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LAW REFORM COMMITTEE

Inquiry into Access by Donor-Conceived People to Information about Donors

Melbourne — 12 September 2011

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Ms H. Kane

The CHAIR — Next up we've got Helen Kane. You were here when I went through my introduction so I won't go through that again. If you're happy for you to do a further submission we can just ask questions when they arise.

Ms KANE — No problems at all.

The CHAIR — If you can start with your name and address, please.

Ms KANE — My name is Helen Kane. I'm a social worker and was the manager for the donor registry service at ITA from 2005 to 2009. Before that my experience was working in the adoption and infertility fields and most particularly in the access to information fields in both areas.

The CHAIR — So your experience is in dealing with social work issues around this field or in the management of data?

Ms KANE — The social issues, yes, so my practice has been as a social worker throughout all of those areas of responsibility but in fact I actually set up the donor registers services. Will I launch?

The CHAIR — Yes.

Ms KANE — What I've done is actually address the Terms of Reference in order so if I start with (a). I believe that it is important that all donor-conceived people possess the right to seek information which identifies their donor, no matter when they were conceived, but that doesn't mean the automatic release of that information without the involvement and agreement of the donor.

The CHAIR — So does that mean that the donor has the right of veto or not?

Ms KANE — The donor has the right to make his own choices so the donor has a right to be aware of the request and to make his own choices. From my experience, the choices can be quite — we tend to talk about black and white names and addresses and the reality isn't like that so that in fact there is much more room for movement; donors who are really uncomfortable with the idea of that information being released in fact will often provide a whole range of other information so there's a process that's associated with this that takes into account the greater complexity of what this means for all of the people concerned.

Ms GARRETT — Just in your experience dealing with donors that have never been contacted, have you found — I know this is just based on your experience — have you found donors to be agitated about the initial contact or have people been open? We've spoken in these forums about the conditions that people donated pre-88 and they were told that they would be kept anonymous and they wouldn't be contacted and they have their lives now, what's your — —

Ms KANE — I guess one of the things is that generally donors were not advised that they would be contacted because it was never thought that it would be possible. And the questions they were always asked — well, firstly, whether or not donors were asked questions at all. I guess one of the points that I would make is there are questions around, particularly the men, the sperm donors, what it was they were actually told and what were their actual choices and how was that articulated at all because you'd need to keep in mind that up until 1984, the first infertility legislation, donors didn't see counsellors, they just saw scientists and doctors for a medical examination. So the quality of discussion, the quality of the consent, in my mind, is actually up for question anyway.

Ms GARRETT — They were never told of whether they had children?

Ms KANE — No. I guess one of the things too is this has been a sort of growing, changing service in that they were not allowed to ask, they were not allowed to be told within the system. Eventually what I'm aware of is that the staff started to tell the donors that there were three children, that the donations had been successful, but certainly most donors would not know how many kids there were, they wouldn't know if it was actually successful or not. One of the questions when we're contacting a donor it's always: how many children are there?

The CHAIR — What about looking at it from the other direction of a donor wanting to initiate contact with an offspring, do you treat them the same way in terms of how you would manage it and as far as what rights they have?

Ms KANE — In fact, it actually raises the question you talked about earlier about siblings. What I've done within this is actually deal specifically with the donors and the donor-conceived person with some reference to others. One of the issues for donor-conceived people is whether or not there are brothers and sisters, how many there are, and certainly one of the side-effects of the new register system of Births, Deaths and Marriages is they can't know how many brothers and sisters there are whereas in fact it was a routine part of the information they received at ITA, and previously I think it had been happening in the clinics as well.

Going back to the early days of adoption information, which gives some useful guides with this because some of the same discomforts were present, it was about, yes, an adult adopted person had the right to seek their original information, most particularly their original birth certificate, so that identified who their natural mother was and sometimes the father as well. The question was: could it happen in reverse? And there are all of the stories about how all these adopted people didn't know they were adopted so therefore in the early days, because birth parents only had certain rights on information and to ask for contact to be made, we would make contact with the parents on the assumption that maybe the kids don't know. What actually came through from that practice is you could spend a lot of time working with adopted parents who had never told their kids and still not have the children aware of their status because there were things in the way of that.

I actually remember one man in his 30s, I think he was, when I finally contacted him directly he said: why did you go to my parents? I'm an adult; you should have asked me. No, I didn't know I was adopted but you should have come to me and I would make the decision. That was a real lesson for me, because those parents couldn't deal with those issues and had never been able to.

The CHAIR — Do you think if they're over 18 it would be appropriate to contact the child themselves?

Ms KANE — Yes, but with services that sit behind that with the child and for the parents.

The CHAIR — Would you contact the parents first, even if the child is an adult, to give them the opportunity to — —

Ms KANE — That's actually what's been happening, or at least what was happening, at ITA. Once again, coming up against the same dilemmas because the issues that the parents are dealing with are complex and have been from scratch. One of the points that I would make is the services you receive at the time that you are having your treatment and having your experience of infertility — and the same for the donors — is that in fact that will have consequences in terms of how you progress and deal with the issues within your family.

I guess one of the classics with male infertility, and I guess it's interesting most of the doctors were men too, so it was a very practical orientation, you've got a couple here where the guy does haven't any sperm. What do you need? You need sperm. Therefore get some sperm and create a baby and problem solved. You need to keep in mind that that was very much the mindset behind this, there was little assistance given to the couple. How could the man say this doesn't feel so good and deny his wife the potential of a child that he felt he was denying her? They then become tied up in she feels bad because she desperately wanted this child and there's a price to pay for it, and so the things they do over time are just so impacted upon what happened at that point and what feelings they had and the power that they each thought they had at the time.

One of the things that we clearly have in place now, and have had for a long time, is we do have services for the infertile couple, there is opportunities for them to think through. Nowadays there are services for the donors. Back then, pre-88, the services didn't exist or existed only in bits and pieces. That's the history, so you're actually trying to come up with something that makes up those shortfalls.

Once again, when I was manager of the ITA service, I had an inquiry, I had a number of inquiries, where we contacted parents first because the child was under 18. Once again, what we were dealing with there is a history of some of those parents not having dealt with the issues, not having told, the 18th birthday was there that said: hang on, something's going to happen here. But usually the donors didn't want to go there, they did not want the children to learn in a negative way, but I guess the thing that came through for me is, once again, we had parents who had such difficulties dealing with the issues. Nowadays VARTA has the education program, there are resources there to help people to tell their kids, so it's a different world now to some degree but, once again, it wasn't so at the time for the children we're really talking about, the pre-88s.

Going back to the first Term of Reference, if all donor-conceived people were able to apply for information about their donor there would need to be an entity that was able to receive this, whether or not the treating doctor or clinic still existed and whether or not the individuals had consented to any release of their information in any way. This could be done if the law recognised the right of an individual to make a request and the necessity of the organisation to locate and obtain information pertaining to that request.

One of the quandaries that you have as a result of the circumstances for these people is that records were in all kinds of places with different status, not covered by law by anybody. Birth, Deaths and Marriages does not have the ambit to retain information, they have the ambit to manage the registers. If it was leading to the person, the donor-conceived person, him or herself, perhaps that might make it simpler to work out.

The CHAIR — When you set up the register under ITA, did you attempt to create a historical rebuilding of the data base at all?

Ms KANE — That was a work in progress because what actually happened through the work and through the inquiries, increasing knowledge all of the time about what had actually happened, who was actually providing services, where were they provided, the quality of the records.

The CHAIR — So if you found that a doctor had a box of records in a garage, would you do something about that?

Ms KANE — What would be really lovely is if you actually made it possible to get those because they do exist. Because one of the quandaries is — I assume it's a quandary for the doctors too — these are private patient records so it's what you do with the private patient records and, yes, there are doctors with records in the garage. But in fact if you actually had a way of them handing over those records, I would imagine some easing of concerns on their part too.

The CHAIR — Is there anywhere where there's a list of those sources or is it just in your head?

Ms KANE — It's not in my head; it's probably in the registers officer's head, Kate Dobby. And the history of her managing the registers and setting up the registers, that was before I was employed, was of actually sussing out, working out, because the parents would say where they had their treatment so we knew about private clinics, we knew about the doctors and the doctors who were providing donor insemination in their private rooms. The question always was where did they get the sperm from? But in fact some of those doctors actually had links with, I guess, healthy young men; the doctors were not necessarily using their own sperm. Up until freezing of sperm, which was the late 70s, it was always needing to be fresh sperm so it was how would you get sperm quickly? So that would be the phone call to the guy to come in.

I'm conscious that I might be covering some of the ground we've already done. There are practical issues which relate to the way the records have been kept. Private doctors in their private practices, as well as doctors within public and private hospitals, have all provided donor treatments since well before the 1940s, with a huge increase in the 1970s and into the 1980s. There was enormous variation in the way that the records were kept but, most importantly, they were not all kept at the time, or were destroyed when medical practices closed down. We're all aware of at least one of those private suburban practices where the records were literally destroyed.

The CHAIR — Are you aware of the obligations medical practices and doctors have to retain records?

Ms KANE — They are very slight. I don't recall when the Medical Practices Act and the Medical Records Act came in — 70s or 80s — the practice had always been, in my experience, seven years was how long you kept a patient's records for. The doctors were not breaking any laws with what they were doing, it was more not understanding the information and the importance of what they held in their records.

The CHAIR — I don't think we asked Kate this question last week but how many of these little pockets of records are likely to be around the place that you could collect together if — —

Ms KANE — Very few.

The CHAIR — Very few?

Ms KANE — Yes, very few.

The CHAIR — A few sources, or two or three or 10?

Ms KANE — I'm not sure. What you actually have, and once again an issue for your committee, is the practice of private doctors working in public hospitals as well as in private hospitals so that what you actually have are the private doctors' private patient records; you have the records that say the insemination clinic might have kept and you have the records of private hospitals.

I guess if we call a spade a spade, let's go back to Queen Victoria Hospital and Epworth — this is way back in the 80s — the donor records and the treatment of the donor were managed in the private place. Queen Victoria Hospital was where IVF was developed, sperm was obtained from the other place and used with the patients of the Queen Victoria Hospital under the particular doctors. The inseminations of the private patients took place at Epworth, so you actually had three different places with a status of those records each being quite different but in fact dealing with the same people and also the same doctors. So that's your complexity.

One of the issues would be for you is how would you be able to cover all of those variations and status of records. Once again, my point would be if we could come back to the donor-conceived person himself, and if you have the capacity to request and obtain the information, wherever it was, you've got half the problem solved. Whether or not they exist is the other question but in fact you can try.

Ms GARRETT — Can I just ask, again based on your experience of the donors who were contacted, what percentage, and I understand it's rough, would you say said: no, I don't want to take this any further?

Ms KANE — Very, very rarely did they say no.

Ms GARRETT — If you can break down those who said no, those who said I'm happy to provide information but I don't want to take it any further, and those who were open?

Ms KANE — I guess the first kind for the system was that these guys had wondered. They didn't know if there were children and so the first question literally was: how many are there? I'm approaching you because of your inquiry from a donor-conceived person born in such and such a year. And his question is: right, how many others are there? I've been thinking about it — this is really typical — I've wondered if there are children, I've wondered how many children there are. So for them no matter what happens further down the track what they've discovered is, yes, there are six children.

One man that I approached, who was shocked at being approached because he'd understood that his sperm was used for research but in fact his sperm had created eight children, so we had an application from the eldest of the eight, who were all in different families, so his feeling was: this isn't supposed to happen, that's not what I was told. He actually demanded to see his original consent and all of those things, which in fact thankfully we were able to give him, and it did actually state that his sperm would be used to create children for infertile couples. But I guess, once again, he'd had no discussion, he'd just fronted up to the hospital on a regular basis and donated. So his question was: what about the others? He said: I don't want contact, can I do a veto on all of them? And I said: no, you can't do a veto on all of them. Because what he thought was: okay, that means I've got to go through this eight times? And I said: yes, maybe. But that in fact he couldn't do a blanket. What he did do is go away and he came back and said: no, I don't want contact but I will provide this information for that young woman. And she was satisfied with that.

Mr NORTHE — Just going right back to the very start. One of the things that's been rattling in our minds is how do you make contact with the donor without imposing upon their privacy?

Ms KANE — The privacy is really important. The accuracy of the records is a crucial issue. When I went to ITA what I did was negotiate with the Electoral Commission on the basis of the fact that we were administering an Act gave us the capacity to ask them to access the closed electoral roll, and so what that meant is that we were able to identify the right person because of the details that are kept in those records of date of birth, the name and a current address. In fact the first thing was knowing we had the right person. If you had several people who could be him, once again going back to the adoption days, what we would do is send a vaguer letter to all three parties and see what happened.

The CHAIR — How do you deal in that situation where no one else in the family is aware?

Ms KANE — Registered mail. Which means, of course, everybody else in the house knows he's got it.

The CHAIR — What's that really important thing that's just arrived that you just signed for? It seems to be a really vexed part of the whole process, even if you accept it you — —

Ms KANE — Except that it's a no win in that if you're going to contact him at all, he actually has to know that it's legitimate, that you are a legitimate authority, that you do act in relation to something that he has been involved with in the past. People have often talked about making a phone call, get the discreet telephone call. They don't believe it.

The CHAIR — Wouldn't it be better to make a discreet phone call and then ask for an address?

Ms KANE — No, I don't think so because I think they will say no. To me it sounds too much like a hoax phone call. What I've also discovered is that people need to have time to think, they need to be able to read and reread the letter. You've planted it in a way that it's real and, yes, it does relate to that time when I was donating sperm to Prince Henry's Hospital. That's what it's about. I know I was a donor and I knew that this was the purpose. What we always had to explain, of course, is who ITA was because we obviously weren't Prince Henry's, so we would actually say: we have responsibilities under the Act.

The CHAIR — Would you have a sample of one of the letters?

Ms KANE — You would need to ask VARTA.

The CHAIR — Do you have ideas, if you were to draft a letter now that would be an ideal one to send, would that be something you could provide to the committee, do you have the time?

Ms KANE — You actually will find those letters with VARTA because in fact it's really very basic, it's establishing who you are, who we are, it's establishing why we are contacting him, it's connecting him to something that he knows about, and it's saying that we've received an enquiry which we would like to discuss with you, and the person then usually knows what it's about. But the important thing with the letters is you don't have to make a quick decision, you can think about it, go and talk to your wife. The donors often haven't been as secretive as people have expected. They haven't told kids, their children, but they've probably told their partners, with exceptions.

Ms GARRETT — Just back to the previous question. You're saying in your experience there was a very small percentage of people who didn't want anything to do with it?

Ms KANE — Yes. And in fact there were people who were prepared to explore it further; that was the norm.

Ms GARRETT — So the overriding thing was people were open to it?

Ms KANE — The overriding thing was what the men spoke about continually were the needs of the child. What does she need from me, what does she need to know from me? I've had contact with donors who have come onto the voluntary registers because they were concerned about what the children might actually need from him. It was saying: I don't want to take action, I don't want contact to be made, but I want to be available. But it was often in terms of: I've raised kids myself now. I guess one of the things that we forget is the passage of time and, once again, it relates back to the quality of consent and consent to what? Your understanding of what it is you're doing when you're 25 is very different from what it is when you're 45. So the decisions you've made then you've often rethought and along comes a consequence, if you like, and it actually is different so there's a reconsideration and a rethinking.

Mr NORTHE — Can I just ask from your experience with donors themselves, is there much kickback or enquiry, I guess, around concern that the donor-conceived person might contest their estate or legalities around that and how do you deal with that?

Ms KANE — The simple statement is that at no point in law is a donor regarded as a parent, and that was as a consequence of the Status of Children Act. That's actually all it takes, that you are not recognised as a parent.

Mr NORTHE — Just to extrapolate that a bit more. In your experience if it has been conveyed that I'm concerned about the contesting of my estate and maybe thinking I don't want to know the donor-conceived person, does that change?

Ms KANE — Yes, it does because I guess within the family there can be those concerns. What does this mean? What does she want? The classic question that everyone asks: what does she want? And that is actually partly why the contact with the applicant is so important because it is: what does she want? And to be able to answer that question honestly so, no, she doesn't want a portion of your estate, and in fact she has no right anyway.

Mr NORTHE — Would it be right to suggest then that if you do an advertising campaign where you're trying to seek donors to put their name down on the register to know who their child might be, if you outlined that there are no legal obligations in that instance, maybe the take-ups might be even greater?

Ms KANE — I think it's always been part of the advertising, the underlying thing. I actually don't think it's a big issue. It's a logical question. Keeping in mind too that it was only with the Status of Childrens Act that it became clear and one of the feelings that I've had is some of the secrecy stuff around donor conception before that was really about we're not entirely sure this is okay legally because the man listed on the birth certificate is not the biological father and we know he isn't, so I think that's what this unease was about.

Mr NORTHE — We've heard evidence suggesting that Births, Deaths and Marriages maybe could enhance particular aspects of — —

Ms KANE — Actually I really need to correct what Nick said about that in relation to adoption because, once again, I worked in the Adoption Information Service for the 1980s so before legislation was actually enacted. All the Births, Deaths and Marriages actually held were the birth certificates and the court records that related to the adoption, which was logical, because this was the older certificate that became confidential records and the new birth certificate replaced it and that is all that they had.

What was actually happening within the adoption agency is the applicants were receiving all of their service, all of their information within the agencies, including when the Department of Human Services set up its Adoption Information Service, so in fact the crucial exploration and the dealing with the application, dealing the practicalities of providing information from the agency records, all took place with nothing to do with Births, Deaths and Marriages at all.

When an adopted person received their certificate at interview they had to have a mandatory interview that related to the Births, Deaths and Marriages records but in fact it was a logical part of what was happening. They would be issued with a certificate at interview and they would go into Births, Deaths and Marriages and receive the original birth certificate. Births, Deaths and Marriages provided no services. When they actually had to deal with the issues of somebody fronting up for their birth certificate in the usual manner, to find that the birth certificate didn't make sense because the second birth certificate, up until changes were made, did not include place of birth, and they had a different form, so that what Births, Deaths and Marriages found that is they were the ones, their counter staff were the ones who were telling somebody: that's because you're adopted. What they then did, very sensibly, is they formed a relationship with the Department of Human Services Adoption Information, the person who received that news over the counter was sent immediately to see the intake worker within the Adoption Information Service so that was the connection. All the private adoption agencies and the Department all had really positive, good relationships with Births, Deaths and Marriages but the delivery of service was not occurring at their place. They did what is their role, they held the records.

Mr NORTHE — Obviously we've heard some evidence around counselling services that exist at the moment. In your humble opinion, how many staff or counsellors would be required?

Ms KANE — When we could go back to the VARTA model, they had 2.2, as opposed to four departments.

Mr NORTHE — Was it adequate?

Ms KANE — It would grow with time because of the education components, which is actually a crucial part of it. A lot of it is to do with education and support. I guess one of the things too is that what we've had more recently is the direct experience of people using the registers to make contact with each other. Towards the end of my time at ITA, a typical applicant that is sent to the registers was a same sex couple who had a child conceived with donated sperm and they were wanting to establish contact with him. They also wanted to establish contact with any other children that he may have conceived. Within the clinics nowadays they have often met each other, although the new recruitment, if you like, of the private donors presents other issues but within the clinic they would often have met anyway but the clinics didn't see it as their role to set up ongoing arrangements and ongoing contact.

So what happened was that the children were starting to ask questions at four and five so there were questions that the parents couldn't answer so it was actually: what can we do about this? It actually went very smoothly but we've been through the practice in this and that will be an ongoing service area, I would imagine, if there is a place for that to happen. At the moment there is nowhere for that to happen, other than within the clinics.

Mr NORTHE — You would advocate that VARTA is the best place?

Ms KANE — Yes, I am, in that it is a logical place. What you actually have at the moment is such fragmentation of a service system — you would probably have to contact VARTA to find out even where you start to seek information. VARTA has the education responsibilities, and that's a huge component of the work that needs to be done, and it's identifiable, one place, so once again if the legislation was amended to make it possible with that capacity to seek to locate, bring together and deliver the services and also deliver the services further down the track.

Going back to my adoption information experience, the first step is the exchange of identifying information and perhaps the meeting. What then happens is a slow process of building relationships, making connections and making connections as a family. What was really useful for those people was to be able to access services if they needed them, and if they didn't need them that was fine, and support groups were actually developed as well. In fact, it isn't all over at that point and what we used to argue is that it takes about seven years to reach a point where everybody is totally comfortable with each other.

The CHAIR — As far as adoption goes, on the issue of claims on the estates, it's a different situation for an adopted child?

Ms KANE — No because, once again, the child ceases to be the legal child, it's the cutoff of the legalities, and the adopted parent is the parent as if the child was born to them. I guess, once again, with Nick referring to surrogacy as well, that's also a huge issue because I would agree with him that children have feelings about surrogates too, even if they're not the biological parent so there's that complexity.

The other issue, of course, is the huge numbers of children. The worst that we had was 30 per donor, so not quite the 300 that people actually talk about at times.

The CHAIR — I read in the paper, The Age, a couple of weeks ago, in the States, they've got websites where the 100 kids or so will get together and organise functions together and get to see each other. In your experience is that happening in Australia?

Ms KANE — We haven't got to that yet because more recently the number of children it actually becomes more — that 30 is not typical, what is more usually the small number.

The CHAIR — Is there generally a desire for siblings to connect with each other?

Ms KANE — Yes. Once again, one of the crucial things with the consanguinity problem is that what we routinely gave all donor-conceived people was a list of siblings by gender, by month and year of birth because it meant that they could eliminate the people within their network because there are issues, that fear, that: how would I know I wasn't marrying my brother? It doesn't identify anybody but in fact you know that if your new boyfriend was born in that month you might just ask him a few questions and if he wasn't, you don't have to worry. In fact, it's a very simple, simple thing. It now can't happen. I think that has consequences for the donor-conceived person because the fear is real. When fresh sperm was used, that meant lots of women had lots of pregnancies at the same time so that meant that you actually have, are likely to have, a group of children all conceived within weeks of each other in the same geographical area.

There have been arguments at times about the geographical area. One of the things that you would say about infertile couples who have been able to form a family is they are very, very serious parents and that means the private school. So even if you live somewhere else, your kid may well end up at the same private girls' school as the other children, and that's actually happened. With the more recent experiences with parents being open, the story of two parents having this conversation with their kids in prep and realising that in fact they were both from the same sperm donor and that was a private school. So in fact the locality then becomes irrelevant because people have common concerns, common interests and heading in similar directions.

I think Kate Dobby's submission referred to the issue of children in other states. There are births which are actually on the register legally as part of the existing register, who can't ever receive information because their donor was actually from South Australia and the South Australian legislation does not allow them to release information to Victoria, even though this is where the children were created. So there are those broader issues of Australia-wide and the movement of sperm. It's not unusual.

In the more recent years, Queensland couples had a choice of New South Wales sperm that didn't have any openness attached to it, and Victorian sperm which actually had the registers attached to them, and they were often choosing the Victorian sperm because of the rights it gave the children.

The CHAIR — All right. Any final questions? Thank you very much for coming in.

Ms KANE — Thank you.

Witness withdrew.