INTRODUCTION

My name is Helen Kane, and I make this submission as a private person, as an addition to my original submission to this inquiry, dated 5 August 2010. The points that I made in that original submission remain unchanged, but I wanted to make some additional points, as a result of the Interim Report at September 2010.

I am a social worker with many years of experience as a social worker in the adoption, infertility, access to information (both adoption and donor conception), and in public health and private infertility clinics. I was the Manager of the Donor Registers service at the Infertility Treatment Authority in Melbourne from 2005 to 2009, when the changes in legislation led to the closure of these Registers, and the transfer of their functions to other bodies. I had previously managed Adoption Information Services in several private adoption agencies, and had been involved with the implementation of the 1984 Adoption Act in Victoria, which introduced access to information for adopted people, no matter when the adoption took place, It was retrospective, and was a clear and positive success, as long as it was accompanied by good counseling and linking services, which acknowledged the needs of all the people concerned. I was also involved, as a member of the Victorian Infertility Counsellors Group, with developing a model of practice for use with people wishing to access information in relation to donor conception, as a consequence of the 1984 Infertility legislation.
ADDITIONAL MATTERS IN RELATION TO INQUIRY, AT 9 AUGUST 2011

Use of donor gametes to achieve pregnancy in Victoria has a long history, with huge variation in practice over time. Families were advised not to tell their children, and often had very little counseling or assistance to deal with the issues inherent in their situation, at the time of treatment, or since. Sperm donors in particular were only considered as a source of the necessary material to achieve a pregnancy, and so the information that was provided to them was minimal, as was any opportunity to explore what the issues might be. They did not see a counselor, until this was required by the 1984 legislation.

At the time, no one really seemed to think much about the needs of the person who resulted from this treatment, but everyone seemed to be in agreement that he/she shouldn’t be told. There were real issues around the legal situation for the child, in relation to who was the father, until the Status of Children’s Act clarified this.

I think most people would agree that the practice in this area was unclear, ambivalent, with huge variation in what was said and done. I think that the members of the Law Reform Committee should assume that no one before 1988 was amply assisted to deal with their situation, and to make good and informed decisions.

Donor conception is a family business, and includes the person conceived, the parents and the donor or donors. And we would now include surrogate women who carry to birth a baby for others. So a child can have 2 legal parents, sometimes 2 donors, and one surrogate. As well as that, there are all the other children connected to all these people, siblings one way or another of the child. In the worst scenarios, from the Donor Records, there can be as many as 30 half siblings just through the sperm donor. Thankfully limits are now in place, but this does not change the result of past practices.

There are no simple answers with how best to assist people, but it is clear that all of those concerned have rights and needs.

THE ITA DONOR REGISTERS SERVICE

There was a failure to act by government in relation to the implications of the access to information aspects of both previous legislation in Victoria, and this only changed when the first children conceived under the 1984 Act were due to turn 18 years of age, with the right to request information, and most importantly, the right of the donor to request information as well.
This led to my employment by the Infertility Treatment Authority in 2005, and the creation of the Donor Registers Service – the donor registers had been administered by the ITA for some years, with the use of private counselors to meet the counseling requirements of the act. It was a very basic service, which was not able to manage the newly emerging complexities.

We proceeded to set up a Service which reflected my experience of working with access to information in adoption, and the sound practice model in place in that field at that time, i.e. an interview with the applicant, the release of information, the discussion of options and wishes, and assistance in acting on these, with provision of counseling and support to whoever was affected by this. This included the adult adopted person, the parents when requested, the birth family, and siblings. The non-identifying exchange of information, what is referred to as “letter drop” in the Interim Report, was an essential part of that service. It meant that people could take gentle steps forward, according to comfort, and make their own decisions in the process.

At no point did the Law Reform Committee look at what had been set up at the ITA from 2005, because it postdated the review on which it based its report. We were politically naïve at the ITA, and did not press forward with up to date information about what the Registers Service was achieving. And there were no complaints in all the years that we ran the service, and so did not come to the attention of the Minister for Health, who funded the service, and appeared to have forgotten we existed.

I refer back to my earlier articulation of the donor conceived person as part of a large family. The legislation was wrong to separate the child from the parent’s infertility, and reflects the ongoing stigmatization of infertility and diverse families. There was no sound basis for removing the child from family, for purposes of services. It is the services that need to be diverse.

We were able to work with parents around how to tell their children about their donor status, and this was through counseling and education. We were able to come up with a flexible service model which gave everyone in the situation respect, and room to move. It was a service model which was beginning to demonstrate its robustness, in that it was dealing with increasing numbers of children connected to each other through their common donor, as well as dealing with levels of great complexity for all concerned. The underlying principles were respect for all concerned, and a right to make their own decisions, with whatever support they needed.

This was not a service model which could survive the separation of the information from the service, and the reduction of counseling to one session, prior to receiving information, from a program which has no contact with the reproductive technology field, and little understanding of the experience of the parents or the donors.
It is less than two years since the ITA Donor Registers Service was dismantled. It is not too late to go back, and recreate that service, within VARTA. The expertise has not entirely disappeared as yet, and the support within the field was very strong, and the good will no doubt continues to exist.

The service needs to be able to assist parents, donors, the donor conceived person, siblings, and the professionals working with all of these. It needs to be able to access whatever information exists and to use that within the legal framework, to locate the other parties, to set up agreements and information exchanges, to establish direct contact if desired, and to provide counseling to deal with the challenges, and the disappointments.

The issues around protection, storage, and access to records must be protected by legislation. The particular problem will be the occasions when no information can be located, because it did not exist in the first place, or has been destroyed. The private doctor who did inseminations in his suburban practice did not keep records, or destroyed them when the practice closed. The hospitals who deliberately kept records separately, so that different legal requirements applied to each of them, and it has proven impossible to bring the two together again, when the child, or the parents are seeking information.

At such times, the quality of the search for records, and the quality of the counseling provided are crucial. The Registers Officer at ITA had extraordinary gifts in searching, locating, and connecting, information for the applicants to the Register. The counseling and linking processes we provided at ITA was second to none, and were seen as ground breaking. The disappointments were many for the people concerned, but we were able to provide a good service, which left them feeling that at least they had been heard. We did not have one single complaint in the 4-5 years of the Service.

It is possible to recreate that service, and for it to work with the clinics and with the Registry of Births Deaths and Marriages, if it was to continue to maintain the legislated Registers.
CONCLUSION

It remains absolutely clear to me that all donor conceived people should have equal rights to seek information about themselves and their donors. It is also absolutely clear that donor conceived people are members of families in the broadest sense, and all the parties to this conception also have the right to respect and information for themselves, and relevant services. Attending to the needs of parents with how to tell their child about the conception does not conflict with attending to the needs of the child to know and understand, and to seek contact with the donor, and of the donor to know more, and contribute information and connection. And we should not forget the need to know about siblings. The current Registers do not include that information, and it would appear that this connection will become impossible to make in the future.

The information contained in records is often problematic, in that it is inadequate, inaccurate, or does not exist. The use of the Registers held at Births Deaths and Marriages are not relevant to the people who would be seeking information from the past. There is no counseling provided for those who have no entry on a Register at Births Deaths and Marriages.

All parties have a right to services which support their processes, and can be responsive to their needs in the particular situation. The ITA Donor Registers Service was able to do that, and ought to be reinstated, with the necessary changes to legislation which would allow this.

I am happy to appear before your Committee, if you wished to discuss my submissions.

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Social Worker

9 August 2011