Submission to the Legal Affairs and Safety Committee for the inquiry into matters relating to donor conception information.

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Introduction

This submission is based on the premise that there is a significant overlap between matters relating to adoption legislation in regards to release of information and also the issue of appropriate professional support to affected parties. I make these comments and suggestions on the basis of being a Social Worker who has worked in post-adoption support in Queensland for the past 13 years, in multiple capacities, across multiple organisations. In these roles, I have also heard from individuals affected by donor conception who do not have access to any funded support and are limited in their ability to access information about their origins or the child that was born as a result of their donation. I have also had contact with professionals who work for funded support services in other states of Australia who have shared their learnings. Additionally, I completed research as a part of a Psychology Honours thesis in 2008 which explored the psychological impacts of adoption on adopted people.

There is a need for legislation and funded support to address access to information and donor linking in Queensland.

It is essential that donor conceived individuals be granted the same human and legal rights that adopted persons have throughout Australia. Since 2009, all adopted people and their biological relatives within Queensland have had the right to receive identifying information about one another after the adopted person reaches the age of 18. In addition, since 2009, the Queensland Government have funded Post Adoption Support Queensland (The Benevolent Society) to provide search and intermediary support to those affected as well as counselling or group support. This means that adopted people, and their biological relatives can receive free support to locate their relative (based on the adoption information provided by the Queensland Government) and to have a professional third party to outreach to that relative on their behalf to ascertain their relatives wishes around possible future contact. In this way, all parties are able to receive support to navigate the practical and emotional challenges associate with such contact, and to receive assistance in navigating any ethical dilemmas that may arise as a part of this process.

Furthermore, since 1991 adopted people and their biological mothers have had the right to receive identifying information about one another provide a ‘contact veto’ had not been lodged by the other party (contact statements were removed from the legislation in 2009).

There is no Queensland legislation which regulates access to information in relation to donor-conception nor support services, which is an extremely concerning state of affairs.

Legislation is needed to regulate donor conception practices.

Whilst, no legislation exists in Queensland to govern and regulate donor conception practices, fortunately, the **Surrogacy Act 2010** exists which addresses 'transfer of parentage' and mandates against commercial surrogacy (therefore avoiding situations where children are treated as commodities). The 'guiding principle' of the act is to uphold the best interests of the child born as a result of surrogacy throughout his or her life. The Act states "A child born as a result of a surrogacy arrangement should be cared for in a way that promotes openness and honesty about the child's birth and parentage and that promotes the development of the child's emotional, mental, physical and social wellbeing". In relation to this, the act specifies that all parties to the arrangement must receive appropriate independent counselling and this includes exploring with the intendant parents, how they plan to communicate with their child in an honest and open manner. This act also allows a child born as a result of a surrogacy arrangement to access the relevant court records after the child turns 18. This provides access to the surrogate's name. Similar legislation needs to be introduced to protect the rights of all donor conceived people.

2016 Queensland Labour Party policy statement:

Whilst not enacted, in 2016, the labour party outlined a policy statement that stated:

"Labor will legislate on the rights of donor conceived individuals:
- For the right to identify information on their donor, regardless on when they were born
- For the retention of information on donor conception in a government registry, to which all clinics must supply donor conception information.
- For a mechanism for accessing identifying information on their donor and birth information, including medical history of donor siblings
- To allow donor conceived individuals to request contact with donors and donor siblings supported by counselling services
- To protect the rights of donors and donor siblings by allowing them to veto contact."

These undertakings would be an excellent start. However, the issue of vetos should also be re-considered as such a provision would mirror archaic adoption legislation that has not existed since 2009.

The issue of appropriate professional support must also be considered and addressed urgently.

Privacy Considerations (including parallels with adoption):

Prior to the opening of adoption records in 1991, opponents argued that biological parents were promised anonymity at the time the adoption occurred and that therefore, records should remain sealed. Similarly, this argument has been made in various Australian jurisdictions in the context of donors being promised anonymity at the time of donation. However, it is now widely accepted that adopted people have a right to information about their own genetic origins and that this right outweighs any right to 'privacy' on the part of the biological parent. Both adopted and donor conceived people were not party to the decision of their conception and information about their own biology is a basic human right. Donors, if approached, have the option of declining contact as any member of society has a right to choose who they associate with. Other laws come into play in instances of harassment or intrusion by another person. The introduction of an appropriate support service to facilitate search and donor linking would also help mitigate any possible negative effects of donors being contacted by their offspring.

Human Rights Considerations:

In Queensland, current adoption legislation and practice is based around the principle of 'in the best interest of the child throughout his or her life'. However, in the case of current donor conception practices, the focus appears to be on the needs of parents seeking to have a child through these practices in the absence of any legislation that affords consideration to the rights of the child that is born as a result of these practices (particularly when they reach adulthood).

Victorian legislation's retrospective access to information about donors is supported by a human rights analysis. Specifically, articles 7 and 8 which highlight that children have the right to know and where possible, cared for by their genetic parents and acknowledgement of the right to an identity, nationality, name and family ties (United Nations General Assembly, 1989).

Lessons from other jurisdictions

Victoria

Victoria was the first jurisdiction in the world to regulate Assisted Reproductive Technology in their 1984 legislation which came into effect in 1988. The 2017 amendment to their current Act ('Assisted Reproductive Treatment Act 2008') recognises that all donor conceived people (sperm, egg and embryo donation) have the right to know their genetic heritage irrespective of when they were born (retrospective access). That is, for donations that occurred prior to 1998, donors are no longer able to prevent the release of their identifying information, but can determine how, or if, they have contact with an applicant through a contact statement. The option of a 'contact' statement mirrors current adoption legislation in Queensland. If a 'no contact' statement is breached, penalties may apply. This is similar to Queensland's 2009 adoption act which provided for penalties (fines or jail terms) if a contact statement was breached, however these penalties have since been removed from the Act.

In Victoria, responsibility for managing a central and voluntary register moved to The Victorian Reproductive Treatment Authority (VARTA) on 1 March 2017. They also provide government funded information and support to all parties. This includes assistance with the exchange of information and meetings between all parties.

Western Australian

Western Australia's Human Reproductive Technology Act (1991) now mandates that clinics must provide donor codes to donor conceived people, which can be used to facilitate matching via. a contact Register. A voluntary contact register is maintained by a non-government organisation with experience in post-adoption support.

New South Wales

New South Wales has since 2010, operated a central register based on the *Assisted Reproductive Technology Act 2007* (NSW). This is operated by the Department of Health. It requires clinics to place information about people conceived after 1 January 2010 to NSW Ministry of Health for inclusion on the register.

For donor conceived people conceived before 1 January 2010, they can register information about themselves on the central register as can donors. With both parties consent, information about one another can be exchanged.

Findings of the Federal Government’s 2011 inquiry

Thirty two recommendations were made. The first recommendation was for the development of assisted reproductive technology regulation and legislation in Queensland (as well as the NT, ACT and Tasmania). This has not occurred. They suggest that legislation regarding ART should be consistent across Australia.

For this reason, Queensland would be wise to model its legislation off Victorian Legislation.

Implications of direct to consumer DNA matching

Direct to consumer DNA profiling and matching websites such as Ancestry.com are being utilised widely and allow donor conceived people to connect with biological relatives regardless of legislation and in the absence of a funded support service in Queensland. This is concerning because of the complex issues involved for all parties. Funded adoption services receive enquiries from donor conceived people and other family members that have identified their donor’s offspring through DNA testing and who request support. However, these services are limited in what they can offer due to parameters and limited resources. Therefore, there is a need for funded support in this area, even prior to the establishing of legislation and a central register in Queensland.

Unregulated practices

Online groups exist to facilitate ‘do it yourself’ practices regarding donor conception due to the excessive costs involved. Therefore, there are donor conceived people who have been conceived through these informal arrangements. This presents issues in donor linkage as there may be no records to facilitate entry onto or matching via. a central register. It also means that protections offered in the National Guidelines are not available to these individuals. The only option available to these individuals is AncestryDNA testing and similar. Therefore, it is crucial that these individuals have access to a support service.

Support needs

There are many similarities between the experiences of those affected by adoption and those affected by donor conception. Like adopted people, donor conceived people lack crucial information about their own identity and need access to information about their genetic background and ancestry, including medical information. Other issues include:

Late Discovery

Similarly to those who experienced past adoption practices, donor conceived people frequently find out about their status later in life. A 2020 survey by the international group with 4000 members (‘We Are Donor Conceived’) revealed that 57% of respondents found out of their donor conceived status as an adult (often by DNA testing through websites such as ancestry.com or being told by a family member). In the context of adoption, such as revelation has been termed ‘Late Discovery

Adoption' and is associated with negative psychological impacts. Such disclosures also cause sometimes irreparable damage to close family relationships. Such individuals frequently report feelings of betrayal, disbelief, confusion and anger. Therefore, it is crucial that such individuals have appropriate professional support available to them.

Donor linking (Search and reunion)

In the context of post adoption, the terms 'search and reunion' are used to describe the process of locating and contacting biological family members. In the context of donor conception, this is termed 'donor linking'. When contact is sought with a biological family member, a myriad of outcomes are possible and individuals often request support at this time. The support may initially focus upon considering the impact of the outreach on various parties, including the legal parents of an adopted or donor conceived person who may fear losing their child to the biological parents. After contact is attempted, individuals may require support if the other party does not want contact, due to the grief associated with this outcome. If both parties do wish to form contact with one another, they will benefit from the option of having a third party facilitate this contact initially due to complexities that often arise. Eg. A donor may not have told their subsequent partner or family about the donation and may need time to decide how they wish to communicate or proceed. The third party can provide a supportive buffer. There may also be decisions that need to be made regarding contact between siblings who share the same donor, including children raised by the donor.

Issues facing legal parents

The legal parents of donor conceived individuals report experiencing fear around telling their children that they are donor conceived and uncertainty about how to do so, or how to handle questions that arise. These parents require support from professionals who have appropriate knowledge and expertise. If these disclosures are not managed skilfully, parents may experience relationship breakdowns with their children later in life when the secret is revealed. Indeed the 2020 'We are Donor Conceived' survey (https://www.wearedonorconceived.com/2020-survey-top/2020-we-are-donor-conceived-survey/) results indicated that only 37% of respondents said that their parents were aware of their true feelings about their conception. This indicates a need for parents to receive support and education to understand their children's needs and the act of disclosure. Further supporting this is the fact that the survey highlighted that those who learned about their donor conceived status before the age of 3 were more likely to categorise their overall experience of being donor conceived as positive.

Donors experiences

Similar to biological parents of adopted people, some donors have expressed later in life feeling a sense of loss around being the biological parent of children that they do not know. They may go on to have other children whom they raise, who may also wish to know their sibling/s (donor conceived person/s). In the case of embryo donation, the donor conceived person may have two biological family and siblings who are a cohesive family unit. All individuals involved require specialised support to navigate these complex feelings, processes and relationships.

Separation Trauma

In the instance of surrogacy, the children born to this arrangement and then separated from their surrogate at birth may experience the same separation trauma that has been widely documented in the context of adoption separation. The effects of this trauma are life-long and have been linked to higher rates of mental health difficulties. These are documented in the Australian Institute of Family Study's 2012 study into past adoption experiences – (https://aifs.gov.au/publications/past-adoption-experiences). This study also documents that adopted people do not feel that their trauma is understood or recognised within society.

Siblings

In states that have contact registers, it has been noted that a significant number of those who apply are parents with young donor conceived children who want to connect with other parents who may have children born to the same donor. Similarly, adult donor conceived people seek to connect with siblings as well as donors. This includes other siblings born as a result of donor conception and children born to and raised by the donor. In these cases, a support service that facilitates contact in the first instance is considered important.

Birth Certificates

Another important consideration is that of birth certificates. Unlike adopted people who have two birth certificates (an original birth certificate with their birth mother and sometimes father's name recorded) and a legal amended birth certificate that lists the names of their adopted parents, donor conceived people are currently only issued with one birth certificate. This lists their legal parents names (not their genetic parent). Based on the Queensland 'Status of Children Act' 1978, the recipient parents are automatically assumed to be and are recorded as the child's legal parents. This places donor conceived people in a difficult position when seeking information about their donor. They are at the mercy of a clinic that may or may not be supportive of their request or have appropriate systems in place. Additionally, there are inequalities as different clinics respond differently to such requests. These experiences often cause great distress. Whilst the establishment of a central register would address the issue of information release, there are still other considerations regarding birth certificates.

In regards to adoption, two states of Australia (New South Wales and South Australia) currently have legislation that allows for 'integrated birth certificates'. These documents allow adopted people to have a legal birth certificate that lists their original parents (no longer legal) and their adoptive parents (legal parents) as well as their pre and post adoption names. Adopted people report that the ability to obtain such a document has greatly aided their sense of identity and psychological wellbeing. As similar document should be considered in Queensland for both adopted and donor conceived people.

Conclusion

Legislation and a funded support service is urgently needed in Queensland to support donor conceived people and all parties linked to them. Queensland would do well to carefully consider Victorian legislation which is the most developed. Retrospective access to information is considered vital. Queensland should also carefully consider the support services that exist in Victoria and Western Australia as a model, as well as the close link between the needs of this group and support services that already exist in Queensland to offer similar services to those affected by adoption. Queensland should consider the pro's and con's of a central register being held by government vs. a non-government organisation and how the information release and support process can work together to meet the needs of those affected.

Further, there is currently no Queensland Health or other government website that provides any information for donor conceived adults (and those linked to them) about their rights or options for support. This should be established urgently. Many donor conceived people do not have knowledge of the clinic where they were conceived, or have attempted contact with a clinic that may have since closed or contact a clinic who is unwilling to support them in their quest for information.