

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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**Submission by International Social Service Australia to the
NSW Legislative Assembly Committee on Law and Safety**

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Inquiry into Managing Information Related to Donor Conception

Submission:

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

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 at 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. 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 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."³

ACCESS TO INFORMATION

Question 1: Should donor-conceived adults have retrospective access to donors' identifying details?

ISS Australia strongly believes that donor conceived adults should have retrospective access to their donors' identifying information. We support the Parliament of Victoria Law Reform Committee's recommendation that the

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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

Victorian Government enact legislation that allows all donor conceived people to obtain identifying information about their donors. We would also support the other Australian States and Territories to follow this recommendation as we believe this is best practice.

If donor conceived people have identifying information about their donors withheld it is likely that long standing identity issues will manifest, we have learnt this from our experience of working with adoptees. 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.

Question 2: If retrospective access were granted what conditions should apply?

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 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. However it is important to stress that such a provision would never prevent the release of identifying information about the donor.

Question 3: What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required?

ISS Australia strongly supports the provision of counseling and support services. In NSW ISS Australia is one of the four government funded specific post adoption support services. ISS Australia is solely responsible for supporting any NSW resident (adoptee or birth family) with an international element to their search and reunion. For example, a person may have migrated to Australia and the adoption taken place overseas or the adoption occurred here and subsequently one or more of the people concerned may have gone overseas. For both the adoptee and birth parent, their search and reunion can be a very complex and emotional journey; therefore we recommend the provision of professional 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 donor conceived people when accessing information about their donors and attempting to initiate contact have many similarities to adoptees accessing their birth information. Therefore ISS Australia believes it is imperative that a support service is funded by the NSW Government to provide specialised free counseling, search, mediation and contact services for donor conceived people and donors. ISS Australia believes a post adoption service would be the most appropriate agency to become a funded specialised service for donor conceived people and their donors, as it is the closest equivalent

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

professional field. An example of this may be found in the pilot voluntary exchange and contact register for adults related through donor conception launched in the UK, called UK DonorLink. UK DonorLink was based in a post adoption service (After Adoption Yorkshire) and employed staff from the post adoption field.

While we recommend a specific specialised support service is established to meet the increasing needs of donor conceived people and their donors for counseling and contact services, ISS Australia does not support the provision of mandatory counseling for donor conceived adults to access their information. As mentioned earlier we believe it is a basic human right and of great importance for donor conceived people to know their family and medical history.

MANAGEMENT OF DONOR REGISTERS

Question 4: Which agency is best placed to manage the register of donor conception information (donor register)? Is the current management of the register adequate?

It is difficult to identify a current appropriate body / agency to manage the register of donor conception information, especially since NSW does not have a service or authority dedicated solely to meet the needs of donor conceived people and their donors.

ISS Australia strongly believes the Ministry of Health is not the most appropriate agency to manage the register. The primary issues donor conceived people will face when accessing their information are to do with identity, relationships, grief and loss and contact – they are not medical issues. ISS Australia believes the health sector has little understanding of or concern for the possible lifelong identity issues faced by some donor conceived people, or their need to know about their biological and medical history. This also applies to follow up counseling or support donor conceived people may require if they decide, after receiving information about their donor, to pursue a journey to connect and have contact with their biological parent.

The NSW Registry of Births, Deaths and Marriages (BDM) may be the most appropriate body to manage the register. BDM are experienced in record keeping and management, but they would need to work closely with a specialised counseling and support service to deliver the range of services. Alternatively a specific service or authority set up to work solely with donor conceived people and their donors could also be an appropriate agency to manage the register.

Question 5: Should a standalone body be established to manage the register? What other areas could it have responsibility for?

ISS Australia supports the establishment of an authority similar to VARTA (Victorian Assisted Reproductive Treatment Authority) or a similar service delivered by an NGO, for example a standalone body capable of managing the register. The standalone body could also provide public education and resources for professionals and the community on fertility and issues related to assisted reproductive technology, including IVF, surrogacy and donor-conception.

COUNSELLING AND SUPPORT SERVICES

Question 6: Should counselling and support services be offered to those seeking donor conception information from the donor register?

It is in our view imperative that a specialised counseling and support service is established to meet the growing need of donor conceived people accessing their information. It is important to note that the primary issues donor conceived people will face when accessing their information are to do with identity, relationships, grief and loss and contact – they are not medical issues and therefore the counseling and support should not be provided by a health

service. We believe an agency experienced in post adoption issues should deliver the specialised support service as it is the closest equivalent professional field to working with clients facing these issues. We know both donor conceived people and adoptees can yearn for knowledge about their biological family and medical history and need to connect with people to whom they are biologically related.

Similar to adoptees, some donor conceived people have described living with a feeling of 'not fitting in' with their family. The importance of knowing one's identity cannot be underestimated. For adoptees and donor conceived people, 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 adoptees and donor conceived people may feel torn or disloyal to their parents if they instigate contact with their biological parent. Adoptees and donor conceived people 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.

Question 7: Are there other types of support that could be offered?

One of the key components of post adoption practice is providing a professional intermediary and contact service. In NSW there are four funded NGOs specialising in intermediary and contact services, plus three accredited adoption agencies (Anglicare, Barnardos and CatholicCare) and the Adoption Information Unit – Department of Family and Community Services (FaCS), all providing professional intermediary and contact services.

We believe using a professional intermediary is a less intrusive approach and respectful of other parties' privacy and wishes. Therefore ISS Australia recommends that the specialised counseling and support service for donor conceived people and their donors also offers professional intermediary and contact services.

Question 8: How would support services be funded? By the government, the individual seeking the service, or by ART clinics?

As mentioned above, the NSW Government currently funds four NGOs to deliver post adoption services free to NSW residents affected by adoption. ISS Australia strongly encourages the NSW Government to fund a dedicated, specialised support service to meet the growing needs of donor conceived people and donors accessing information.

The NSW Government could impose a compulsory levy on all clinics using artificial reproductive technology procedures that could contribute towards ongoing funding for support services for donor conceived people and their donors.

It has been estimated that between 20,000 to 60,000 donor conceived people are living in Australia and as the most populous state in Australia it is evident that a large proportion of this total will be living in NSW. The number of donor conceived people will continue to grow rapidly, as it is been estimated that at least 600 – 1,000 babies per year are born in Australia using sperm or embryo donations.

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 their information and specialised support services free of charge.

Question 9: How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a standalone body (as has been recommended in Victoria)?

ISS Australia believes it would be appropriate for one specialised support service to provide the range of services required by donor conceived people and their donors. This would include counseling and support, intermediary and contact services, as well as public education and resources. A standalone body in NSW (an agency or authority) could become a 'one stop shop' providing a range of services relating to donor conception.

RECORD KEEPING

Question 10: How long should ART clinics be required to retain records?

ISS Australia supports the NHMRC guidelines that records should be kept indefinitely. From our experience in handling many historic post adoption cases, the importance of accessing one's records is undeniable. If an adoptee or a donor conceived person finds out their records have been destroyed it is likely to be a source of ongoing frustration for the individual and could create complex identity issues. The NSW Adoption Regulations 2003 Clause 73 (3), states "The case records are not to be destroyed".

Many adoption professionals still encounter significant numbers of 'late discovery adoptees' from the closed era of past adoption practice. These people discover later in life that they were adopted; this often comes as a tremendous shock and can create a range of intense emotions, including disbelief, confusion and anger. It is also probable that a substantial number of donor conceived people are growing up believing they are biologically related to both their parents and will also find out the truth about their conception later in life. It is for this reason that ART clinics should always retain their records indefinitely.


Question 11: What should happen to records if a clinic closes?

If the ART clinic closes then their records could be stored by the standalone specialist organisation established to meet the range of services provided to donor conceived people and their donors.

Question 12: How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with.

ISS Australia would support legislation to prohibit tampering with, or destruction of, any records relating to donor conception information with strong penalties for those breaching such requirements.

Thank you again for the opportunity to comment on the issues raised by the *Inquiry into Managing Information Related to Donor Conception*. Please do not hesitate to contact me if you require further information.


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