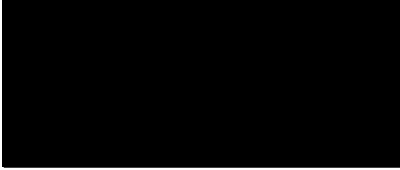


Submission re: Review of the Assisted Reproductive Treatment Act 1988 (SA)

28/02/2016

Lauren Burns



- 1. Please comment upon the requirement within the Act that the welfare of any child born as a consequence of assisted reproductive treatment (A.R.T.) is treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of the Act, as well as in the provision of assisted reproductive treatment.**

I strongly support the requirement within the Act that the welfare of any child born from ART is of paramount importance, and the implementation of this principle, because the child is the most vulnerable party in the arrangement. Infertility should not be overcome in a way that is reliant on transferring burdens onto the child that is conceived, e.g. the burden of not knowing where one comes from. The word paramount means above all others, and this principle should inform legislators that the rights of the child must come first. This principle is consistent with domestic and internal legislation involving children and family building, for example in administering adoptions and the child protection and fostering systems.

In practical terms the paramountcy of the welfare of children born through ART means that their rights, interests, and welfare must be considered above the adults involved in this process, including the intended parent(s), the donor(s) and other associated parties such as the ART clinical businesses and staff.

This principle must not be merely words, it must be part of the fabric of the legislation, and be translated into practical and actionable rights, such as the right to access information on biological relatives such as donors and half siblings. As a donor conceived person I consider that it is critical that DC people have the choice to obtain information, including identifying information, about their donor(s) and half siblings. This information is so important because it informs us of our health history, social history and provides the opportunity to develop kinship links that are meaningful and important to many people, and help answer the myriad questions of identity as to where we come from, and where we inherited our looks, personality, aptitudes and other traits.

- 2. Please comment upon the replacement of the previous licensing scheme with a registration scheme for A.R.T. clinics—noting that the registration scheme now relies upon framework legislation whereby:**
 - the Minister registers fertility clinics provided they satisfy specific criteria
 - the clinics must adhere to:
 - conditions of registrations set by the Act, the regulations and the Minister
 - the national accreditation scheme implemented by the Reproductive Technology Accreditation Committee (RTAC) as established by the Fertility Society of Australia,
 - the RTAC Code of Practice, and

- **the National Health and Medical Research Council's Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2004 (revised 2007), which are currently under review.**

I believe that the licencing scheme of ART clinics should be transparent and independent. The national accreditation scheme currently implemented by RTAC is not truly independent as it is run as a sub-section of the Fertility Society of Australia who control key appointments, such as the chair of the RTAC committee. The FSA is itself made up of professionals who work or run the clinics that RTAC is accrediting, which is where there is a potential break-down of independence and the ability of conflicts of interest to arise. It would be a vast improvement in governance if the accreditation of ART clinics was overseen by a truly independent body, and one that provided transparency. This body could be funded by a levy on ART clinics

RTAC is currently not publicly transparent as to which clinics are in breach of particular sections of the NHMRC guidelines, and what consequences or action plans are put in place for these clinics to become compliant. I suggest that RTAC or the relevant accreditation organisation should be compelled to provide an annual publicly available written report to the Minister of Health outlining the compliance or otherwise of ART clinics to the NHMRC ethical guidelines.

Furthermore, the NHMRC ethical guidelines on the use of ART in clinical practice and research are not enforceable, which means that it is difficult to guarantee they are being adhered to. There is anecdotal evidence that they are not being adhered to, for example, accounts given by donor conceived people that clinics are not willing to contact past donors to obtain their consent to release information, despite this being contained within the guidelines.

3. Please comment on the dissolution of the SA Council on Reproductive Technology and its Code of Ethical Clinical Practice.

ART practice results in the creation of human life, with lifelong and potentially intergenerational consequences on individuals and families if mistakes are made. Nothing is more important than getting this right, therefore I believe that ART legislation should be accompanied by a dedicated independent government body to perform functions such as administer donor registers and related services (e.g. counselling, search, intermediary outreach and information release) and consider ethical questions that arise.

As an example, in Victoria the relevant legislation establishes the Victorian Assisted Reproductive Treatment Authority (VARTA) which provides public education and from 2017 will administer the donor registers and related services such as counselling, search and information release. In Victoria the legislation also establishes the Patient Review Panel which deals with ethical questions such as:

- applications for posthumous use of gametes and embryos
- applications for treatment in circumstances in which a registered assisted reproductive treatment provider or clinician is concerned about the risk of abuse or neglect to a child that may be born as a result of the treatment
- applications for treatment in circumstances in which the applicant does not meet the criteria for treatment
- applications for extended storage periods of gametes or embryos or removal of embryos from storage

I recommend that a similar model be developed in South Australia. Furthermore, I recommend that bodies such as the Patient Review Panel, and the governing board of an equivalent organisation to

VARTA include people born from assisted reproductive treatments, such as people born from donor conception and surrogacy, as a means of ensuring that the principle of the welfare of the child conceived from ART remains paramount in the administration of legislation and decision making processes of ethics committees.

4. Please comment on the effectiveness and operation of the legislation regarding access to assisted reproductive treatment in South Australia. In particular, the conditions set out in the Act and in the regulations that relate to the circumstances in which, and to whom, A.R.T. may be provided.

In being consistent with the guiding principle that the welfare of any child born from ART is of paramount importance it should be noted that people do not have an inherent 'right' to a child. It should also be noted that in many cases ART medical treatment is publicly funded via Medicare, and there is a potential duty of care of the State to the children who are conceived.

Similar to safeguards developed for family building via adoption I believe that it is appropriate that there are basic checks to uncover cases where the intended parent(s) have serious criminal histories such as violence or sex offences. This does not mean that people with violent criminal histories should be automatically disqualified from seeking assisted reproductive treatment, but there should be clear criteria, a review process such as a patient review panel and an appeals process (in Victoria decisions concerning providing treatment can be reviewed by VCAT).

This issue sounds like a theoretical concern, however I am personally friends with donor conceived people who grew up in households where they experienced violence and sexual abuse. In some cases when their parents sought treatment they had already acquired serious criminal histories, however no questions were asked.

This viewpoint is controversial within some sections of the community, who point out that child abuse happens to children who are naturally conceived. However I believe we should come back to the guiding principle of the Act that the welfare of any child born from ART is of paramount importance. There is a further point of difference here in that the conception of children via ART involves third parties (donors) and the financial support of the State. I believe that a person relinquishing a child to adoption would have a reasonable expectation that their child would not be adopted by a family where prior criminal convictions suggested that the child could be unsafe, and similarly I believe that people who donate their gametes have a reasonable expectation that the children who are conceived should not be exposed to potential abuse from a family with a prior history of abuse or serious neglect. Therefore I believe these safeguards are also important in maintaining the integrity of the donor programs.

5. Please comment on the effectiveness and operation of the Act in relation to it providing for the establishment of a donor conception register.

I recommend that as a matter of priority the South Australian Health Minister should use his/her powers to establish a donor conception register(s) that enables donor conceived people, intended parents, donors and their relatives to exchange information.

This register(s) should be set up based on the Victorian donor registers model, which has been operating since 1988. In Victoria, there is a Central donor register which enables donor conceived people and donors to seek non-identifying and in some cases identifying information about each

other. In recognition of the paramountcy of the rights of the child, recent legislation has been passed in Victoria that will enable all donor conceived people to apply for identifying information about their donor (where it exists), regardless of previous assurances of anonymity. This was balanced by the right of donors (and donor conceived people) to lodge contact preferences before identifying information is released, which allows them to control the level of contact they are comfortable with and maintain their privacy. These contact preferences are enforceable with penalties. In addition, donors can request identifying information about their donor conceived children, however this is only released with the consent of the DC person.

Victoria also administers a Voluntary donor register. In particular the Voluntary donor register allows for donor conceived people to connect with their half-siblings. However the Voluntary register can also be used by donor conceived people, donors, intended parents and their relatives to connect with one another.

It should be noted that there remains some flaws in the Victorian donor registers system, particularly for donor conceived people who do not have records or a donor code. This can occur for a variety of reasons e.g. because records were never kept, or they have been misplaced or destroyed. It is recommended that donors and DC people without donor codes still be permitted to add their details to the donor register(s), and that database tools be used to identify potential matches e.g. through information such as clinic, year of donation/birth and blood type. In these situations there is scope for voluntary DNA samples to be provided as an avenue for donor conceived people to connect with their donors, half siblings, or other relatives (e.g. grandparents).

There is also a provision in Victoria's legislation that allows for information concerning health history to be exchanged between donor conceived siblings, even in cases where the donor conceived person receiving the information is unaware they are donor conceived.

It should also be noted that the Victorian experience shows that in order for donor registers and information release to function it is critical that they are complemented by associated services including search, intermediary outreach and counselling. In particular the importance of having access to specialised search expertise to locate the current contact details of donors and donor conceived people cannot be overstated. It is meaningless to empower DC people with the right to access information about their donor but have no means of contacting the donors.

Furthermore, some donors received past assurances of anonymity, therefore it is critical to have services such as intermediary outreach and counselling available for all parties, and their families. Public education is another example of an important service, as it is necessary to advertise any changes to existing laws or arrangements concerning ART. In Victoria ITA/VARTA provide a model of how it is possible to incorporate donor registers and associated services in a way that is both low-cost and provides a high quality of service to people accessing these services.

6. Please comment on the effectiveness and operation of provisions within the Act for record keeping and confidentiality.

It is important for the functioning of the donor register(s) and the well-being of affected parties such as donor conceived people and donors that records are retained and archived with appropriate safeguards on confidentiality.

Once again, I point to the example of the Victorian legislation that has clauses enabling the government to obtain donor conception records by collecting copies from organisations and

individuals for the purpose of, as far as possible, ensuring the completeness of the donor registers. I recommend that legislation should enable donor records to be obtained from ART clinics and other institutions or organisations that have guardianship of records from ART clinics that they have bought, or that have previously closed down e.g. Flinders University. It should also enable the collection of records where they exist with individuals such as doctors or their families.

It is also important that legislation prohibits and proscribes penalties for the deliberate tampering or destruction of donor conception records, and preserve whatever records still exist in perpetuity.

7. Please comment on any other matter you see as relevant to the review of the operation and effectiveness of the Assisted Reproductive Treatment Act 1988 (SA).

It is meaningless to create a system enfranchising certain rights upon people born from assisted reproductive treatment when that person might never be aware they are donor conceived because their family never informs them.

In Victoria, the potential for donor conceived people to be unaware of their origins has been dealt with by legislation requiring that donor conceived people have an addendum added to their birth certificates that states that further information is available and directs them to the donor register service. This change was implemented prospectively to people born from donor conception after 1st January 2010.

In practical terms it means that donor conceived people born after this date have an independent means of finding out the truth about their origins when they apply for a birth certificate after they are 18 years old. This provides a very strong incentive for parents to tell their children the truth, and intended parents are informed of this when they undertake counselling as part of their assisted reproductive treatment.

I recommend that South Australia implement a similar provision in their legislation as a safeguard against donor conceived people being unable to exercise their right to information because they are unaware they are donor conceived.

