Submission to the Legal Affairs and Safety Committee of the Queensland Parliament's Inquiry into matters relating to donor conception

1. Introduction

VANISH Inc. (Victorian Adoption Network for Information and Self Help) appreciates this opportunity to make a submission to the Legal Affairs and Safety Committee of the Queensland Parliament's inquiry into matters relating to donor conception.

VANISH strongly supports initiatives to reform law and practice relating to support and assistance for people affected by donor conception. Specifically, VANISH supports the implementation of legislation which gives all donor conceived people the right to identifying information about their natural or biological donor parents and measures to facilitate searching for them.

VANISH profoundly understands that knowledge about parentage, and genetic and cultural heritage, contributes significantly to a person's sense of identity and so strongly supports the right of all donor conceived people to access identifying information about their natural/biological parents/donors regardless of when and where they were conceived. VANISH strongly supports retrospective legislation which allows all donor conceived people to be equally eligible to access identifying information about their donor parent.

Our submission comprises background information in relation to our organisation, followed by our position on donor conception including the principles we hold and the rationale for these. We then address the questions posed by the Queensland Parliament in relation to policy and practice in Queensland.

2. About VANISH

VANISH is a secular, community-based, state-funded organisation established in 1989 by the Victorian Government to provide information, search, and individual and group support services to people separated from family members in Victoria. This includes working with people living in other states and territories of Australia and overseas. We have 33 years' experience providing family search and support services to people who have been separated from their natural relatives through adoption, state wardship and donor conception.

VANISH is governed and staffed by individuals with a relevant lived experience, who have a sound understanding of the complexity of the lived experience for people who seek our assistance and support. This includes people who were raised apart from one or both of their natural parents, mothers and fathers separated from their child(ren), siblings separated from siblings, and the family members of these groups of people. We are well informed as to the impacts of separation from natural relatives and families on the individual and their family across the lifetime and subsequent generations.

Over the past three decades VANISH has been involved with, and provided services to, people impacted by donor conception: donor conceived people, their biological parents/donors and the families of both. This has included undertaking advocacy with, and providing support to, individuals affected. VANISH has undertaken searches on behalf of donor conceived adults, donor parents and recipient parents both directly and through arrangements with the Infertility Treatment Authority (ITA), Victorian IVF clinics, and the Victorian Assisted Reproductive Treatment Authority (VARTA).

A few examples of the advocacy and support VANISH has provided are:
- 1993 VANISH arranged for Bill Cordray, a donor conceived person from the US, to come to Australia to speak to the VCOSS conference on "Let the Offspring Speak";
- 2003 VANISH panel discussion event "The personal and social implications of donor conception" with speakers with a lived experience and professionals from Melbourne IVF and ITA;
- 2004 VANISH submission to Victorian Law Reform Commission review "Assisted Reproduction & Adoption: Should the Current Eligibility Criteria in Victoria be Changed?";
- 2013 VANISH assisted with the establishment of and hosted a Melbourne-based support group for donor conceived adults;
- 2015 VANISH assisted a group of donor conceived individuals to raise funds for and run the first National "RUDC" Conference; and
- Multiple submissions to reviews and inquiries in Victoria and other states over the last two decades.

3. VANISH Position on Third Party Reproductive Treatments and Practices

VANISH holds that society must learn from past experiences. In recent years, numerous national, state and agency apologies have been made to the thousands of Australians who have suffered, and continue to live with, the unintended consequences of legislation, policy and practices that were, at the time, considered to be 'in the best interests of the child'. These include Aboriginal and Torres Strait Islander people (The Stolen Generations), those with an experience of state care/wardship (Forgotten Australians), and those with an experience of past and forced adoption practices. Public recognition of the need for such apologies demonstrates the importance of exercising extreme caution in considering the potential long-term consequences of policy decisions and practices.

VANISH holds that any third-party method of human reproduction or family formation must meet all aspects of the *United Nations Convention on the Rights of the Child* 1989 (UNCROC), which Australia ratified in 1990. That is, the rights and needs of people born through donor treatment procedures including any future donor conceived person, must be considered as paramount and must be enshrined in all legislation, policy and practice. UNCROC enshrines the principle that it is a person's birthright to know their heritage, including identifying information about each person who biologically and/or genetically contributed to their creation, irrespective of the circumstances of their conception.

The medical nature of donor conception has traditionally determined that the desires of the parents using donor treatment procedures take priority over the rights and needs of donor conceived people. VANISH recognises that donor conception is a complex and emotionally fraught matter, and that the desire to have children involves an intricate mix of biological, psychological and social factors. Whilst acknowledging these factors, we hold to the principles that, as enshrined in UNCROC, children have a universal right to be raised by the mother and father from whom they were biologically/genetically created. This is not the same thing as being raised by the parent(s) who sought the child's creation. We also hold to the principle that there is no human right to be a parent and 'the best interests of the child' should always take priority.

Donor conception, as with adoption, legally replaces one parent/set of parents with another, and the donor conceived person is recognised in law as if having been naturally born to the parent(s) who undertook third party reproductive treatment. This represents a number of losses for the donor conceived person and violates their inalienable birthrights to preservation of family name, heritage and identity, and potentially also to preservation of their family relationships across their life cycle and subsequent generations.

4. Principles and their rationale

VANISH holds, where donor conception occurs, it should be undertaken according to best practice principles. These principles include that:

- Donor conception should never be permitted on an anonymous donor basis. This includes that prohibitions should be introduced and enforced in relation to Australian citizens travelling overseas in order to access anonymous sperm, eggs or embryos, and on obtaining anonymous sperm, eggs or embryos from overseas via the internet or other means.
- The posthumous use of gamete is a breach of the human rights of the child to be born. It is unethical and should not be permitted or supported by legislation and practice.
- Donor conception should be restricted to altruistic arrangements. That is, gamete and embryo exchange for money should be prohibited and these prohibitions enforced. VANISH views the reimbursement of reasonable costs to donors as a slippery slope that can easily lead to payment for gametes, embryos and/or a baby, if not closely monitored and regulated.
- Professional pre-counselling by an appropriately qualified and experienced professional (e.g. social worker or psychologist) should be mandatory for potential recipients of donor conception treatment. This should include exploration of how they will feel and respond if/when their child expresses resentment about their lack of connection with their donor parent or siblings, and related scenarios.
- Donor conception assisted reproduction services should be highly regulated and closely monitored by suitable regulatory authorities that are independent of assisted reproduction service providers.
- Assisted reproduction service providers should be required to retain and securely maintain all relevant records, including those containing identifying information about the donor, for an indefinite period of time. It should be an offence to destroy, redact or withhold such records from donor conceived people.
- There should be openness, accuracy and transparency in all aspects of donor conception. The child must be provided with full and accurate information regarding the circumstances of, and contributors to, their creation and birth. This necessarily involves the recording of comprehensive identifying details pertaining to each party involved in the child’s parentage and birth on the child’s legal birth registration records (for example, an integrated birth certificate). A donor conceived person should not have to wait until they reach the age of 18 to apply for an accurate and comprehensive birth certificate.
- Genetic relatives are entitled to seek information about donor conceived relatives. For this purpose, VANISH holds that genetic relatives should be entitled to apply to the relevant authorities which, in turn, should be required to proactively facilitate connection between the applicant and the person(s) sought.
- Information, counselling and support services should be available at no cost to all parties affected by donor conception across the life-time. These services should be delivered by organisations that are governed and staffed by people with a lived experience and are independent of assisted reproduction treatment service providers.

- Information and education about the long-term impacts of donor conception practices should also be provided to the wider community, by an agency that is independent of assisted reproduction service providers. Such education is important to address the likely future and long-term needs of the innumerable people who do not know they are donor conceived and the implications for their health, well-being and family relationships.
- Advocacy on behalf of people affected by donor conception practices should be government funded and provided by an organisation(s) that are governed and staffed by people with a lived experience and are independent of assisted reproduction treatment service providers.

VANISH holds, where donor conception occurred anonymously in the past, that:

- Retrospective legislative provision should be made for donor conceived people to access identifying information about their donors and the circumstances of their conceptions.
- In regard to cases where it is not possible to access the information sought (for example, because the relevant medical records have been destroyed), a government funded and supported DNA testing service and databank should be established and made readily accessible to donor conceived people and donors. This position is supported by Recommendation 12 s7.76 of *The Senate Legal and Constitutional Affairs References Committee: Donor Conception Practices in Australia* (2011) report, which recommended that any voluntary registers incorporate a DNA databank in order to enable donors and donor conceived persons to have their details placed on the register for possible matching in circumstances where records relating to their identities have been destroyed.
- Consideration should be given to the impact of releasing identifying information about donor parents on the donors and their families. However, such privacy concerns should never be prioritised ahead of the rights of donor conceived people to know their identity.
- Specialised search and support services should be provided at no cost to those affected in order to assist them in connecting with their natural/biological family members. These services should be provided by organisations that are governed and staffed by people with a lived experience and that are independent of assisted reproduction service providers.

VANISH holds, in general, that:

- Legislation pertaining to donor conception should be nationally uniform.
- Legislation in Australian states and territories should, as far as possible, treat all donor conceived people equally and consistently, regardless of when or where the donations that led to their conception were made.
- Such legislation should be regularly reviewed and updated, given the continuous and rapid evolution of assisted reproduction technologies and treatments.
- Such legislation should also be reviewed for consistency with other related areas of legislation – including, surrogacy and adoption. There should be a holistic and harmonious approach to legal provisions pertaining to access to information, contact statements, birth certificates, etc., across all forms of third party human reproduction and family formation.
- Independent research is necessary to address the substantial knowledge gap in long-term outcomes for people affected by donor conception. This work must be funded and conducted independently of the assisted reproductive technology industry; those seeking to utilise assisted reproductive treatments; those advocating for increased access to assisted reproductive treatments; and the authorities responsible for monitoring and regulating assisted reproductive service providers.

5. Responses to the Committee's Questions

5.1 Rights of donor-conceived persons, including to know their genetic origins
As stated above, knowledge about identity is a basic human right (see for example UN Convention on the Rights of the Child Sections 7, 8 & 9) and should not be compromised by the wishes of any party who does not want to be known about or contacted. All those involved are adults and anyone not wanting contact can make their wishes known, as do adults in other spheres of life. Not wanting contact is not sufficient reason for either party to be denied information about the other.

The Government provides the legislative framework within which third party reproduction occurs and as such, has a duty of care to provide adequate support services so that donor conceived people do not have to deal with the consequences of being born and raised separately from one or both of their biological parents alone. The state cannot separate itself from the risks, responsibilities and costs of the consequences of that which it has legislated for.

It is evident that many adults who are donor conceived through the use of donor gametes desire and seek to contact and establish an ongoing social connection with their genetic father. There is less evidence on how donor conceived adults born of egg or embryo donation feel, however, it is likely they will also want to know about and seek to have contact with their genetic mother. Many donor conceived people also express a desire to know their siblings from the gamete donations by their genetic parent(s) and as a result of the union with a partner(s).

It is also evident through the Victorian experience that gamete donors seek to know about or contact the children they assisted to create. Their overwhelmingly altruistic motives and strong wish to help others become parents extends to a desire to know whether they were successful in this hope and what became of the children created using their gametes. It is important to acknowledge that some donors were not informed that their gametes would be used for the purposes of artificial reproductive technology and are not aware of their donor parent status, for example where they donated their sperm for medical research.

As with adoption, there are also scenarios whereby donor conceived people or donor parents might not wish to have contact or establish a relationship, but do wish to pass on vital medical information regarding heritable diseases and conditions, based upon their own health status or that of their relatives.

People who are not adopted or donor conceived can find it difficult to understand how important biology is to one's identity. This viewpoint is further promoted by the people it serves, in particular those involved in the infertility industry. Yet, paradoxically, genealogy and family history are at the peak of their popularity, reflected in the millions of viewers of shows like Who Do You Think You Are and Long Lost Family, together with the meteoric rise of DNA testing companies such as Ancestry. It is high time that the drive and need to know natural/biological relatives be completely normalised and validated as well as recognised as a right.

5.2 Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors;
38 years ago Victoria faced almost this exact same law reform scenario. Adopted people and natural parents were increasingly speaking out about the physical, psychological and emotional damage caused by the secrecy provisions in closed adoptions and the harm caused to adoptees by their inability to find out the identity of their natural parents. They were faced with strong opposition, mainly relating to previous promises of anonymity given to natural parents at the time of the adoption and concern for the privacy of natural parents who did not wish to be contacted. Over time

we came to understand that many natural parents had not wanted or asked for privacy and those driving for secrecy were the institutions involved in arranging past closed adoptions. In 1984 Victoria was the first Australian state to introduce what has become accepted as ground-breaking legislation, allowing all adoptees access to information about their natural parents. Other state governments followed in due course.

In February 2016 the *Assisted Reproductive Treatment Amendment Act 2016 (Vic)* was passed, amending the Act so that all Victorian donor conceived people have a right to identifying information about their donor, contact preferences are available to donors and donor conceived people allowing them to determine the way in which contact will occur, and responsibility for managing the central and voluntary registers was moved to VARTA. The legislation was implemented from 1 March 2017.

These precedents, together with adoption legislation reform in Queensland, means that the Queensland Parliament has available to it the legislative models and decades of experience which provide evidence of the success of discarding secrecy provisions and allowing people access to information concerning their identity.

VANISH is not privy to conditions stated on the consent forms or ‘contracts’ donors signed and whether these prohibit the release of information about their identity to either the donor-conceived person or a third party (e.g. a central register). We would note though, that a contract between a donor parent and child would have been impossible, due to the child not yet being in existence, and therefore unable to be bound to a contract.

5.3 Access to historical clinical records and implications of retrospectivity;

Where records relating to donor conception exist, for example in a hospital or clinical setting, the people to whom those records relate have a right to access the information contained within those records. It is hoped that records relating to donor conception that occurred in a clinical setting are intact. In cases where records have been destroyed, which is devastating for the affected people, there should be the option of assistance with Direct to Consumer DNA testing and analysis to establish the identity of relatives. It should be illegal for any records pertaining to third party reproduction to be destroyed and what constitutes a record should be defined in the Act to provide clarity and assist with ensuring accountability.

Changing laws retrospectively always causes discomfort, particularly in the legal and regulatory professions. However, there are certain circumstances where inadvertently, a group of people’s rights have been breached by previous laws and it is necessary to right the wrongs of the past. In Victoria, changing the Adoption Act 1984 to allow access to identifying information was as a result of a long and hard campaign. There was a high level of fear about the potential disruption to people’s lives, particularly by adoptive parents who had been advised by the adoption agencies not to tell their child the truth of their identity and adopted status. The emergence of truth is always a threat to those who seek to hide it, but this should not be a reason to keep secrets about something as fundamental as a person’s genetic parentage. Furthermore, in practice and with tens of thousands of records having been opened, people’s fears were not realised. For the most part, outreach and contact has been undertaken discretely and respectfully and the proportion of negative experiences has been low. Contact and reunion while complex, has brought considerable relief, healing, joy and a sense of completion to many.

Direct To Consumer (DTC) DNA testing has significantly changed the landscape with individuals undertaking tests just to find our their ethnicity, then discovering they are donor conceived or that they have donor conceived siblings or cousins. Genealogists believe that due to the exponential rate of growth in the use of DTC DNA testing companies, it will not be long before there is sufficient data for any person of anglo-celtic background to be identified. Discovery of donor conception through DNA testing can be shocking and distressing so it is important that information is publicly available about how to make outreach or respond to outreach as well as support to process this life-changing news.

The most important benefit to changes to the secrecy provisions in donor conception is that it will redress the balance of rights and allow donor conceived people access to vital information regarding their identity. Some donor conceived people may be satisfied knowing the identity of their donor parent, receiving medical information, or having some of their questions answered. Others will wish to exchange letters and photographs or meet their relatives, or pursue an ongoing relationship. These wishes depend on the individual and can often change over time. Similarly, some donor parents have a keen interest in knowing the children they assisted to create are happy, healthy and loved. Some may be happy to answer specific questions, and some may prefer to choose not to pursue a relationship. The impact though, will be empowerment and choice, as opposed to the government restricting all flow of information from donor parent to donor-conceived person, and vice-versa.

5.4 Access to support and counselling for donor-conceived persons and donors

Removing secrecy provisions must go hand-in-hand with establishing search and support services. The state has a duty of care to offer accessible specialist services to all donor conceived people who have been subject to secrecy about their identity. Much like people affected by adoption, individuals need access to search assistance, intermediary services, information, education, specialised counselling and peer support. Yet many donor conceived adults continue to be denied access to specialist counselling, because of the lack of recognition of these needs or the lack of willing to provide and pay for them.

Counselling is vital. It can be life-saving. It can assist an individual manage some of the more complex aspects of being donor conceived such as genealogical bewilderment, as well as the potentially distressing consequences of contact with natural relatives such as genetic sexual attraction. These issues are common and well understood issues in professional fields, yet they are rarely discussed with or by treatment providers, despite the risks involved.

Not all donor conceived adults will need support or counselling, but for those who do, it is essential that they have access to a professional with a good understanding of the impacts and the skills to assist individuals process their feelings and questions. Donor conceived adults can experience grief and loss associated with being separated from one or both biological parents. Their counsellors and support service providers must be professionals who will not invalidate or dismiss these feelings and questions due to their own ignorance or bias.

VANISH recognises that the nature of donor conceived persons' desire to know about and/or have relationships with their biological parent/donor varies, as do the individual journeys and outcomes of donor-linking efforts. The provision of specialist information, education and support are vital to assist people in navigating search processes with a view to achieving the most satisfactory outcomes for all parties concerned. This should involve counselling and support by individuals and organisations that are independent of and not affiliated with the providers of donor conception treatment service. It is preferable that counselling and support services are governed and staffed by people who have a lived experience of donor conception.

5.5 Whether a register should be established

It is essential that a register be established so that information about individuals affected by donor conception can be recorded and released to the relevant parties.

It has long been argued by members of the donor conception community and their allies that a national register should be established. This was also recommended in the 2011 Senate Committee Report. A national register is required because although legislation and regulation of third party reproduction may be the remit of the states and territories, donor conception practices have not been retained within state boundaries. The transfer of sperm from state to state, together with the mobility of donor parents, families with donor conceived children and donor conceived adults, mean that there are multiple scenarios where a person in one jurisdiction is seeking to identify a relative in another.

VANISH therefore recommends pursuing a national register with other states, concurrently to establishing a register in Queensland. The model in Victoria of having a central register and a voluntary register, while initially confusing for some people navigating the system, seems to work reasonably well and would be a good model to learn from and replicate. In our view the registers, particularly the central register should be held by government, although we do see the potential for a voluntary register to be established and maintained by an accredited organisation, funded by government and not associated with treatment providers.

Alongside the establishment of registers, should be the provision of search and support services, involving skilled search professionals to locate the person sought and assist the person searching to make an outreach and manage the outcomes. VANISH recommends that this funded service be separate from the institution managing the registers. Post adoption support agencies have for decades provided individuals with assistance to apply for their records then undertake a search and make contact if that is what they wish to do.

Victoria was the first state to introduce retrospectivity and the legislation was drafted with significant caution. Some of the measures in the Act are viewed by the community as overly restrictive and not in alignment with a rights-based approach. For example, the legislation requires that identifying information about a donor parent be released within three months of the donor conceived person applying to the register being made. If the donor parent is located, they are contacted, advised that their information will be released and offered the opportunity to lodge their contact preferences.

If the donor parent is not found within the required timeframe, their identifying information is released and the donor conceived person is then left to their own devices to continue their search without professional assistance unless they source and pay for it themselves. Further, it is prohibited in the Act for them (or someone assisting them) to make contact with their donor parent. Instead they are required to provide their search results to VARTA so that VARTA can undertake the outreach and secure the donor parents’ contact preferences. Making a direct outreach to the donor parent is an offence under the Act and involves a hefty fine. This is overly punitive in the context of righting the wrongs of the past and in effect, it outsources the risks and responsibilities of the search to the individuals the Act is supposed to serve. It also introduces additional risks, for example it puts the donor conceived person in a vulnerable situation with regards to not knowing who to turn to for search assistance and potentially being scammed or provided with incorrect results. It could also act as a disincentive to every effort being made to complete the search within the legislated timeframe because outsourcing the search to the donor conceived person is ultimately a cheaper option.

VANISH is of the view that it would be more appropriate for the model to be based upon well established post adoption search and support whereby the government department holds and releases the records and the funded agency provides search and intermediary services and supports all parties to navigate contact if that is what they desire, or the consequences of contact not being wanted.

5.6 Benefits, risks and implications on donor conception practices arising from any recommendations.

The introduction of retrospectivity will bring significant benefits to people involved with donor conception practices, past and future:
- donor conceived people subject to anonymous donation will realise their human right to information about their genetic parents and siblings and be supported in the process;
- donor parents will get answers to their questions regarding the children they assisted to create;
- recipient parents will get support to tell their child(ren) and to navigate the new family dynamics
- media attention to the issue as it becomes public will encourage parents to advise their donor conceived children of their donor conceived status
- media attention will encourage individuals who suspect they might be donor conceived or adopted to connect with services and peer support groups for information and support.
- people considering donating their gamete will consider the needs and rights of the children when making this decision
- people considering third party reproduction will consider the needs and rights of the children which is not always in front of mind when going through infertility and fertility treatment.

There are often alarmist reports of sperm shortages which are said to be as a result of the fact that donors can no longer provide sperm donations anonymously. However the reality is that it not that there is a shortage but rather a huge increase in demand. It is VANISH's view that this demand is generated by the industry and media and is founded upon the general lack of understanding of the impacts of donor conception on the donor conceived person.

5.7 Other matters.

The committee has indicated it will consider whether any model should include information from private donor arrangements. VANISH is of the view that it should, as this would ensure equality for all donor conceived people, regardless of the conception process involved.

The committee has noted it will consider the costs of any proposal including a user-pays model. VANISH is of the view that it would not be appropriate to charge donor conceived people to be able to access information and services. It would, however, be appropriate to:
- require the clinics and other providers of assisted reproductive treatment to contribute to the costs of establishing and maintaining the central and voluntary registers. This would be in recognition of the fact that recipient parents, donor parents and donor conceived people are all their clients to whom they owe a duty of care, over and above their shareholders.
- include in the fees the clinic charges to intending recipient parents to undertake third party reproductive treatment, a set contribution to the cost of maintaining the central and voluntary registers to which they will provide information.

VANISH appreciates the opportunity to contribute to this important inquiry and welcomes further questions from the Committee.

Charlotte Smith
CEO
VANISH Inc

May 2022