



International
Social Service
AUSTRALIA

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**Submission by International Social Service Australia to the
Review of the Assisted Reproductive Treatment Act 1988 (SA)**

April 2016

Submission:

Thank you for the opportunity to comment on the *Review of the Assisted Reproductive Treatment Act 1988 (SA)*.

International Social Service (ISS) Australia is a national charity with over 50 years' experience providing a range of social work 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 an international network spanning over 120 countries, based in Geneva, with advisory status with the United Nations. ISS Australia is a not-for-profit, non-governmental organisation.

One of the core services provided by ISS Australia and the ISS network is international post adoption tracing and family reunification. Although there are differences between adoption and donor conception, there are lessons which can be learned from adoption policy and practice, and the experiences of adopted people, which can inform legislation and practice in donor assisted conception. ISS Australia draws on this in the following responses.

Paramourcy of the Welfare of the Child in Assisted Reproductive Treatment

'The welfare of any child to be born as a consequence of the provision of assisted reproductive treatment in accordance with this Act must be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of this Act.'
Section 4A of the Assisted Reproductive Treatment Act 1988 (SA)

ISS Australia endorses the 2010 intention to provide greater emphasis on the welfare of the child born as an outcome of A.R.T.. ISS Australia further supports the prioritisation of the child's welfare over and above the interests of would-be-parents or medical practitioners. However, there are some potential obstructions to this occurring in practice.

Firstly adoption, unlike A.R.T., is a service for children already in existence, who are unable to be safely cared for by their biological family. The wellbeing of an existing child can therefore be more easily placed at the center of the adoption process. Ideally the decisions around adoption should be driven by the child's best interests (it is acknowledged that this is not always the case). However, no child exists when A.R.T. is first initiated. Thus, there is an increased possibility for A.R.T. to be solely driven by the wishes of the prospective parent[s] as A.R.T. is a service formed around the prospective parent[s]. Although the 'hoped for' potential child is motivating perspective parents towards A.R.T., the future child and their needs are invisible and unknown, and therefore may not be at the centre of the process.

Secondly the *clients* of a clinic, practitioner or business providing A.R.T. services, are the applicants seeking to conceive a child. This is not dissimilar to adoption where the *client* of the government department assessing and approving applicants for adoption (or private agency in many countries) is the adult hoping to be a parent through adoption. However, as previously mentioned, the needs and wellbeing of a child in existence are more visible, and in good adoption practice, the needs and wellbeing of the child in question drives the allocation and matching of a child to the client or rather prospective parents.

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Furthermore in good adoption practice, the child for which an adoptive placement is sought is supported and advocated for by a different professional to that of the applicant (although again it is acknowledged that this is not always done well).

A third potential obstruction is where A.R.T. provides a financial benefit to a clinic or individual. Although Australia operates through a highly regulated government intercountry adoption system, the impact of financial gain on ethical processes and best interests of a child has been demonstrated where countries utilise private agencies, regardless of the presence of legislation and regulation. Where an individual, business or clinic is able to financially benefit through the provision of A.R.T, or any aspect of this (including payment for egg, sperm, or embryo donation, but also the service and procedures); it is possible that there is a greater risk to the welfare of the child not being at the centre.

Registration Requirements for Providers of A.R.T. in South Australia

ISS Australia strongly encourages a rigorous registration and monitoring process for all providers of A.R.T. in South Australia. If the welfare of the child is indeed the priority, then processes that protect the integrity of procedures, prevent commercialisation, and ensure a central, accessible and permanent record for the person conceived through A.R.T. is a priority.

Given the applicant is the person seeking A.R.T, it is possible the focus may instead be on the welfare of the paying customer, rather than the potential child conceived through A.R.T. Therefore, it may be prudent to have the assessing / approving body differ to that of the service or practitioner being paid by, or financially benefiting from A.R.T. delivery.

Drawing on the history of adoption practices and processes around the world, it has been demonstrated that where individuals or businesses financially benefit, a greater vulnerability to unethical processes exists and are more likely to occur. This vulnerability is potentially further exposed where there is a lack of registration and monitoring by a central authority.

Access to Assisted Reproductive Treatment

Fact Sheet 2 '*Welfare of the Child: Paramourcy of the Welfare of the Child in Assisted Reproductive Treatment*' refers to the physical welfare of the child born as a result of A.R.T., including the need for protection from significant medical risk from a procedure, and screening for hereditary disease, as well as screening applicant for histories which may impact on the safety of a child in their care.

ISS Australia advocates screening applicants who wish to undergo A.R.T. for histories of '*physical and/or sexual abuse of others, neglect of children in their care, family violence, and/or drug or alcohol problems that may impact upon the child*', or untreated/unmanaged mental illness, in the same way that foster parents and adoptive parents are screened. Foster care, adoption and A.R.T. all engage a purposeful process toward parenting and each involves a service or medical professionals assisting them toward their parenting journey. This brings an obligation for services and practitioners to make efforts to ensure the child is to be born into a family where their physical and psychological wellbeing is probable. Therefore, if the welfare of a child born as a consequence of A.R.T. is considered paramount, then creation of a life through medical acts entirely generated by desires of the applicant to become a parent, screening for these things is only reasonable.

Fact Sheet 2 '*Welfare of the Child: Paramourcy of the Welfare of the Child in Assisted Reproductive Treatment*' poses the existential dilemma of whether screening the prospective parent[s] is in a child's welfare interests, if that process results in that child not being born. However, in the case of A.R.T., prior to the screening of the applicant, the child does not exist. The child's life is being deliberately brought into being through specific actions of medical staff in response to an applicant's desire. Therefore, when considering a child's welfare being paramount, it seems logical that there is an obligation to screen.

It is the view of ISS Australia that this screening is done by a Police and Child Protection check, rather than by a Statutory Declaration. Ideally each Australian jurisdiction would have the same checks and

the same criteria for approval of an applicant, which would avoid a declined applicant seeking A.R.T. treatment at another clinic.

Donor Conception Register: Access to Information

“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”¹ and equally important. This medical information is crucial for donor conceived people and for their children, in order to gather accurate medical history”. Damon Martin, Manager ISS Australia 'Managing information related to donor conception (Inquiry)', NSW, 14th February 2013

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 their experience working with adopted people and their natural desire to seek information about their biological history. The reasons for seeking information may include the 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 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. In the 50's, 60's and 70's in Australia's past, 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 high priority is given to the development of a donor registry, and that the 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 South 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. is to be treated as being of 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.

¹ Centers for Disease Control and Prevention (CDC), *Awareness of Family Health History as a Risk Factor for Disease*, 2004, *Morb Mortal Weekly Report* 1044

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.

The guidelines around who can access adoption records in South Australia may provide a suitable framework for legislating who may access information about the donor. In 1988 changes to the Adoption Act recognised the natural desire and benefits for people to have access to records that provided information about their history.

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.

Support Services

If the welfare of any child to be born as a consequence of the provision of A.R.T. is to be considered paramount then funding and provision of services specific to their needs should be provided. Again, drawing on the lessons learned through adoption, support services have been well utilised by all parties affected by adoption. Complex identity development journeys, disenfranchised grief and loss, yearning to know biological relatives, and seeking a sense of belonging, are just some of the life-long issues which may ebb and flow throughout different periods of life for people who were adopted. Counselling, education and support provided through post adoption support services may assist adopted people in their journey and it is likely that those conceived with the assistance of a donor will have similar needs.

Post adoption support services also provide assistance, mediation and counselling around search and reunion, and for those unable to find the sought for person or where the sought for person is unwilling for contact. Search and reunion can be a very complex and emotional journey for both the person searching and for the person who is sought. We also believe it is best practice to use a professional intermediary when approaching another party with a request for contact as it is less intrusive and respectful of the other party's privacy.

A support service of this kind could also provide counselling, advice and assistance to donors who are facing disclosure of their status to the donor conceived person.

Although it is recommended that records and a donor register are maintained by a central government authority, and that registration and monitoring of providers of A.R.T. is the responsibility of a government central authority, it is proposed that a support service for donor conceived people and donors is best provided through a non-government entity.

Record Keeping and Confidentiality Provisions

Section 18 of the Assisted Reproductive Treatment Act 1988 therefore now provides (among other things) that a person must not disclose the identity of a donor of human reproductive

material except as required or authorised by or under the A.R.T. Act (or any other legislation) or with the donor's consent.

ISS Australia believes that accurate and complete records are imperative. This is both for the medical reasons cited in Fact Sheet 7 '*Record Keeping and Confidentiality Provisions*' which states; "A child born as a result of A.R.T. that has involved donor-conception and/or surrogacy, may require access to information about all those involved in their conception and birth. Records may also be important for research on longer term health outcomes for children born as a result of A.R.T.; and health outcomes for recipients and donors".

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 records are kept permanently by a central authority as per adoption practice, as they hold important information about 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 the issues raised in the *Review of the Assisted Reproductive Treatment Act 1988 (SA)*. Please do not hesitate to contact me if you require further information.

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