love for a child is so great that it will automatically ameliorate any negative consequences the decision has on the child?

Just as there are offspring who are traumatised by their donor conception, there are others who are happy. Similarly, I would not want to have been conceived from the gametes of a person who has died, while others may be fine with that. But just because a proportion of outcomes are positive does not provide ethical or moral grounds to justify negative outcomes. The end should never justify the means."

In terms of the HRT Act interacting with those described in the terms of reference, any changes to the HRT Act must be appropriately catered for in those other Acts. From the perspective of recommendations, if Western Australia is to follow the lead of Victoria and potentially South Australia in acknowledging the rights of all donor conceived people under the HRT Act and Surrogacy Act to know who their progenitors are, rather than the discriminatory two-tiered paradigm that currently exists, then those changes must be reflected in the other Acts, particularly the Births Deaths and Marriages Registration Act (1998). This right of a child to know their progenitors should be reflected in the listings on the Birth Certificate which should be a factual document relating to genealogy. It is not a certificate of ownership and if the Birth Certificate is to be also used as a means of determining parentage, then all parties; progenitors and legal parents should be listed.

• Rights to storage of gametes and embryos including –
- rights upon separation or divorce, or the death or the physical or mental incapacity of an individual, or one or both members of a couple.

When undergoing fertility treatment it must be mandated that these issues be considered, agreed upon and signed by both parties before undergoing treatment. This agreement could be subject to change at a later date if one or both parties withdraw their consent in writing. By coming to terms before proceeding and considering possible outcomes it removes ambiguity and also has the potential to reduce costly court proceedings.

- rights of third parties such as subsequent spouses, and the rights of other relatives.

Third parties should not have rights over the storage and use of gametes, such as a mother of a sperm donor who dies and she subsequently wishes to use his sperm with a surrogate and donor egg to create a grandchild. Such 3rd party access should be prohibited.

• The storage of gametes, eggs in the process of fertilisations and embryos (including the duration of storage and procedures for extension of storage periods).

There should be a distinction made between gametes/embryo that are stored by donors and those autologous (their own) gametes/embryos stored by people for their own use. For those using their own gametes, the storage length should be up to the people who have stored them provided that they have paid the corresponding fee for storage. If they are non-contactable after a certain period of time the embryos should be allowed to expire. Under no circumstances should they be used as donor embryos without the original commissioning people's consent.

For gametes/embryos stored from donated material the length of time should be different. We have to consider the welfare of the child and their ability to know who their progenitors are. If for example a clinic has taken a sperm donation from a man who is 40 years old but then stores it for 20-30 years before using it to create a child, then he is likely to be over 60 years old by the time the child is born and then possibly over 80 years of age by the time the child reaches the age of maturity and searches them for contact. As 82 years of age is the current expected age of death in Australia it is incongruous to the welfare of the donor conceived person that the man that they have descended from and who they may be searching for has died of old age. Subsequently, we must factor in the age of a donor and the length of time the gametes are kept in storage to ensure that the donor conceived person has a reasonable expectation that their progenitor will be still alive by the time they reach the age of maturity and are possibly searching for answers.

• The Chief Executive Officer's (CEO) power to issue directions, the power to make a Code of Practice, regulations and guidelines, and the scope and effect of the existing directions and regulations under the HRT Act.

A Code of Practice must be implemented as the NHMRC Guidelines are a blunt instrument that has no force of law whereas a “Code of Practice” can. The Code can also be used to identify areas of legislation and or guidelines that lack clarity and provide the direction required. The Code of Practice must first and foremost follow the principle of looking after the welfare of the most vulnerable as the primary consideration, and in which the most vulnerable is always clearly the person created through these technologies.

• *The effectiveness of powers of enforcement and disciplinary provisions under the HRT Act and the adequacy of offences and penalties.*

Monetary penalties under the Act are grossly inadequate. The fertility industry has become a $500 million dollar business in Australia[9] with many clinics now operating on the stock market. The financial penalties currently prescribed under the Act do not provide sufficient disincentive to clinicians.

Imprisonment penalties are currently satisfactory.

• *Whether there should be a process of review or appeal of decisions made (by the Reproductive Technology Council (Council)) under the HRT Act.*

If the Council in its full capacity, including all members, preside over judgement then the decision should be final. The reason being as the Council has the expertise to deal with the situation presented, whereas a “higher authority” such as the Minister or a Court of Law does not have the expertise to make judgements on the case. Unless the case dealt with the enforcement or interpretation of the Act, then such jurisdiction would fall to the higher authority.

One caveat would apply to such a recommendation, and that would be that the Council membership must be altered to include the triad of donor conceived person, infertile person and donor of reproductive material as described in more detail later on.

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[9] http://www.news.com.au/lifestyle/parenting/babies/the-ivf-business-is-worth-half-a-billion-dollars-but-are-they-peddling-false-hope/news-story/036cb27530075169dfbe8bfa82db478a

• The impact on the HRT Act of relevant Commonwealth and State legislation, and aspects of legislation of other jurisdictions which could be incorporated into the HRT Act.

Any changes to the WA HRT Act should be in harmony with the legislation that currently exists in Victoria and that proposed (recommended) for South Australia. Primarily being that donor conceived people must not be discriminated upon based upon when they were conceived. Rather that all donor conceived people must have equal access to identifying information on who their biological parents (progenitors) are, and additionally any of their donor conceived siblings that are born in another family using the same donor. Furthermore, this must not be a one way street, but donors must also have the same right to access identifying information on who their donor conceived children are if they so wish.

In enabling contact between parties an organisation that specialises with reunions such as those agencies that assist adopted people to reconnect with their birth families should be used to facilitate contact and offer counselling, if and only if both parties wish to undergo counselling and use a 3rd party mediator. Counsellors from clinics have a vested interest in the running of a clinic and cannot provide completely unbiased counselling.

While it is vitally important that there are equal rights in every state of Australia and that there is harmony between jurisdictions, if there are opportunities to do things better, then those steps must be undertaken. It would also move Western Australia toward fulfilling the recommendation by the Senate Legal and Constitutional Affairs References Committee (2011),[10] whom stated that we needed nationally consistent legislation as part of their inquiry into donor conception practices in Australia.

Guidance from other jurisdictions such as the United States is not recommended. ART practice in such jurisdictions is highly commodified which only serves to devalue the welfare of the child and exploits people of lower income to sell body parts (gametes) or the use of their body (surrogacy).

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[10] Senate Legal and Constitutional Affairs References Committee. Donor conception practices in Australia (Senate Report). 2011.

• The effectiveness of the current licensing regimen, including fee structure, reporting requirements, powers of inspection and powers of obtaining information.

Clinics should be inspected by an independent auditor to ensure that they are following all licensing requirements, NHMRC guidelines and any appropriate codes of practice are properly adhered to. The auditor must also ensure that appropriate records are being kept such that donor conceived people, donors and other parties as specified can access identifying and non-identifying information as required. Inspections by an auditor who is already within the industry must be avoided to remove any bias from the auditing procedure (such as being audited by members of the Fertility Society of Australia who have a vested interest).

• Management of information / the Reproductive Technology Registers, including;

- Confidentiality of information,

Information should remain confidential within the realms of those immediately affected. That includes the donor conceived, the donors, the recipient parents and any siblings. Confidentiality and privacy have never been absolute in Australia and it is discriminatory to have one group of donor conceived who cannot access information on their genealogy and health history while another group born after a certain date can. This situation must be rectified.

It has been argued that those donors who were promised anonymity should be entitled to keep that anonymity.[11] While such arguments have been dismissed by others for a variety of reasons,[12] central to this discussion is that the child's welfare must be paramount and therefore their interests must override those of the donor or anyone else. To that effect their welfare needs to be appropriately catered for. Currently, however, I would put forth the position that their welfare needs are not being met. Particularly for those people conceived before the HRT Act and NHMRC guidelines were introduced and who do not have

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[11] Sauer JL. Competing interests and gamete donation: the case for anonymity. Seton Hall Law Rev. 2009;39(3):919-54; Pennings G. How to kill gamete donation: retrospective legislation and donor anonymity. Hum Reprod. 2012 Oct;27(10):2881-5.

[12] Chisholm R. Information rights and donor conception: lessons from adoption? J Law Med. 2012 Jun;19(4):722-41; Rees A. Keeping mum about dad: "contracts" to protect gamete donor anonymity. J Law Med. 2012 Jun;19(4):758-68; Adams DH. Gamete donor medical records: whose information is it? Med J Aust. 2012 Nov 19;197(10):543; Schneller EA. The rights of donor inseminated children to know their genetic origins in Australia. Aust J Fam Law. 2005 Dec;19(3):222-44.

the ability to access identifying and familial health history information on the donor; as well as those who are unaware of the identity of their siblings in order to prevent a consanguineous event which has occurred elsewhere and therefore a concern.[13]

The problem of consanguinity is a concern that many donor conceived people have and given the population size of the city of Perth, and if there have been large numbers of donor conceived people born from the one donor (prior to limits being set), then there is a very real chance that their paths could unknowingly cross. If they are then unaware that they are donor conceived, as is the case for the majority of donor conceived people,[14] they will not be able to take the appropriate steps to prevent a consanguineous event from occurring. It is therefore pertinent that all donor conceived people are aware of their donor conception status. The informing of the donor conceived could be made possible through the inclusion of details on the birth certificate which the donor conceived would need to access to obtain a drivers licence for example.

- Use of data for research,

The WA Reproductive Technology Council currently publishes annual reports. These reports contain some data such as the numbers of donors, treatments and births. The continued collection of such data which is publicly available should continue, not only for the public but also for researchers who may need access to such information (for example see Adams et al. 2016).[15] The collection of data is vital for scientific analysis to ensure that practice follows evidence. All perinatal and maternal data should be mandatorily collected for all births occurring in Western Australia and subsequently made available to researchers, to

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[13] Yoffe E. My Wife Is My Sister. Slate, Feb 19, 2013. http://www.slate.com/articles/life/dear_prudence/2013/02/dear_prudence_my_wife_and_i_came_from_the_same_sperm_donor.html

[14] Golombok, S., F. MacCallum, E. Goodman, and M. Rutter. 2002. Families with children conceived by donor insemination: a follow-up at age twelve. Child Development 73: 952-968; Broderick, P., and I. Walker. 2001. Donor gametes and embryos: who wants to know what about whom, and why? Politics and the Life Sciences 20(1): 29-42; Brewaeys, A., S. Golombok, N. Naaktgeboren, J. K. de Bruyn, and E. V. van Hall. 1997. Donor insemination: Dutch parents' opinions about confidentiality and donor anonymity and the emotional adjustment of their children. Human Reproduction 12: 1591–1597; Lycett, E., K. Daniels, R. Curson, and S. Golombok. 2005. School-aged children of donor insemination: a study of parents' disclosure patterns. Human Reproduction 20: 810–819.

[15] Adams DH, Ullah S, de Lacey S. Does the removal of anonymity reduce sperm donors in Australia? J Law Med. 2016 Mar;23(3):628-36.

enable population wide epidemiological studies to be conducted.[16]

- Use of data for purposes of national data collection and;

See point above regarding research. Further to that point, nationally available data would be better than just state based and improve the quality of research conducted and evidence available to improve practice. Data should therefore be made available for a national database.

- Access to information about donation, genetic parentage and donor conception,

Currently, discrimination is occurring within Australia in regard to the access of information about a donation, whether to the donor conceived themselves, the donors or even the recipient parents. This discrimination occurs across state borders whereby a donor conceived and donor's right to access information on each other is dependent on what state the conception and or donation took place. Also, in respect to every jurisdiction except Victoria, it is also dependent on when the conception took place, such that all donor conceived people conceived after 2005 have the ability to access identifying on the donor, their progenitor (biological parent). However those conceived prior to that, do not. This creates a two-tier society with one group being treated as second class citizens with lower rights than the other. These rights are granted purely on the era in which a person was conceived. This is discriminatory and unethical. This inequality is not supported by the United Nation's Convention on the Rights of the Child (UNCROC),[17] to which Australia is a signatory.

Information should not be restricted to identifying information but also should include a health history if the donor conceived should choose to seek such information. Knowledge of a medical history has serious implications for early diagnosis,[18] as well as the ability to make

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[16] Davies MJ, Rumbold AR, Marino JL, Willson K, Giles LC, Whitrow MJ, Scheil W, Moran LJ, Thompson JG, Lane M, Moore VM. Maternal factors and the risk of birth defects after IVF and ICSI: a whole of population cohort study. BJOG. 2017 Sep;124(10):1537-1544; Adams D, Fernandez R, Moore V, Willson K, Rumbold A, de Lacey S, Scheil W, Davies M. Sperm donation perinatal outcomes in an Australian population cohort. J Obstet Gynaecol Res. 2017 Dec;43(12):1830-1839.

[17] United Nations. Convention on the Rights of the Child. United Nations. 1989.

[18] Centers for Disease Control and Prevention (CDC). 2004. Awareness of family health history as a risk factor for disease--United States, 2004. Morbidity and Mortality Weekly Report 53(44): 1044-1047;Hastrup, J. L. 1985. Inaccuracy of family health information: implications for prevention. Health Psychology 4(4): 389-397;

lifestyle choices for the prevention of diseases such as type-2 diabetes and heart disease. As some donors may be young and relatively healthy at the time of donation but suffer from illnesses later in life,[19] any updated health information must be accessible on a more frequent basis otherwise the information will be obsolete. Evidence for the need to access the donor's medical history as well as having it updated was presented before the Law Reform Committee of the Parliament of Victoria inquiry into access by donor-conceived people to information about donors.[20] This report showed evidence of donor conceived people whose lives were adversely affected by the lack of this information.

Access to medical history information is not only important for the donor conceived themselves and their family, but it is also a public health issue. Early diagnosis and prevention also reduces the health care burden to society.

- The Voluntary Register (donor-assisted conception).

All records should be duplicated and centralised to create redundancy. Too many times have other donor conceived people reported to me that they have been told by a clinic that their records were destroyed. Some of these cases may be true, but for other cases including my own, the clinic has lied. For my own situation I was told on differing occasions that the records were destroyed and lost. However, upon using a Freedom of Information (FOI) request the records miraculously reappeared. I know of several other people who have also had their records be "un-destroyed" when a FOI request has been lodged. While lies have been used there have indeed been instances of not only destruction but also redaction.[21]

To avoid record loss, records should be duplicated and stored in a central repository such as Births Deaths and Marriages. Given that they could be issuing birth certificates that include information on the donor or that the person is donor conceived it is logical to have all the information stored in the one location.

Ravitsky, V 2012, 'Conceived and deceived: the medical interests of donor-conceived individuals', Hastings Center Report, vol. 42, no. 1, pp. 17-22.

[19] Adams DH. Gamete donor medical records: whose information is it? Med J Aust. 2012 Nov 19;197(10):543.

[20] Law Reform Committee. Inquiry into access by donor-conceived people to information about donors: final report. Victoria: Parliament of Victoria, 2012.

[21] http://www.abc.net.au/news/2014-08-18/code-breaking3a-abc-journalist-sarah-dingle/5676544

As I recommend that all donor conceived people have access to information regardless of when they were conceived and the ability to access identifying information should therefore be made retrospective, the need for a voluntary register becomes obsolete as it would be superseded by a mandatory register of all parties.

• ***The effectiveness of the operation of the Council and committees of the Council;***

The council is prescribed to be made up as follows:
The Council shall consist of —
(a) 10 nominated members, to be appointed by the Governor on the recommendation of the Minister, of whom —
(i) 7 shall be individuals respectively selected from panels comprising the names of not less than 2 individuals submitted in accordance with section 9(1) by each of —
(A) the Royal Australian College of Obstetricians and Gynaecologists; and
(B) the Australian Medical Association; and
(C) the Law Society of Western Australia; and
(D) 3 other bodies, being bodies having interests relevant to this Act; and
(E) the Minister charged with the administration of the Children and Community Services Act 2004; and
(ii) 3 shall be individuals selected by the Minister having regard to section 9(2); and
(b) an ex officio member appointed by the Minister, subject to subsection (3), as the Executive Officer of the Council.

There is omissions which must be corrected. That is it must also include a person who is an advocate for and is a product of these reproductive technologies such as a donor conceived individual. While a person who is conceived via IVF may also be able to fulfil this role, those conceived with 3rd party gametes provide a unique and special interest group which require special consideration given the complexity of their situation. After all we do not have councils or groups that deal with other special interests groups such as indigenous affairs without having an indigenous representative on said council/group. To not include one is disingenuous. Furthermore, it would also be appropriate to have an advocate for those people undergoing reproductive technologies (such as an infertile person themselves), and also a donor of reproductive material. This would fulfil the 3 bodies having interests relevant to the Act under Part 2 Section 8(a)(i)(D). One donor conceived person, one infertile person and one donor.

- ***The need for the continuation of the functions conferred, on the Council and on the CEO respectively by the HRT Act.***

The functions of the Council and CEO should continue.

The review of the Surrogacy Act 2008 to include the effectiveness and operation of the Act with particular reference to:

- ***Interaction with the HRT Act;***

The Surrogacy Act should be consistent with the HRT Act in all aspects, but particularly when addressing the welfare of the child. To avoid possible conflict it would be logical if both Acts were combined into one Act. That way whenever any future amendments were made it would be impossible not to ensure that any changes were consistent between both scenarios, however, by keeping them separated it runs the risk that one Act could be amended while ignoring or forgetting about the other.

- ***The need for provision as to the administration of the Surrogacy Act and any functions to be conferred on the Minister, Council, CEO and assisting staff/persons, respectively by this Act;***

Provisions should remain consistent with the HRT Act.

- ***The effectiveness of the current regime, reporting requirements, powers of inspection and investigation, powers of obtaining information;***

See response to similar question in HRT Act. Surrogacy typically implements donated gametes/embryos and therefore should follow all the same regimes, reporting requirements, inspection/investigation and powers to obtain information as contained in the HRT Act, with the proviso that in both instances (HRT Act and Surrogacy Act) all follow the best interests of the child principle.

- ***The effectiveness of powers of enforcement and disciplinary provisions under the Surrogacy Act, the adequacy of offences, penalties and timeframe for bringing proceedings;***

Imprisonment penalties are satisfactory, however, considering the amount of money that can potentially change hands in surrogacy arrangements; the financial penalties are not severe enough. Commercial arrangements in the USA can involve substantially greater incentives than the penalties presented. Therefore the penalties must be increased in-line with what may be received. For example, the Surrogacy Act specifies in Division 2, Section 8:

“Making surrogacy arrangement that is for reward
A person who enters into a surrogacy arrangement that is for reward commits an offence.
Penalty: a fine of $24 000 or imprisonment for 2 years.”

However, when we consider the reward that is available in commercial arrangements and using a website from the USA as an example, that $43,000-$53,000 (US or $54,000-$67,000 AUS) can be paid to a surrogate,[22] then the $24,000 penalty is inadequate.

- ***The impact on the Surrogacy Act of relevant Commonwealth and State legislation and aspects of legislation of other jurisdictions, which could be incorporated into the Act, including consideration of harmonisation of domestic surrogacy legislation;***

Harmonisation is always important provided that the welfare of the child is appropriately catered for. If the welfare of the child is to be reduced in the movement towards harmonisation, then it should not occur, rather best welfare principles must apply.

- ***The need for continued prohibition on commercial surrogacy;***

Commercial surrogacy is the commodification of human life. Women who agree to be a commercial surrogate are nearly always of lower class than the commissioning parent(s). I am unaware of any cases where a wealthy woman has agreed to be a commercial surrogate. This shows us that there is a power imbalance and that the financial status of the surrogate has a significant influence on their choice to become a surrogate. We have also seen whereby, in jurisdictions such as Australia, wealthy Australians will commission a commercial surrogate either in America or a country where there is considerable poverty. These countries have typically involved India, Thailand, Georgia and the Ukraine. The USA becomes a destination of choice because of the ease at which a surrogate can be sourced if a person is willing to pay the high price.

The use of impoverished women is simply exploitation. The treatment of them and the babies as commodities to be bought and sold has seen India and Thailand crack down on

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[22] https://www.conceiveabilities.com/surrogates/surrogate-mother-pay

and ban international commercial surrogacy. Thailand was highlighted through the Baby Gammy case which involved a couple from Western Australia.[23]

Some have argued that cases such as Baby Gammy provide evidence as to why Australia should allow commercial surrogacy to occur here under tighter control. I completely disagree with this position. It does nothing to the power imbalance and the fact that poorer women are being exploited by the wealthy. Child birth is one of the most dangerous things a woman can go through in their life with 830 women dying every day during childbirth.[24] Yet commercial surrogacy provides an inducement to women to risk their health and their life for financial gain.

Not only is child birth inherently dangerous but surrogacy in and of itself increases the risks to both the mother and child. Surrogacy typically uses donor eggs or donor embryos which are associated with increased risks of preeclampsia.[25] Preeclampsia is a pregnancy condition that is a leading cause of foetal and maternal morbidity and mortality.[26] Subsequently the health and life of both the mother and the child are at increased risk by undergoing surrogacy. All for what? Financial gain. Under no circumstances should the life and health of both a mother and child be put at increased risk for financial benefit.

We do not pay people for the donation of blood, organs such as kidneys, or even gametes (only reimbursement is allowed), and under no circumstances should this position change for surrogacy. It must remain altruistic.

- ***International commercial surrogacy arrangements;***

International commercial surrogacy arrangement should be prohibited and have the appropriate penalties. Problematically, NSW, Qld and the ACT have all prohibited international commercial surrogacy and have penalties that apply if it is conducted, however, not one person has been prosecuted or penalised for breaching those Acts. The

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[23] http://www.abc.net.au/news/2016-04-14/baby-gammy-twin-must-remain-with-family-wa-court-rules/7326196

[24] http://www.bbc.com/earth/story/20161221-the-real-reasons-why-childbirth-is-so-painful-and-dangerous

[25] Tranquilli AL, Biondini V, Talebi Chahvar S, et al. Perinatal outcomes in oocyte donor pregnancies. J Matern Fetal Neonatal Med. 2013; 26, 1263–1267;Klatsky PC, Delaney SS, Caughey AB, et al. The role of embryonic origin in preeclampsia: a comparison of autologous in vitro fertilization and ovum donor pregnancies. Obstet Gynecol. 2010; 116, 1387–1392; Salha O, Sharma V, Dada T, et al. The influence of donated gametes on the incidence of hypertensive disorders of pregnancy. Hum Reprod. 1999; 14, 2268–2273.

[26] Backes CH, Markham K, Moorehead P, et al. Maternal preeclampsia and neonatal outcomes. J Pregnancy. 2011; 2011, 214365.

Acts in those states have become blunt instruments that the citizens of those states are willing to exploit as they know they will not be prosecuted.

The majority of these penalties involve imprisonment, which perhaps is a factor that the courts take into consideration in that they are unwilling to “lock-away” a parent of a new-born child as they deem this to be unfair to the child. Perhaps, more severe financial penalties would be a better disincentive if the courts would be more willing to impose financial penalties than imprisonment.

The Baby Gammy case, the wealthy Japanese man who fathered 13 children to surrogacy,[27] the UK brother-sister-parent surrogacy scandal, [28] the US Congressman’s $5 million surrogacy scandal,[29] and the Australian woman jailed in Cambodia for operating a commercial surrogacy company, [30] are just examples of the many problems faced with not only international surrogacy but commercial surrogacy in general. So long as people are willing to pay fees around $100,000 to commission a surrogacy pregnancy (cost for American surrogate and why many people turn to “cheap” third world surrogates),[31] and it is a billion dollar industry,[32] then exploitation can and will occur.

- ***International trade in gametes and embryos;***

Firstly the donation of gametes or embryos in Australia is only ever conducted altruistically. We have recognised this as being vitally important such that there is no inducement to donate and that donors’ are not exploited, but to also prevent the commodification of human life. It could be extremely traumatic for a donor conceived or surrogate child to know that the only reason for their existence was because they were paid for. It is an offence to basic human dignity. If we are to source gametes and embryos from overseas markets, there is no control over the commodification of gametes. Typically in places like

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[27] https://www.theguardian.com/world/2018/feb/20/japanese-man-custody-13-surrogate-children-thai-court
[28] http://www.dailymail.co.uk/news/article-54972/Surrogacy-scandal-thats-shocked-world.html
[29] https://www.bionews.org.uk/page_96299
[30] https://chinapost.nownews.com/20180108-196323
[31] https://www.vice.com/en_us/article/exq7nz/how-commercial-surrogacy-became-a-massive-international-business
[32] India alone had a billion dollar surrogacy industry. See: https://www.vice.com/en_us/article/exq7nz/how-commercial-surrogacy-became-a-massive-international-business

America, donors are paid and can be paid quite large sums especially for egg donors.[33] This would be completely incongruous with the ethos and paradigm in Australia.

Secondly, in Australia we have recognised that donor conceived people (which includes those born through surrogacy) have a right to know who their biological parents are. Many donors in overseas programs are allowed to remain anonymous. Even though clinics in Australia are supposed to follow the same guidance of using identifiable donors, the process lacks the same oversight that it has here. We are relying on the overseas clinics to provide correct information, of which we have no inspection or auditing rights over those clinics to ensure the records are accurate. Furthermore, if the child wishes to find out information on their biological parent(s) or even perhaps contact them when they reach the age of maturity, the task is made so much harder by having the donor reside overseas. These donors and their donations are also not subject to the same limit on the number of children created or families assisted as we do in Australia. There have been reports of donors in America having hundreds of offspring[34] which can potentially be extremely traumatic to the child created to know that they have essentially been farmed out like livestock with no real possibility of forming a meaningful relationship with all of their siblings.

We also need to be very careful about trying to meet the market need. The reason why Australian clinics would opt to source gametes or embryos from overseas is because they would be struggling to meet the demand here. However, just because there is a larger demand for something than the supply can fulfil, does not mean that we should use sub-standard methods of meeting that demand. We have a shortage of kidney donors in Australia, however, we do not source kidney donors from overseas and then pay them to meet our demand. We should never sacrifice standards simply to meet the demands of those who wish to have a child when such procedures are exploitative and do not have the checks and balances required to ensure that the welfare of the child is appropriately protected. Therefore, gametes and embryos should not be sourced from overseas.

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[33] One Australian clinic is offering $5000. See https://www.smh.com.au/national/egg-donor-money-fertility-clinic-offers-women-5000-20150411-1miw9h.html

[34] http://www.nytimes.com/2011/09/06/health/06donor.html

- ***The effectiveness of the operation of the Council and committees of the Council;***

See response to the same question in the HRT Act. The council membership must be altered to include a donor conceived person, a recipient parent and a donor for reasons outlined in that section.

- ***Whether there should be a process of review or appeal of decisions made (by Council) under the Surrogacy Act.***

See response to the same question in the HRT Act.