

## **Assisted Reproductive Treatment Act 1988 Review**

Submission – Kylie Dempsey

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### **Background**

“In 2009, the South Australian Government introduced significant changes to the *Assisted Reproductive Treatment Act 1988 (SA)* (PDF, 92KB) (the Act) via the *Reproductive Technology (Clinical Practices) (Miscellaneous) Amendment Act 2009*. Changes to the Act came into effect on 1 September 2010. To ensure that those changes were evaluated over time, the Government included a requirement that the operation and effectiveness of the Act be reviewed after the fifth anniversary of the changes to the Act. The review of the Act is now due, (What’s Happening, <http://yoursay.sa.gov.au/decisions/yoursay-engagements-review-of-the-assisted-reproductive-treatment-act-1988/about>, accessed 15/04/2016).”

### **About Me**

I was conceived from donor sperm in 1982 by anonymous donor.

I always knew I was donor conceived, all my family knew, it was just a fact. When I was under 8 years old answers to my questions about my donor father by my parents were sufficient. At about 8 years old I wanted my parents to find out more, but I didn’t ask as I thought I might hurt them. At about 12 years old I asked my parents to find out more and they took me to the clinic, limited information was available. At about 16 years old I asked my parents to find out more and we went back to the clinic, to hear the same information again. At about 21 years old I approached the clinic of my own accord and was advised no further information was available.

After contacting the clinic for the third time, I realised I needed to look elsewhere. I started seeking out stories of others like me, joined groups and lobbied to change the legislation so that anonymous donations would stop, documentation would not be destroyed (thus information lost) and for a registry to assist connection between donors and offspring.

I participated in the Senate Inquiry of Donor Conception Practices in Australia when I was 23 and am now participating in this legislative review at 33 years of age. The impact of donor assisted reproduction has been lifelong for me and it will affect the lives of any children I have.

I have limited information about my donor. I do know my biological father has the same colour hair, eyes and height as my Dad. If given the opportunity, I would like to thank the man for his donation and ask for a medical history. If he was open to it, I’d like to know why he donated. Anything else would be a bonus.

### **Upholding of the paramountcy of the welfare of the child**

It may be that the paramountcy of the welfare of the child provision is being upheld in practice by specific clinics or professionals at certain points in time, however, without consistent independent review and regulation, there doesn't appear to be assurance that it is being upheld. This is especially true given that we might not know of poor practices until many years after reproductive assistance when the child grows up and starts asking questions or requests information about what occurred.

We know from the Senate Inquiry that when there is a failure to uphold this provision the ability to correct the situation is limited (eg. some children will never have access to information about donors and their medical history because records were not kept or were destroyed).

Further we know from the resulting activity of the Senate Inquiry that any improvement to the situation will come at a significant cost; monetary, time and health (physical and mental) of those involved, including the child, family, donor, clinic and the government. Thus, it is in everyone's interests, including the child's, to ensure with evidence and rigour that the provisions are being upheld in practice. With consistent oversight any issues will be identified and there will be a greater opportunity to rectify the situation with less impact on all involved.

Such regulatory oversight may also assist clinics that are already supporting the intent of the act, by holding other clinics accountable to the same requirements.

### **Considerations during donation and approval for assisted reproduction**

#### **Donors**

I support the NHMRC Guidelines that detail the considerations that should be made with regard to the welfare of the child at time of donor provision with the addition of the following;

I believe donation is a privilege not a right.

I believe Doctors should have the ability to require donors have counselling and a psychological review if they believe the donor does not fully comprehend the immediate and future impacts of the donation before they accept the donation. There should be a framework around this to support Doctors, if one does not already exist.

It is my opinion that criminal convictions should also be a compulsory part of the consideration to accept a donation. People who are convicted of serious criminal crimes or serial offending are not likely to provide a positive influence on the child, and in fact, will likely have a negative impact. Convictions should be considered in context and Doctors should have a framework that supports them declining a donation based on criminal convictions. Further, just like medical information is provided to Potential Parents, criminal convictions should also be provided to Potential Parents so they can make a fully informed decision.

There should be an independent appeals process for declined donors to ensure natural justice and an independent centralised record of declined donors that includes reasons for decline to support consistency of application of the provision across clinics (ie. allow clinics to identify declined donors before undertaking all tests and requesting reports).

## **Potential Parents**

I support the NHMRC guidelines that detail the considerations that should be made with regard to the welfare of the child at the time of application for reproductive assistance with the addition of the following;

It is my opinion that Potential Parents seeking reproductive assistance should be screened for the likelihood of future physical or psychological harm to the child and that the likelihood will be impacted by things including but not limited to previous harm caused to other children (ie. criminal convictions not directly related to children may also be relevant). There should be a consistent practice for all such assessment activities where the welfare of the child is paramount (eg. Potential Foster Parents, Potential Adoptive Parents, etc..)

Doctors should have the ability to require counselling and psychological review of the potential parents before proceeding where risk warrants it and there should be a framework around this to support Doctors do this, if it doesn't already exist.

Further, there should be an independent appeals process to ensure natural justice and an independent centralised record of declined applicants that includes reasons for decline to support consistency of application of the provision across clinics (ie. allows clinics to identify declined potential parents before undertaking all tests and requesting reports).

## **Registration Scheme - Artificial Insemination**

I am unsatisfied with the current registration scheme as it allows a medical professional to provide artificial insemination services without registration where the sperm is provided by someone known to the recipient that is not the partner.

It is not clear to me, why children conceived in this manner (sperm from a donor known to the parents) should have different rights to children conceived in other manners, including children conceived with sperm from unknown donors to the parent, when the intent of the act is to keep the child's welfare paramount; As artificial insemination by a donor known to the parents does not have to be provided by a registered medical professional, those providing this service are not required under legislation to comply with the NHMRC guidelines and it is the guidelines that detail how the child's welfare must be protected, including what information must be recorded and made available about the donor.

If this exception clause is not removed from the legislation, children conceived through sperm donation by a party known to the parents will continue to be born without rights or mechanisms to find out who their biological fathers are and what their medical history is etc.. It should not be assumed that because the parents knew the donor that this information was shared with the child.

Further, I am not in an informed position to comment on the medical risks associated with artificial insemination (by partner or donor known to the parents) outside of the registration scheme and NHMRC guidelines, I do believe this is something that should be reviewed by experts this field.

## Independent oversight

I don't believe the requirement to adhere to the NHMRC Guidelines and activities of the RTAC and Fertility Society of Australia (FSA) alone provide sufficient assurance of clinic compliance or adequate legislative management. I think that the Government should ensure independent oversight of this legislation and compliance to it.

It is great to see that currently, in order to maintain RTAC accreditation, regular internal audits of compliance to the NHMRC Guidelines is required. Further, it is great practice that copies of the internal audit reports must be provided to the RTAC for review in order to maintain accreditation. It remains unclear to me, how often external audits are undertaken of clinic compliance to the NHMRC Guidelines and of the clinic's internal audit process; There is a level of inherent bias in internal auditing. Further, if the internal audit function is not operating as better practice dictates, then the internal audit reports may not be providing the assurance intended. I am also concerned that when the FSA, RTAC and/or the NHMRC are modified this may reduce the oversight. Further, the FSA is the Peak Body for the clinics and by nature of this role, their decisions will likely be in favour of the clinics instead of a balanced view from all stakeholders.

The Ethics Health Advisory Council (EHAC) appears to independent, have broad functions and encompass wide members from several disciplines. The EHAC Tri-annual Report October 2010-2013 shows, however, that there was no advice in the assisted reproductive technology space. The EHAC appears to respond to requests referred to it and it has not reported to have monitored the FSA, RTAC and NHMRC. The EHAC is less proactive than I would like to see in an independent oversight Committee.

An active Committee could be formed whose role includes providing assurance to the Minister that:

- a) the intent of the act is upheld through the legislation
- b) clinics are compliant with the legislation (including oversight of external audits and/or internal audits\*),
- c) the legislation remains current (the NHMRC may change, the RTAC and Fertility Society of Australia may evolve etc.)

\*The current legislation could be changed to assist this oversight by requiring clinics to provide copies of the internal audit reports that they must provide to the RTAC under the NHMRC (and any other relevant internal and external audits), also to the Minister.

Such a committee could identify and expedite through the Minister any recommended modifications to the legislation after reviewing changes to the Fertility Society of Australia, RTAC and NHMRC. This would allow improvements to the way assisted reproductive technology is provided and quickly resolve any emerging contradictions between the legislation and other requirements. I recommend the Act should prevail until any contradiction is resolved.

Membership of a committee like this could benefit from experts in their fields and the inclusion of a person who was conceived through assisted reproductive technology.

## **Donor Registry**

### **Legislation**

I note that the Commonwealth Government has stated that it does not have the power establish National Register. Whilst the Commonwealth Government may not have this power at this time, I believe amendments to the federal and state legislations could be explored to allow this activity - perhaps model legislation could be developed and states could elect to adopt it. Any activity in this space should support the development of a register in South Australia now and not delay it.

### **South Australian Registry**

I believe a donor-conception registry should be established in South Australia and done so immediately.

It took many years to gain a Senate Inquiry into Donor Conception Practices in Australia (started in 2010 and report released in 2011) that discussed donor registries, another two years for public consultation concerning registries in South Australia (2013) and another three years for us to discuss it again (now 2016). If included in legislation as a result of this discussion, a registry it will take another few years to fully establish. This covers a span of 10-15 years, however, in reality, people conceived over 30 years ago, like myself, have been waiting much longer.

I acknowledge that a registry may not provide me with more information/answers, however, for others a register may assist. The longer a register/information sharing is delayed, the less likely information will be available - it will become harder to locate people to get up-to-date information and some people, donors in particular, may have passed on and the opportunity for connection, if wanted by both parties, may be lost.

### **Information on Registry**

At a minimum, I believe the register should keep the details clinics are required to keep under the NHMRC Section 10.3 'Record of Information about donation, use and storage of gametes and embryos.' It should also allow updates provided by the donor, parent or child including name, contact and medical history updates.

The NHMRC Sections 6.10 'provide gamete recipients with relevant medical history' and 6.11 'Provide donor-conceived persons with information about their gamete donor' are inconsistent; It reads to me that children can have more information when they reach 18 or suitable maturity than their parents. I do not agree with this - children should be able to be raised knowing they were donor conceived and have identifying information/contact information available to them about the donor through their parents, thus the parents should be able to have access to the same information as the child to facilitate this. All this information should be on the registry.

Should parents or a child over 18 years of age approach the register administrators, I believe historical and updated information about the donor should be provided.

Further, at 18 years old, children should be advised that they were conceived through donor – parents may not have told them and/or they may not know they can access information. Children deserve to know the way they were conceived, whether or not their parents have told them. Appropriate supports should be in place during this process.

When considering conception, potential parents should be advised the child will be notified when they are 18 years old and it is strongly encouraged that they are open with their child about how they were conceived as they are raised.

I believe those administering the register should be given the rights through legislation to update contact details of those on the register by accessing contact details from other sources (ie. other State and Federal Government Departments). Those administering the register should be compelled to do this when a request for information is received if the information is not accurate and legislation should allow the register to be kept up to date proactively. I believe a register should be established in full knowledge that it may not be accessed for 10-20 years or more (as the child grows in maturity) and that as such, mechanisms must be put in place to ensure that it is maintained and up-to-date, ready for access at a later time.

### **Access to the Registry**

I believe that until the child reaches 18 years of age, the parent should have rights to access the register. I believe there should be an ability for the parents to leave messages for the donor and for the donor to leave messages for the parents.

Once the child reaches 18 years old, access for the parents should stop and the child should then have access to the information. I believe there should then be an ability for the child (who is 18 years old or more) to leave messages for the donor and for the donor to leave messages for the child.

I believe donor medical history should be provided to a child's own children, if they request it and have reached 18 years old or older, but identifying information should not be provided and instead this information should be sought through the child. Should the child die, the child's own children should then be able to access identifying information and leave messages for the donor and the donor for them.

Where a donor has more than one conceived child, I think the children's existence, age/sex should be made available to the other donor conceived child/parent. Messages should be able to be left between the parents, between the donor conceived siblings when they are over 18 years old and between a parent of a donor conceived child who is under 18 years of age and a donor conceived child who is over 18 years old. Should the parents and child die, then a child's own children should then be able to leave messages in a similar way.

### **Donor Anonymity and the Register**

Where anonymity was not promised to donors, I believe donor information should be included in the registry and released when requested. Donors should be notified of this and so should donor conceived children (or their parents if the child is under 18).

Whilst I believe it was wrong to provide anonymity for donors, I do not believe this should be corrected by releasing an anonymous donor's information without their consent. Instead, I think the information should be included in the registry, if available, but the information should not be released. Having the information in the registry means an anonymous donor will have the ability to easily approve the release of their information. Where there are anonymous donors that can be identified and contacted, they should be advised of the register and asked to make their information available for the benefit of the child.

Where identifying information on donors is not available and thus it is difficult to link donors to conceived children, donors and children (including those that self identify as donors or children conceived through assisted reproductive technology by donation in South Australia) should be offered DNA tests and this information should be retained in the database to assist in pairing donors to children and amongst siblings.