

Committee Secretary
Legal Affairs and Safety Committee
Parliament House
George Street
Brisbane QLD 4000

27 April 2022

Re: Inquiry into Matters Relating to Donor Conception Information

Dear Committee members,

Thank you for the opportunity to comment on the issues raised by the *Inquiry into Matters Relating to Donor Conception Information*.

By way of background, International Social Service (ISS) Australia is a not-for-profit, non-governmental organisation with over 60 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 140 countries. Our 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 some similarities between people who are adopted and people who are donor conceived, but also acknowledge there are unique differences.

We write to you to address the following key criteria from the inquiry:

- 1. Issues relating to access to donor conception information, including:**
 - a. Rights of donor conceived persons, including to know their genetic origins;**
 - b. Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors;**

As professionals who have worked in the post adoption field for many years, we are regularly reminded of the mistakes made in past adoption practice. Past adoption practice was shrouded in secrecy and many adoptees were raised with no knowledge of their adoption. The profound effects of past adoption practice are well documented and researched, which is why the practice has now changed to one promoting openness, access to records and information, and often contact with their biological family.

There are many similarities between adoptees and donor conceived children, the most obvious being the importance of identity. Many adoptees and donor conceived persons yearn for knowledge about their genetic heritage and medical history and feel the need to connect to people to whom they are

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biologically related. However, one clear difference is that the paramount principle of adoption is to meet the best interests of the child, whereas the focus in the case of donor conceived children is on the needs of parents.

It is inevitable that one of the most foreseeable needs for donor conceived people is to obtain information about their donor. It is highly probable that a large number of donor conceived people have been conceived in Queensland 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 which no longer continues. We understand anecdotal evidence in Victoria suggests that of those conceived prior to legislative changes in 1998 regarding the anonymity of donors, up to 90% of donor conceived people are not aware of their origins.

The *"world of adoption has a wealth of experience and expertise that should be highly relevant to donor conception."*¹ It is on this basis ISS Australia wishes to comment on the questions raised in this Inquiry, as we believe *"it is a fundamental right and of great importance for donor conceived people to know their family and medical history."*²

ISS Australia strongly believes that all donor conceived adults should have retrospective access to their donors' identifying information. If the information of donors is withheld from donor conceived people, long term identity issues can manifest, a common occurrence which we have observed in our experience of working with people that were adopted.

One cannot underestimate the fundamental human right to have access to information about one's biological parentage. It is critical for all donor conceived people to know they are donor conceived and to have access to information about their donors. Information such as ethnicity, physical characteristics, personality, family history, and so on will assist with possible future identity issues and enable donor conceived people to create a sense of 'who they are'.

In addition, *"the importance of having access to information concerning a biological parent's medical history (whether or not there is a familial history of heart disease, diabetes, cancer, mental health issues, and/or other heritable diseases) is undeniable"*³. This medical information is crucial for donor conceived people and for their children, in order to gather accurate medical history. In fact, we believe for many donor conceived people accessing the medical information of their donor can be more important than any potential relationship or connection with their donor.

ISS Australia acknowledges the difference between accessing information about donors and contact. We appreciate some donors may not wish to receive requests for contact from their numerous offspring and the need to respect their wishes and privacy. Therefore, we suggest that if

¹ *Information Rights and Donor Conception: Lessons from Adoption?* Richard Chisholm, *Journal of Law and Medicine* June 2012, page 740

² [The Right to Information for Donor Conceived People: Lessons Learnt from Adoption](#), Damon Martin 2012, page 1

³ *Centers for Disease Control and Prevention (CDC), Awareness of Family Health History as a Risk Factor for Disease, 2004, Morb Mortal Weekly Report 1044*

retrospective access was granted that a provision similar to the 'contact veto' used in adoption practice be put in place in order to eliminate any unwanted requests for contact. A similar model exists in Victoria and appears to be working well in regards to respecting the privacy of the donor.

However, it is important to stress that such a provision would never prevent the release of identifying information about the donor. ISS Australia strongly believes that a donor conceived person's right to their donor's information should take precedence over the donor's right for their details to remain private or anonymous. However, with regards to contact, donors should still be able to determine if they wish to engage in contact arrangements.

c. Access to historical clinical records and implications of retrospectivity;

From ISS Australia's experience in handling many historical post-adoption cases, the importance of accessing one's clinical records is undeniable. ISS Australia is aware that there have been previous poor practices in record-keeping, and this is problematic when allowing access to records retrospectively. However, when we look at the adoption sector and past practices, poor record-keeping also occurred, and we have learnt over time that operating in a spirit of transparency and openness is the best approach when it comes to accessing and sharing historical records.

Moreover, moving forward, ISS Australia would support legislation to set minimum standards of record keeping of donor conception practices. This legislation could also prohibit tampering with, or destruction of, any records relating to donor conception information with strong penalties for those breaching such requirements.

d. Access to support and counselling for donor-conceived persons and donors;

ISS Australia encourages those involved in donor conception (including the clinics and professionals, the donors, and the parents of donor conceived people) to learn from past adoption experiences so poor practices and mistakes are not repeated. The adoption sector has a wealth of experience and expertise that should be highly relevant to donor conception.

ISS Australia considers it imperative that a government funded specialised counseling and support service is established to meet the growing need of people who were donor conceived in accessing their information. It is important to note that the fundamental issues people who were donor conceived will face when accessing their information are to do with identity, relationships, grief and loss and contact. These are social issues, not medical issues, and therefore the counseling and support service should not be provided by a health service or fertility organization, but rather an organization experienced in social issues related to identity, relationships, grief, and loss.

ISS Australia supports the establishment of an authority in Queensland similar to VARTA⁴ in Victoria, or funding provided to an NGO with suitable experience. This could be a post adoption service as they are the closest equivalent professional field to working with clients experiencing these issues. We know both people who were donor conceived as well as people who were adopted can yearn for

⁴ <https://www.varta.org.au/>

knowledge about their biological family and medical history and need to connect with people to whom they are biologically related.

Similar to people who were adopted, some people who were donor conceived have described living with a feeling of 'not fitting in' with their family. The importance of knowing one's identity cannot be underestimated. For people who were adopted, or donor conceived, having access to information about their biological parent can help them 'fill in the missing pieces of their life'; this is information the majority of us have and have the luxury of taking for granted.

We also know that some people who were adopted or donor conceived may feel torn or disloyal to their parents if they instigate contact with their biological parent. Adoptees or donor conceived may often initiate contact with their biological family alone and not supported by their parents, as they fear doing so may impact on their current relationship. It is for this reason that ISS Australia supports the provision of a government funded specialized counseling and support service, that could also assist in negotiating contact arrangements or acting as an intermediary in establishing the contact arrangements.

We know from our adoption experience, for the adoptee and their birth parent, their search and reunion can be a very complex and emotional journey. Therefore, we recommend the provision of professional practical support and counseling throughout the lengthy process. 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.

The needs of people who were donor conceived accessing information about their donors and attempting to initiate contact have similarities to people who were adopted accessing their birth information. Therefore, ISS Australia believes it is vital that a support service is funded by the Queensland Government to provide specialised free counselling, search, mediation, and contact services for people who were donor conceived or are donors.

Thank you for the opportunity to comment on the issues raised by the *Inquiry into Matters Relating to Donor Conception Information*.

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