



Submission by International Social Service Australia to the Review of the Human Reproductive Technology Act 1991 (WA)

16 March 2018

Submission:

Thank you for the opportunity to comment on the Review of the Human Reproductive Technology Act 1991.

International Social Service (ISS) Australia is a small non-government organization with over 50 years' experience providing a range of social work and legal services across international borders. ISS Australia works with those who are separated by international borders, with an emphasis on the best interests of the child. ISS Australia is the independent Australian arm of the ISS international network spanning over 130 countries. The ISS General Secretariat is based in Geneva, with advisory status at the United Nations.

One of the core services provided by ISS Australia and the ISS network is international post adoption tracing and family reunification. We are aware of the many similarities between adoptees and donor conceived people but acknowledge the unique differences.

One of the most foreseeable needs for donor conceived people is to obtain information about their donor. Both adoption and donor conception practice were historically shrouded in secrecy but adoption practice has now changed significantly and practises in the 'spirit of openness'. "This move within adoption practice to 'openness' attempted to achieve the best of both worlds – providing security for the child and the new family without cutting the child off from knowledge of its roots or totally excluding the birth parents."¹

It is probable that a large number of donor conceived people have been conceived in Australia without any guiding government legislation and while donor anonymity was the practice. It is also likely a substantial number of donor conceived people are growing up believing they are biologically related to both their parents, a practice that occurred in the adoption field many years ago and no longer continues.

The "world of adoption has a wealth of experience and expertise that should be highly relevant to donor conception."² It is on this basis ISS Australia wishes to comment on this Review as we believe "it is a fundamental right and of great importance for donor conceived people to know their family and medical history."³

ISS Australia wishes to only provide comment to the 'Access to information about donation, genetic parentage and donor conception' within the 'Management of information / the Reproductive Technology Registers' section of the Terms of Reference, which relates specifically to the Review of the Human Reproductive Technology Act 1991.

Access to information about donation, genetic parentage and donor conception

One cannot underestimate the importance of the basic human right to have access to information about one's biological parent. It is therefore critical for all donor conceived people to know they are donor conceived and be provided with access to information about their donors. Information such as ethnicity, physical characteristics, personality, family history and so on will assist with any possible future identity issues and enable donor conceived people to create a sense of 'who they are'. However "the importance of having access to information concerning a biological parent's medical history (e.g. whether or not there is a familial history of heart disease, diabetes, cancer, mental health issues, and/or other heritable diseases) is undeniable"⁴ and equally important. This medical information is crucial for donor conceived people and for their children, in order to gather accurate medical history.

Of specific concern and interest to ISS Australia is that of the right and the access of the donor conceived person to information about their genetic heritage. ISS Australia draws on the experience of working with adopted people and their natural desire to seek information about their biological history. The reasons for seeking information may include the

¹ *The Many Sided Triangle – Adoption in Australia*, Audrey Marshall and Margaret McDonald 2001, page 250

² *Information Rights and Donor Conception: Lessons From Adoption?* Richard Chisholm, *Journal of Law and Medicine* June 2012, page 740

³ *The Right to Information for Donor Conceived People: Lessons Learnt from Adoption*, Damon Martin 2012, page 1

⁴ *Centers for Disease Control and Prevention (CDC), Awareness of Family Health History as a Risk Factor for Disease, 2004, Morbidity and Mortality Weekly Report 1044*

deep longing to connect with, and know, their biological parent[s], for medical knowledge, seeking to know someone with a physical likeness, and/or to gain insight and understanding about why they came to be adopted.

It is also acknowledged that many people conceived with the assistance of a donor or surrogate may not be aware that this is their history. Adoption history also informs us that where a child is not *obviously* adopted through strong physical difference, adoptive parents may continue to be reluctant to tell the child of their biological heritage. Sometimes this is because they have struggled to find the 'right time' to share this important information with their child.

Throughout the 1950's, 60's and 70's in Australia, social workers and medical staff advised adoptive families to pretend the adopted child was born to them, believing that the child's best interests would be better served by being unaware of their adoption. However, this led to adopted people finding out their history through extended family, neighbours or family friends at a later stage, or when sorting the paperwork of a deceased parent. This has brought great difficulties for the adopted person in re-arranging their concepts of family, belonging and identity.

Over the more recent decades adopted people were able to educate government and other practitioners about how damaging deceit and / or lack of information around their history was for them. Although there are significant differences in the history of how donor conceived and adopted people come to be in their families, it is likely that donor conceived people, as with adopted people, will crave knowledge about their biological heritage.

Therefore ISS Australia strongly recommends that a donor registry be managed by the State in a similar manner that adoption files are held. It is our belief that these records should include all possible retrospective information gathered from all services, clinics and practitioners in Western Australia. ISS Australia believes that, as with adoption records, records regarding donor assisted conception should be kept indefinitely.

ISS Australia advocates for the right of the donor conceived person to have access to this information, and that this right to information should be retrospective. If the welfare of any child to be born as a consequence of the provision of A.R.T. or surrogacy is to be treated as being paramount, over and above that of the donor, practitioners or others involved in the process, the need for people to have access to their records and information held about their biological history, should be regarded as a necessity.

However in recognition of the difficulties that retrospective disclosure of the donor may pose for those who were not anticipating, and are distressed about, their identity being disclosed, a framework and planning for the implementation of openness should be put in place in advance. There should be time from any announced change to access to retrospective records and the actual ability to access records, to allow donors time to receive counselling, support around how to tell significant people about their donor status and time to discuss with others they feel may be affected by the disclosure. For retrospective file access, a contact veto system may be of consideration to prevent unwanted requests for contact.

It is advised that counselling about the importance of disclosing to donor-conceived children about their status is continued, with follow up education sessions on what to share and how to share in developmentally appropriate ways, for parents at specific timeframes throughout their child's first 18 years. In the early teen years and when approaching 18 years, a focus should be on the young adults entitlement to their records, the process to facilitate this, and the range of issues and outcomes of other donor conceived people who have desired to search for their donor. The sessions around access to information and desire to make contact should be held for parent[s] and their teens.

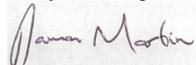
As ISS Australia believes it is a basic human right to have access to information about one's biological parent, we recommend all donor conceived people have access to their information and specialised support services free of charge.

Lastly, ISS Australia believes that accurate and complete records are imperative. This information and research is necessary to assist future applicants to A.R.T. to be provided with accurate information to enable consent to be truly informed, and for medical personal to have improved abilities to predict outcomes for future applicants and any children born as an outcome of A.R.T.

ISS Australia advocates that all records are kept permanently by a central authority, as with adoption files, as they hold important information on the donor conceived person's biological history. This information should not be held about the state in various clinics, as this complicates access for the donor conceived person that is unaware of the clinic their parent accessed, and risks the records being lost or inaccessible overtime. This information will also be of value and relevance to future generations born to the donor conceived person.

Thank you again for the opportunity to comment on this issue raised within the Review of the Human Reproductive Technology Act 1991. Please do not hesitate to contact me if you require further information.

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