

15 April 2016

A/Professor Sonia Allan
A.R.T Act Review
C/- Policy and Intergovernment Relations Unit
SA Health, PO Box 287, Rundle Mall
ADELAIDE SA 500

Dear Associate Professor Sonia Allan

Re: A.R.T. Act Review

Relationships Australia South Australia (RASA) welcomes the provisions made by the South Australian government to undertake a review of the Assisted Reproductive Technology Act five years after the date of enactment.

RASA is an independent, non-profit community organisation which focuses on improving the emotional health and wellbeing of children, youth, adults and families. RASA has significant experience and practice wisdom in relation to the long term effects of separation of children from their families. Our experience is built on providing Post Adoption Support Services (PASS) since 2006, and Post Care Support Services and Find & Connect Support Services since 2012.

Notwithstanding the different circumstances, we are aware of many issues donor conceived children have in common with those children who were separated from their biological parents at a young age as a result of adoption or being placed in alternative care for child protection reasons.

An essential principle which is shared in donor conception, adoption and alternative care contexts and lies at the foundation of our submission relates to the best interests of children being paramount. This principle is enshrined in important international covenants including the UN Convention on the Rights of the Child, the Hague Convention on the Protection of Children and in the SA Children's Protection Act. In addition, an important principle that underpins our submission is that any changes are informed by the experience of donor conceived persons and lessons learned from past practices in assisted reproductive treatment (ART). Finally, a clear and well-resourced system of available and accessible support services is necessary to ensure all parties to donor conception are not put at risk by the changes in the Act implemented in 2010.

A guiding principle from our experience and derived from the UN Convention on the Rights of the Child relates to truth in ART, that is donor conceived person's are told the truth to the greatest extent possible, without breaching the rights of other parties, to full information about their donor and/or genetic relatives.



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Similar to the experience of children separated from parents through adoption and alternative care practices, donor conceived persons can experience confusion, distress or trauma related to their donor conception which can manifest at different stages throughout their life course. An important service delivery principle relates to the need for effective and accessible specialist services that are cognizant of the issues and needs of donor conceived person's and their families. It is important informed, sensitive and respectful services are available to assist and enhance the wellbeing of individuals who seek access to information and support.

Welfare of the child is paramount

The strengthening in the principle of the welfare of a child born from ART to being of paramount importance is a welcome feature of the 2010 amendments. Prospective parents who enter into ART must hold as paramount the best interest of any child born through this process. This includes a commitment to ensuring that true and accurate information about their child's donor conception is available including identifying information about the donor. Children should never remember a time when they didn't know.

Our experience in post adoption and post care work has shown us that truth about origins is a crucial factor for people to understand their own identity and belonging as well as providing them with access to important genetic information about themselves. When this information is withheld or unavailable, identity confusion and subsequent mental health complexities can result, and people are left with feeling they have been lied to and their very existence is questionable. This can also impact negatively on the donor conceived persons relationships with their parents and extended family, particularly if others know about their donor conceived status and they do not. We hear from many adopted people the impact of such secrets and 'being the last to know' has a profound and long lasting impact and gives a sense of secrecy and shame attached to their very existence.

Access to ART

While the paramountcy principled has been strengthened, we are concerned the move to a self regulation framework in the 2010 amendments could act against considerations that affect the welfare of the child. For example, the removal of eligibility requirements in the amended Act and lack of a requirement of providers to undertake assessments of applicants is a significant issue which could compromise the paramount interests of the donor conceived child.

There exist certain risks that should be screened or assessed during the application stage for people seeking ART. We believe screening provisions should be reinstated to prevent people accessing treatment who may pose a risk to the child or otherwise demonstrate the paramount interests of the child would not be upheld. This is particularly evident where there are issues of child protection, child pornography, domestic and family violence, untreated mental health and any other circumstances that present unacceptable risks to a donor conceived child.

Assessment needs to be conducted by suitably qualified Counsellors experienced in donor conception matters who are able to provide information, advice and support focused on the paramount interests of the child. To this extent, the NH&MRC Guidelines (2007) are not satisfactory and need to include reference to applicant risk-screening processes. Support services are needed to ensure people seeking ART and donors have access to information about their rights and responsibilities to ensure the paramount interests of the child.

Establishment of a donor conception register

RASA believes the establishment of a donor conception register in South Australia is essential to enable access to information for donor conceived people. This would support the call for donor conceived peoples birth history to be made easily accessible and for true and accurate records to be created.

The availability of such accessible records is essential to mitigating the trauma, psycho-social and medical impacts that have occurred for those who have been denied information about themselves and their circumstances. The NH&MRC Guidelines need to be updated to reflect the implications for clinics providing ART and support services for donor conceived persons, donors and family members.

The donor conception register should include identifying information about the donor and other family history information. The register should also hold current relevant medical records of the donor and their family and donors have a responsibility to ensure such information is kept up to date especially when it has implications for the health of the donor conceived person.

Our experience highlights how important it is for donor conceived persons sense of identity to have information regarding their donor and donor's family (including other children). This information enables donor conceived persons to gain an understanding about their biological family and to have a sense of how they may be received should they choose to have contact. Such information includes:

- why the donor chose to donate and what led them to making that decision
- if they have discussed their donation with other family members, and if their decision to donate was supported
- the donors thoughts about contact
- notification of the death of anyone involved in the conception (this needs to be explored with Births Deaths and Marriages) to enable other parties to find out contemporaneously rather than at a later date when they may embark on the searching process

The primary people who should have access to the register are donor conceived persons and donors. Donor conceived persons should have access to all information available and should be able to have a say in how much information about themselves be made available to the donor. Thought and consideration needs to be given to those who are donor conceived in regards to their openness in having contact with biological siblings.

It is important specialist services are in place to assist donor conceived persons to provide information and support regarding the choices available and in making decisions. Consideration needs to given to the weight of expectation that may unnecessarily be placed upon a donor conceived person by their donor for information and contact. Regular conversations about this are important for donor conceived person's as they grow up.

It is important that such specialist support services are impartial and independent of ART clinics to assist prospective parents prior to assessment and treatment understand the issues of paramount interests of the child and their obligations to ensure this.

These specialist services can also assist donor conceived people, donors and families in searching, making contact with and facilitating positive relationships between the parties. Our experience

highlights the importance of people obtaining support in preparing to search, possible outcomes of the search including when the other party declines to have contact. While ideally there will exist information in files regarding parties thoughts about contact, it needs to be recognised these can change over time. This service can also assist in the relationship building and supporting the parties to engage in a way that they are all comfortable with.

While the process of making contact will most likely occur when the donor conceived person turns 18 years, it is possible arrangements could be made for this to happen as the child is growing. In such circumstances it is important support is available for the donor conceived child, their family and the donor to ensure there is age appropriate support to understand this relationship in the context of the child's developmental needs.

Record keeping and confidentiality provisions

RASAs experience delivering support services to people who were adopted or placed in care highlights the importance for them of information regarding their biological parentage. From this experience we believe all donor conceived people should have access to information about their status and be at the centre of any decisions in regards to contact with other parties.

The paramount interests of the welfare of the donor conceived person includes their right to access information relevant to them. The current absence of regulations regarding the making of records or keeping of documents is concerning. Files should include documentation of any information that the donor and / or other parties know will be available to the donor conceived person and accessible when requested. Where there is information about other parties to be kept confidential i.e. personal information that is not considered relevant to the donor conceived person, then this should be held separately as an independent file. Any letters, photographs and other documents should be stored in such a way as to ensure that when the donor conceived person requests information they are given original copies. There should be a commitment to keep these records available for an indefinite amount of time to enable future access.

Records should be kept and be able to be matched together in regards to all children the donor has been involved in creating. When a request for information is made by a donor conceived person, it should include how many other biological siblings they have.

RASA appreciates your consideration of these issues and the strengthening of regulations and practices that more clearly meet the objectives of the 2010 amendments.

Yours Sincerely



Jonathon Main
Director, Child Youth and Family Services