CORRECTED VERSION

LAW REFORM COMMITTEE

Inquiry into access by donor-conceived people to information about donors

Melbourne — 5 December 2011

Members

Mr A. Carbines
Ms J. Garrett
Mr C. Newton-Brown
Mr R. Northe
Mrs D. Petrovich

Chair: Mr C. Newton-Brown
Deputy Chair: Ms J. Garrett

Staff

Executive Officer: Dr V. Koops
Research Officer: Ms A. Gordon
Administrative Officer: Ms H. Ross-Soden

Witness

Ms K. Turner (Springfield).

The CHAIR — All the members of this committee are members of Parliament. Parliament has given us a number of inquiries to do, and this is one of them. We gather information from people, we put together a report and give it to Parliament and then Parliament may decide to change the laws based on what we recommend. The information we get from you is really important as we grapple with all the issues around donor-conceived children. We are interested in your story and what you have to say to us. We will have a transcript which you can look at once it is prepared and correct any mistakes. That will form part of the record of what evidence we have looked at in the preparation of our report. You can start with your name and address and then talk us through your submission.

Ms TURNER — My name is Kimberley Turner, formerly Springfield. I am a donor-conceived adult born in 1984, so pre-legislation. I want to thank the committee for having me here and also for giving this issue the time and consideration that it is due. Obviously it is very important to a lot of Australians, so I would like to thank you all. I am also a mother of two boys, who are nine and four. I work as a kindergarten assistant. I am happy to be here to represent some other donor-conceived adults in our community, a lot of whom are very silent.

I am sure this has been said before, but first of all I would like to restate the urgency of protecting and centralising the donor records, because as it stands they are not protected and they are held in all different places. Having those records protected and centralised would keep them safe. It is a bit of a cause for anxiety knowing those tenuous links to your ancestry could be lost or destroyed pretty much at any moment. I think that is really important.

I thought I would briefly explain a bit about how it feels to be a donor-conceived adult and not have access to your full genetic history. It is frustrating and tiring. Seeking a part of yourself which has been continually covered up by others is hard to deal with in the first instance. It is something that is at the back of your mind, if not at the forefront, on a daily basis. It becomes very mentally and emotionally draining. There are all these questions about who you are revolving in your head, and there is no outlet and no answers to these questions.

It leads to a lot of restless nights, I can tell you! It is disempowering — being discriminated against based on a situation in which we have not had a say for something that most of us in society take for granted as a given human right. I heard Damian say before that he never agreed to give away his right to know who he is. I feel the same, and I know many other donor-conceived people do also. I want to know who I am, and I am tired of searching.

I think our country places great importance on our heritage. It teaches us to be proud of who we are and where we come from. Donor-conceived people wish to be proud of who we are and where we come from, but we are not allowed to be. Instead of celebrating our cultural heritage, it is hidden away from us.

The CHAIR — Kimberley, if you need to take a break, feel free to just have a break and start again in a minute.

Mrs PETROVICH — Take your time. There is no rush.

Ms TURNER — We actually just recall the emotional stuff. Instead of celebrating our cultural heritage, it is hidden away from us, and we are made to feel subhuman. I would also like to mention that I consider my social dad's heritage and my mother's to be of great significance to who I am, but that does not replace the lack of genetic paternal heritage, without which my history remains incomplete. This also leaves me, my children and their families without a true medical history, which is vital for health reasons. I know most of you would have spoken with Narelle, and I just think that this is a very real and scary truth of what detriment can come from not having a complete medical history.

The CHAIR — Kimberley, you are in a similar situation to Narelle then, are you? You sought information, and you know that it is there but has not been given to you.

Ms TURNER — Yes. It has been quite a long road. My first point of contact was Monash, and they could not help me. I spoke with the ITA, who offered some counselling and support back then, when they were still offering those services. They were able to find out for me that my biological father's name was still on the file. Originally I had been told by Monash that it was removed, but they were able to find that it was there somewhere. So I had written letters to Monash and also the facilitating doctor at the time, Dr John Leeton, requesting that they act as intermediaries, but they did not feel as though the name was enough to identify him and were not prepared to seek services to search. I have those documents here with me. I was not sure if I would be allowed to present them.

The CHAIR — Yes, you can present them.

Ms TURNER — I might do it at the end. I think the only way to remove the current discrimination against donor-conceived people would be to allow for retrospective access to information regarding the donor-conceived person's true heritage. I also want to point out that the right to information about one's heritage is not the same as having contact. Contact is a separate issue for which both parties would have to be willing participants, so allowing access to information about your heritage, I believe, should be given. Those rights should be granted. That does not mean that the donor-conceived person or even the donor — the seeking party — has a right to contact.

The CHAIR — When you talk about access to heritage, what sort of information would that include?

Ms TURNER — My idea, and I am not sure if it is viable within the laws, is that the records should be opened up, but if the sought-after party wants to veto contact, then I think that should be put in place and the person seeking contact should not be allowed to make contact. There could be something in place like an ITA and how they used to do their donor-linking services in the past, where there could be a letterbox drop so one party could perhaps pass on information and the other party could have time to think about whether or not they wanted contact. I think contact is a separate issue from having information about yourself; that would be an arrangement between the two parties. I think that would be separate and something that would require appropriate counselling.

Something else I wanted to talk about was public resistance to retrospective legislation regarding a donor-conceived person's right to know their genetic history. I believe this resistance or fear comes largely from the lack of knowledge of the underlying issues. I think the families of donor-conceived people may have a fear of the unknown, which often is a misconception perpetuated by the media — that the donor-conceived person or the seeking party or the donor or maybe a half-sibling will invade their privacy or want something from them. I think most of us, I would hope, know that this is not true. The majority of them are just like me; they just want to know who they are and where they come from.

I think wider society tends to overlook the underlying issues for donor-conceived people in part because donor conception is seen as a scientific procedure or a cure for infertility. The nature of the technology allows for detachment, and therefore the significance of the inherent family link gets lost. In that place I think public awareness campaigns are going to be key to educating the public and dispelling people's fears surrounding this issue and what it will actually mean for people. I just think it will help to foster a prepared and accepting society.

I think it may also help encourage families to be honest with their children and also help donors to come forward and be honest with their families as well. We know there is a lot of secrecy that has surrounded this issue for a long time, and while we have the Time to Tell seminar and that sort of thing, it is very targeted at telling young children now. It is not so much targeted at adults, like people from my generation. A lot of them still do not know, and I would not know if it was not for the fact that these things are very hard to keep secret. It was passed down the family. It is not something that was deliberately told to us, and I think that is the same for a lot of families. I think that public awareness and bringing out the openness and honesty in a real sense would help families, donor-conceived people, donors and all of their families just to bring it out into the light and be able to talk about it. I think donors coming forward would also help with records that are incomplete. I think that would be key, so it would help to get them on the voluntary register as well.

As Damian said, retrospective legislation has been done before with adoption, and the sky did not fall in. I have had experience of this: I have a half-brother whom I met when I was eight. He was given up for adoption. My mum had him very young, and the sky did not fall in. He contacted my mum by letter, and she told us what was going on. It was nothing but a positive experience, and I think it was important for him. He needed to know where he had come from, and it sort of filled in a lot of the missing pieces in his life and in ours. I really do not think it is going to be the end of the world.

A support network similar to the former ITA of donor-linking counsellors and intermediary services would be necessary once retrospective access had been granted, in order to facilitate the exchange of information. I believe that they need to have access to centrally located records in order to provide donor linking. Also, counselling is obviously going to be essential for all parties involved. We need to have specialised services and professionals to deal in that area. I really feel that the keeping of records and donor-linking responsibilities should be given to a body independent from the clinics. I just feel in my experience, and also from a lot of things I have heard, that they need to be governed by a body that works in the best interests of donor-conceived people, donors and their families, not in its own best interests, so that is my reasoning for that.

I have got some additional recommendations to my original submission. I will just go over the summary. My recommendations are the protection and centralisation of records; development of donor-linking services; public awareness or education campaigns; retrospective access for donor-conceived people to information; and perhaps a DNA database would help for linking people who have had their records destroyed. That is all.

The CHAIR — Very good. Thanks, Kimberley. Really helpful.

Mr CARBINES — Thanks again, Kimberley. I have a couple of observations. We notice from different people who have made presentations to our committee that for many people it is not the first time they have done so, or at different forums perhaps, and that it can get pretty wearing as these matters have been discussed or dealt with in different ways over a period of time. I do not speak on behalf of the committee members, but I think they all understand that it can be a wearing process and that perhaps this is not the first time people have felt they need to make a contribution when we consider these matters. I pick up too that there has been a consistent message that has come up about securing records. If any changes were to be proposed about the way matters are dealt with, there seems to be a desire to give donor-conceived people some confidence that, whatever might happen in the future, how records are maintained is protected.

A relatively personal question I want to ask you to consider is: given what we are potentially asked to look at in terms of information that could be made available to donor-conceived people — you talk about other generations, and I think Damian did also — do you think you will talk with your own children, and what is going to be helpful for you to be able to have those conversations with them about their family history in terms of what access to information you might have in the future, given what access you have at the moment?

Ms TURNER — Obviously this information does get passed on down the line. I think it is all important. We need to know everything. Was that what you are asking me?

Mr CARBINES — Yes, I suppose how you make decisions about how you — —

Ms TURNER — I feel it is all important. I could not say that, ‘I would like to know this, but I am not interested in that’. I think it all contributes to who you are. It contributes to your health, your identity, so yes, I think we should be allowed retrospective access to information. As I said, I would hope, if somebody did not want contact, that a contact veto could be somehow put in place, and that would have to be respected by the seeking party.

Mr CARBINES — Do you think information that you could get access to would also then be important to your children?

Ms TURNER — So what you are saying is — —

Mr CARBINES — It is about your own family and having access to information so you feel you have got more information you are able to tell them about yourself.

Ms TURNER — Yes.

Mr CARBINES — Sure.

Mr NORTHE — I think you have articulated your position very well, as many others have, so well done, Kimberley. It takes a lot of courage to come up and do what you have done. You have had a very emotional afternoon, Damian and yourself. You have done very well.

Ms TURNER — I do have some additional documents. I did want to keep them confidential — when I say confidential, I mean just not made available to the public. Some of them are letters, correspondence I have had with various organisations and individuals, so clinics and doctors, and there is actually a donor application form which I am not sure if you have seen. It has got bits scribbled out here and there.

The CHAIR — Are we able to accept that if we do not table it? Would that keep it confidential?

Dr KOOPS — Yes.

The CHAIR — We can just have a look at it as a part that we can consider as committee members but we will not actually put it on any record.

Ms TURNER — Yes, that would be good.

The CHAIR — Great. Thank you very much for that. That is very helpful, thank you.

Ms TURNER — No worries. Okay, thank you.

Committee adjourned.