Submission
No 33

INQUIRY INTO LEGISLATION ON ALTRUISTIC SURROGACY IN NSW

Organisation:	Infertility Treatment Authority Victoria
Name:	Ms Helen Kane
Position:	Manager, Donor Register Services
Date received:	29/10/2008

ITA

Infertility Treatment Authority
Professor Jock Findlay AM Chairperson
Louise Johnson
Chief Executive Officer

ABN 94 021 324852
Level 30 570 Bourke Street
Melbourne Vic 3000
Tel (61 3) 8601 5250
Fax (61 3) 8601 5277
Email ita@ita.org.au
Web www.ita.org.au

Our Ref: HK/081029 NSW Inquiry

29 October 2008

Rachel Callinan
Director, Inquiry into Surrogacy
Parliament of New South Wales

Dear Rachel,

Re: submissions in relation to the Inquiry into legislation on altruistic surrogacy in NSW
I have been advised today by Miranda Montrone, a psychologist working with surrogacy in NSW, that an inquiry had been called, and the period for submissions extended. She had spoken with you, and that you had indicated you were happy to receive copies of submissions made to the recent Queensland inquiry in relation to altruistic surrogacy, if the connection to your Terms of Reference could be established.

Item f. The rights that a child born through an altruistic surrogacy arrangement should have to access information relating to his or her genetic parentage, and who should hold this information.

This was the focus of my presentation to the Queensland Parliamentary Committee, and I have therefore attached a copy of this, as my submission to your Inquiry.

Please feel free to contact me should you have any enquiries, or questions.

Yours sincerely,

MS HELEN KANE
Manager, Donor Register Services

PUBLIC HEARING

INVESTIGATION INTO ALTRUISTIC SURROGACY COMMITTEE

7 JULY 2008

12.40 – 1.15pm Child's rights to genetic information

Helen Kane, Infertility Treatment Authority Victoria
Administrator of oldest donor register in Australia.

The terms of reference list Issue for Comment No. 16 as "what rights should a child born through an altruistic surrogacy arrangement have to access information relating to his or her genetic heritage? Who should hold this information?"
Issue No.16 is therefore the focus of the comments I would want to make.

I am a social worker with extensive experience in the obstetrics, adoption, infertility, and access to information services in both adoption and donor conception, as a counsellor and administrator. For the past 3 years I have been the Manager of the Donor Registers Service at the Infertility Treatment Authority in Melbourne, and that position has involved both development of the service, and provision of counseling to people affected by donor conception.

The personal and professional statement that I would make, arising from my experience, is that all children have a right to know how they came to exist, how their family was created, and who was involved. I believe they have a right to access information relating to their genetic heritage, if they want to.
This rests of course on the knowledge of their origins, and that the information itself actually exists. I believe that the information itself has to be accurately recorded, be protected by law, and that clear information about both existence of the information, and the pathway to it, has to be readily available to all. This means the information system and process have to been good, and stand up well over time, and that the community needs to know about it.

THE VICTORIAN REGISTERS

The Infertility Treatment Authority has responsibility for the maintenance of four Registers and for provision of service to applicants to these registers under the provisions of the Infertility Treatment Act 1995. These are two Central Registers which record the births of children under the Infertility (Medical Procedures) Act 1984 and the Infertility Treatment Act 1995. These Registers record information about donors, recipient parents, and the person born, as a result of egg, sperm or embryo donation. There are also two Voluntary Registers, created in 2001, one which applies to births prior to legislation, and the other which applies to all births from the time of enactment of legislation in 1988.

In Victoria, over 1200 donors have provided eggs or sperm to help create over 4000 children since Central Registers were set up to record births from donor conception in 1988. Of these donors, over 700 are egg donors and over 500 are sperm donors.

People were generally unaware of the existence of the Registers, and their rights in relation to them. Parents and donors had had contact with infertility programs at the time of treatment, but were unlikely to know about the Registers at the Infertility Treatment Authority. It was also acknowledged that many donor conceived people would not know of their status.

2006 saw the creation of the Donor Registers Service, and the commencement of a 3-year "How to Tell" Campaign, to inform the public about the impact of the 1984 legislation, as that was the year that the first of the donor conceived people on the Registers became legal adults, which meant that they were able to seek information about the donor, or could be approached by the ITA as a result of an application for information from the donor.

The focus of the campaign was on parents who have donor conceived children, young adults who may wish to seek information or contact with their donor, and donors who may wish to seek information or make contact with a child.

We have provided assistance to parents wanting to tell their children, of all ages. We realized early in the campaign that it was difficult to engage people easily face to face, and so we placed a strong emphasis on developing information available through our website. This information is downloaded at very high rates, particularly the documents which talk about how to approach telling the child.

There have been more than 100 applications for information in the last 12 months. Families are applying to both Central Registers and the Voluntary Registers, wanting information about the donor, but some using the Voluntary Register in the hope that they can have contact with other families with children conceived with the same donor. Donors are predominantly using the Voluntary Registers, wanting to provide information to donor conceived individuals or their families.

We have had few CR applications by donor conceived people, partly because there are only around 500 who have reached adulthood, many of whom are likely to not know of their status. The other factor is simply developmental stages – in the formation of identity, and a readiness to take risks to obtain information, a need to take active steps to find out is most likely to be as the young adult is moving into a permanent relationship and thinking about the creation of the next generation.

We have developed clear service models in relation to both CR applications and VR Matches (the application by two related individuals to the VR). Counselling is a requirement in both models, but also the counsellor has the role of facilitator between the parties. This makes for a responsive, flexible service system, which enables people to reach arrangements that suit them, and in the instances where the outcome is not what was hoped for, the counsellor is able to provide counseling and support.

LESSONS FROM VICTORIAN EXPERIENCE

Part 1 of the issue – what rights should a child born through altruistic surrogacy arrangement have to access information?

1. individuals and families are complex, and the addition of issues such as infertility, non-biological parenting, difference in status between the parents in relation to this, and lack of information and connectedness to the biological parent, the donor, creates particular hurdles for them.

2. Parents have difficulties telling their children about how they were conceived. The things that get in the way are their own feelings about this, and their fear that their child will not accept them as their parents. In the past, silence on the issue has been presented as the best policy by the professionals involved in the infertility field – literally "get on with your lives as if there had been no donor".
But they also don't know how to tell their children, they don't know the words, they don't know how to present the situation.

3. Altruistic surrogacy, like "known donor" implies close relationships between the adults involved, and an assumption that they will be able to deal with issues over time. Relationships change, families fall out, and at times the "known" is simply that they have found each other for this particular purpose, rather than having a developed relationship. They may all require access to information over time, that may not be directly accessible.

IN SUMMARY: The child ought to be aware of his or her genetic history, including that a surrogate was involved, because it simply is a basic human right. But ought to learn of this within the family, as part of being a family. They ideally learn this over time, with having a sense of "always having known". This is the easiest for the parents as well, and allows for the child's understanding to develop over time, and being addressed at the time.

People require information and support in relation to telling their children how their family was created. This is likely to apply to surrogacy, as it does to donor conception.

Part 2 of issue: who should hold this information?

1. The information has to be recorded, and recorded consistently. The clinic involved should keep records. Provision needs to be made for clinics closing, and what needs to happen to their records. Provision also needs to be made for services to their past clients. This should be addressed in legislation.

2. There ought to be a central authority, like the ITA, which maintains the information permanently, and which also has the power to ensure that the information is recorded, together with provision of appropriate services. It may be 30 years or more before a donor conceived person makes application for information about the surrogate, and the information must be there.

3. It is illogical to consider an information system for surrogacy, without this being within the context of access to information for donor conception. It ought to be a "one stop shop" situation of a program which maintains the records, in both areas, and provides services, like the ITA Donor Registers Service.

4. Surrogates ought to have the same rights as donors in regards to seeking information about the family or the child. All parties to the conception ought to have the right to seek information and/or contact in the future.

5. A baby who is born of a surrogate, no matter what state, is legally her child. So a separate issue is the matter of legal parentage. No matter what is the solution arrived at, there need to be clear pathways of information for the child. A solution which encourages secrecy would be working against the best interests of the child, but also the family.

OTHER MATTERS

1. There needs to be community education in relation to altruistic surrogacy, and clear information disseminated in relation to any change in law. There needs to be a process which moves away from secrecy, and places these particular families within the umbrella of diverse families.

2.The professionals working with families created in this way also need to be educated and aware of the issues that can arise in families. However, we also need to have a clear idea about what those issues are. This requires research, but also services like the ITA registers, which people use for their own needs, but in the process educate us about what it has been like for them, and what are the issues that have presented for them.

3. The education material and opportunities should be wide ranging and accessible. The "How to Tell" campaign, and the use of media, has been very successful in reaching people, and encouraging them to think about the issues, but the material on our website, the opportunity to talk by phone, or to meet with a counsellor, have been crucial, with the individuals themselves able to access the information that they need.

4. The numbers of surrogacy arrangements which result in a child is likely to be small. If a single point of maintenance of records and provision of services existed, understanding and development of appropriate services is more likely to occur than if they could only go back to the original service provider, i.e. the clinic, which may no longer exist. That understanding can then be fed back to the field, and to other professionals, such as family and individual counselors in the community. If this service was placed with a service relating to donor conception, it would be ideal.

HELEN KANE
MANAGER, DONOR REGISTERS SERVICE

3 July 2008