Legal and Constitutional Affairs References Committee

Inquiry into the past and present practices of donor conception in Australia

Submitted by Monash IVF

Introduction

Donor IVF treatment is a growing area providing many people with the opportunity to have a family where they would not have otherwise been able. We now have the experience of over three decades of clinical practice under models ranging from no regulation to some well structured models for provision of services and maintaining accurate records. There is still a very long way to go in terms of implementing consistent donor treatment practices across all States and Territories and ensuring the rights of all parties to third party reproduction are respected and upheld.

(a) Donor conception regulation and legislation across federal and state jurisdictions

<u>Problems -</u> Inconsistencies

The legislation across States is inconsistent ranging from highly regulated and punitive, to no regulation at all.

Monash IVF operates clinics in Victoria and Queensland and has developed internal protocols to ensure consistency of quality, and efficiency of systems across all sites. Inconsistency in existing donor related legislation across jurisdictions makes it particularly difficult to comply with particularly when it is contradictory. It also creates increased difficulty in managing the psychological wellbeing of patients when people are caught between having treatment and consenting under one Act and then having rights removed under a new Act. A particular difficulty is when embryos in storage are created under one set of rules and rights, and are later affected by a new set of (potentially contradictory) rules and rights in a new Act.

An example of gross inconsistency in a piece of legislation is the introduction of the new ART Act 2008 in Victoria with particular reference to Section 32, which deals with the prohibition on storing embryos except in particular circumstances.

Section 32, (2c) states the persons who have produced the gametes from which the embryo has been formed have consented to its storage for the purposes of later transfer. Note this is consent about the EMBRYO not gametes. Apart from being fraught with many practical challenges this is also in direct contradiction to Part 14 of the Act which deals with the definition of parentage in situations where donor gametes are used. In essence meaning the woman and her partner are the legal parents of any child born from donor gametes and that the donor does not have any legal parenting rights over the child.

It is clearly problematic a donor has the right to say how long a person's embryos may or may not stay in storage when the embryo is also genetically half of the other person (recipient)? This is incongruent and inconsistent with the spirit of the act of donating in the first place.

The rights of the donor conceived person

The model for information collated by Victorian Central Register has been adopted in Monash IVF's Queensland clinics; in the event that legislation does change in Queensland in the future, Monash IVF patients and donor conceived people may have the opportunity to access adequate information about their donor origins.

At this point however, the rights of a donor conceived person in Victoria born after 1998 compared to someone born in Queensland is vastly different with the Victorian person having the legal right to identifying information about their donor.

Due to changes in legislation in Victoria there are some families with donor conceived children who were born under different iterations of the legislation therefore each child/person having different sets of rights in terms of what information that person is entitled about their genetic origins.

The feedback from working with the families and children in our clinical practice who are effected by these differing legislations is that the implications of the legislation is psychologically traumatising and has enduring lifelong implications for the effected person/s.

Recommendations

- Uniform legislation across all States in Australia.
- The Victorian model of a Central Register be adopted as a National standard.
- All donor conceived people should have the right to accessing identifying information about their biological origins.
- The psychological impact of donor conception should be recognised. One option to deal with this is through the provision of specialised counselling services by appropriately qualified practitioners to provide a uniform and standardised practice of care to those people making applications for information from registers.

The current model of counselling provided in Victoria under the ART Act 2008 for applicants to the Birth Deaths and Marriages Central Register could be improved as it does not recognise the longer term needs faced by this population of people. The previous model of donor linking counselling which operated under the Infertility Treatment Act 1995 provided by the Infertility Treatment Authority was an ideal model to serve the needs of this group of people.

(b) The conduct of clinics and medical services

The conduct of clinics and medical services is regulated by State legislation in some States and by the Reproductive Treatment Accreditation Committee. This provides for consistency of service in terms of quality management and clinical practice.

Problem

The inconsistency of legislation across States means that for some States the repercussions for non-compliance are much more severe and punitive if breaches occur.

Recommendation

- Uniform legislation should be implemented across all States.

(i) Payment for donors

Problem

Monash IVF suggests a suitable reimbursement to donors should be allowable to acknowledge the time and commitment these people put into attending appointments and disrupting their own lives to become altruistic donors.

There are problems with the current system where only minimal payment is permitted to cover bare minimum costs of travel, etc. The time commitment of attending appointments within business hours and potential disruption to one's life recovering from a medical procedure (such as for an egg donor) is significant disincentive for people to become donors. This needs to be balanced against the risk of exploitation if the sum of money was the only reason a person was becoming a donor.

Recommendation

- A more generous donor compensation scheme should be considered to recognise the time commitment and disruption to their own lives in becoming donors.

(ii) Management of data relating to donor conception

Monash IVF prides itself on the maintenance of its database with regards to donor conception. Although different legislation prevails across the States where Monash operates clinics, Monash IVF has implemented its own systems in Queensland which are in fact modeled on the legal requirements in Victoria in order to ensure consistency in quality assurance.

Problem

Problems may occur in States where regulations about the responsible management of records do not exist in circumstances where a clinic closes down.

Recommendation

- Uniform legislation across all States about the requirements for data management to be consistent with the Victorian Central Register model.

The reasons why this is so important are:

- Easier to report statistics and donor conception activity if all clinics are operating under the same definitions and regulations.
- Easier for parties to a donor conception to access information about their genetic origins if uniform systems are in place.
- Easier to keep a track on how many families a donor has formed and control the issue of consanguinity.

(iii) Provision of appropriate counselling and support services

The RTAC guidelines require all clinics to provide counselling to all donors and recipients before donating or undergoing treatment with donor gametes or embryos.

There are lifelong physical and psychological implications for prospective donors, prospective parents and the children born as a result of these procedures. It therefore extremely important that the counselling is conducted by an appropriately qualified professional with counseling training and knowledge regarding infertility issues and donor / adoption issues.

If a National Donor Registry is established then it is imperative appropriate counseling and support is provided to applicants who are requesting information from the Register. It is vital that this is managed sensitively and professionally and meets the needs of the applicants. This means that more than one counselling session may be required and may take a period of time for the applicant to consider all the issues and potential impact an such application for identifying information may have on their lives.

Some examples of the issues that would need to be considered include:

- Motivation for application.
- Expectations the applicant has about what receiving the information will mean for them.
- Are the expectations realistic?
- Are there any life stressors or circumstances that are impacting on the person making an application?
- What will be the consequences for the applicant if their expectations are not met, e.g. the donor does not wish to meet them?
- Does the applicant's birth family know about their intention to make an application? How is this being managed? What has been the response?
- What support if any does the applicant have?
- What will it mean to the applicant if they find out there are other half genetic siblings formed from the same donor?
- If contact is going to be made, how will this be managed? What are the potential outcomes?

Recommendation

- Counselling should be mandatory for all donors, donors' partners, and women and their partners intending to undergo donor treatment. The sessions should be tailored to meet the needs of the individuals and be at the discretion of the professional providing that service.

- Counselling should be mandatory for all donor conceived people, parents of donor conceived people and donors and any other related party (e.g. genetic sibling) making an application for information from a Donor Register.

- The Central Register should have attached to it a specialised donor linking counselling service that meets the requirements of the applicants and who can case manage the applicants' needs over a period of time. An example of such a model is one formerly provided by the Infertility Treatment Authority in Victoria (now VARTA)

(c) The number of offspring born from each donor with reference to the risk of consanguine relationships

In Victoria the limit is 10 women whereas under previous legislation it was 10 families. In some States the limit is five (5) families.

Monash IVF suggests the limit on the number families a donor can help to form should remain at 10 families and NOT 10 women. Limiting the number of women does not take into consideration same sex couples where both women use the same donor so that their children are part of the SAME family socially and genetically.

The other issue of concern is that due to the limited number of donors already available limiting to less than 10 families will severely limit the number of people being able to access donor treatment.

Recommendation

- Make the maximum number of ***families*** 10.
- Legalising payment for donors (within reason and set at a capped level for all clinics).

(d) The rights of donor conceived individuals

The Office of United Nations High Commissioner of Human Rights in their Convention on the Rights of the Child, Article 8;

"1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.

2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity. "

The development and maintenance of donor registers in some States have gone a long way towards respecting and upholding the rights of child to know his or her identity. Genetic and biological origins are an important component of one's sense of identity.

Inconsistency across States and across different Legislative instruments in the same State makes it very difficult to adequately preserve a person's rights to information about their biological origins. In fact some of the systems currently in place could be argued to be discriminatory giving some people rights and others none purely because of the timing of their birth.

Recommendation

- Legislation to enable retrospective access to be made available for all donor conceived people about their genetic origins, as modelled on previous adoption laws in Australia.
- Appropriate counselling and support provided to all parties impacted upon by changes to such legislation.