CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne — 5 December 2011

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Professor K. Daniels.

The CHAIR — Welcome, Ken. My name is Clem Newton-Brown. I am the chair of the Law Reform Committee. This is a joint parliamentary committee. We have various members of various parties on it. We are given terms of reference to look at. This is one of three that we are looking at at the moment. We gather information and then write a report with the assistance of our officers here. That will go to Parliament and things may or may not change as a result of it. That is where we are at today. We take everything down and then a transcript is prepared. You can correct any mistakes once you get a copy of it. Just for the purposes of the transcript, if you could start with your name, professional address and who you represent, and then talk us through your submission.

Prof. DANIELS — My name is Professor Ken Daniels. I am an adjunct professor at the University of Canterbury in Christchurch, New Zealand. I am here only representing myself because I have been involved in research and policy advice to governments around the world in this area for about 35 years. It is in that capacity that I am here today.

The CHAIR — Would you like to take us through your submission, highlighting the main points?

Prof. DANIELS — I will begin by saying that I am very impressed with this report, and I think that the task you now have is the most challenging, really. It really is a very complicated and very difficult area. It is for that reason that no other jurisdiction in the world has actually done what might happen here in terms of the retrospective release of information. Most people have taken the stand that anonymity was guaranteed or promised and therefore that promise cannot be broken. I take a different view than that, as my submission suggests, in that we now live in a much more enlightened age than what we did. The culture has changed dramatically over the last 35 years or so, and the needs and rights of the offspring are becoming much more recognised and heard, and they have to be responded to.

The CHAIR — Do you think that is because the offspring from that early time are now coming to an age where they are independent and wanting to find this out for themselves, or do you think it is more to do with the way the society has changed in that time?

Prof. DANIELS — I think there are two drivers. One driver is the parents — the parents who actually told their kids, when in fact they had been advised to keep the use of donor insemination a secret, were really swimming against the tide. They were saying, ‘Hey, this is not acceptable. We don’t want secrets in our family’. They have also been instrumental in arguing, and there is some very interesting research that is available that shows that a number of parents in the early days — I am talking about 30 or 40 years ago — did not want to tell their children because donor records were not available and they thought they might actually create a situation in which, ‘Here is my child knowing half of a story but can’t know the other half’. That was a reason they did not tell.

But the other thing, I think, is that the offspring themselves are saying, ‘Hey, I have some rights in this situation’. Certainly both the two court cases that I was involved in as an expert witness — one in the UK, which led to the change in the law there; and one in Canada, which has led to the change in the law there, but the government has stepped in and said, ‘Hey, we want to revisit this’ — were initiated by offspring, but with a great deal of parental support.

The CHAIR — Could you give us more details about the changes in the law in those two jurisdictions?

Prof. DANIELS — Yes, what happened in the UK was that a young woman — an Australian, actually, by birth who was living there — Jo Rose, took a case with the support of one of the human rights groups, Liberty, and also a parent who had a young child, a three-year-old, I think it was at the time. They wanted access to the records. The records had been destroyed almost certainly, but she was fighting the cause. The judge’s response to having heard all of the evidence was, ‘Look, this is really an issue for the government to deal with; it shouldn’t be dealt with in the courts. My response’ — she said — ‘is to give the government 18 months to sort this out or otherwise I will find against them’ — and no government wants to be found against by a High Court judge. The government changed the law and removed donor anonymity and made provisions for access to records, but of course only from that time.

Ms GARRETT — Prospectively.

Prof. DANIELS — Yes. But it did fund a voluntary register which was being managed by a group called UK DonorLink, which is quite independent and has had all sorts of difficulties with funding.

Mr NORTHE — Ken, sorry, on that point did any vetoes apply?

Prof. DANIELS — No.

Ms GARRETT — Because it is voluntary?

Prof. DANIELS — Yes.

The CHAIR — So that was the UK.

Mr NORTHE — New Zealand has a different scenario, though.

The CHAIR — What was the other jurisdiction? New Zealand?

Prof. DANIELS — No, the other one was Canada; it was British Columbia. A young woman, Olivia Pratten, took the case there. It was virtually the same case, although they were arguing it on different grounds. The judge there ruled that it was unconstitutional that she could not have access to this information and that it was hers as of right, and ruled accordingly. Then there was a bit of a problem because the government decided that there was an issue about the adoption legislation, which was being used as a model to argue some of these things. It is back under consideration. It is in an appeal process, and who knows when that will happen. Again, that judge established the principle: you have a right to this information.

They do not have any voluntary registers in Canada. We have a voluntary register in New Zealand. Not many people have joined it, and I do not actually think we need it. I will just briefly tell you that just recently I had somebody come to me — a student, who approached me after a lecture I had given — and say, ‘I was conceived by donor insemination but I never knew there was a possibility of getting access to the records. My parents never told me that’. I was able to get back to the clinic where her parents had gone for treatment. They had a note from that donor, who said, ‘I’m willing to be contacted’. He had already put his name on the voluntary register. So we did not have to go to the voluntary register; we made the connection through informal linkages. They are about to meet.

Ms GARRETT — Through you, Chair, in New Zealand how widespread was the practice of donor insemination?

Prof. DANIELS — Reasonably widespread. We are a small country; we are only the size of Melbourne, in terms of population. Nobody ever knew what the figures were because it was all being practised under the — —

Ms GARRETT — Which is similar for some of those issues here, no doubt about it, about exactly the extent.

Prof. DANIELS — Exactly; yes, that is it.

Ms GARRETT — What is New Zealand’s system now? Do you have an anonymity issue there as well?

Prof. DANIELS — No, we do not. What happened was that in 2005 we introduced legislation which removed the anonymity of donors and set up the official record-keeping system, which is managed by Births, Deaths and Marriages.

The CHAIR — It is not retrospectively, though?

Prof. DANIELS — No, but what is interesting is that for the last 18 years the clinics have not been recruiting anonymous donors; they just would not take them on. So the law followed the professional practice change.

Ms GARRETT — Okay, the practice.

Prof. DANIELS — That is the only country in the world where this has happened. In other jurisdictions what has happened is that the law has forced the professionals to change, and of course all the hands have gone up and there have been all the reactions, et cetera.

Ms GARRETT — That is really interesting.

Prof. DANIELS — I describe it as: we took an educational approach. We managed to change the attitudes of some of the key doctors, and it just flowed on and on.

Mrs PETROVICH — On that basis, they will not take on anonymous donors, has that impacted on the number of donors now available?

Prof. DANIELS — That is a major issue. There was a shortage of donors before this ever happened. I think that is the first thing that needs to be said. The second thing is that I have been asked to write two review papers for journals on donor recruitment issues. I have shown in those, with a survey of the literature, that while there tends to be a decline immediately in the number of donors, it goes back up, but that the characteristics of the donors change quite significantly. I did the first work in Sweden, following the legislation there. Everybody said, 'Look, they cannot get donors in Sweden', and my colleague gynaecologist over there and I showed from the figures from the Swedish department of health and welfare that that was not the case. What happens is — and this is an overview of it — that the donors who are willing to be open tend to be older men, married and with children of their own. The donors who tend to be interested in anonymity are younger, single, have no kids and are getting paid. That is a generalisation, but it is a general pattern. So removing the anonymity, removing the compensation, has had some temporary kind of effect but it has not been long lasting. But there is still a shortage. I mean, it is not the kind of thing that most people want to do; let us face it.

The CHAIR — On the issue of siblings, I notice in your submission that you recommend contact between half-siblings. Practically, how do you achieve that? It is a bit different, is it not, in that the donor knows he has donated but potentially the siblings do not know they are siblings? How do you deal with that? Would it only be through people voluntarily being on a register that they would come into contact? Or in your scenario could a half-sibling be contacted out of the blue and discover that they were donor-conceived — through a half-sibling getting in touch with them?

Prof. DANIELS — That relates to the donor issue as well. I do not think anybody can be contacted out of the blue. That is just too dangerous. We are thinking about families here and about family relationships, and those family relationships have been based on certain understandings and values, if you like, and to suddenly be thrown aghast by somebody knocking on your door, I think, is the wrong way to go. What I would be suggesting is that people who want to make contact obviously put their name forward, and if a link is possible then there be some contact requesting that, but it be done in a very careful way and with appropriate counselling and support; it not be left to the people to make the contact themselves. It is the same with the retrospective aspect of donors. It seems to me that — and I argue this in my submission — yes, there does need to be retrospective legislation, but I recognise that a lot of records are not there any longer. But I think that a lot of the offspring I have spoken to who want to have information would be very happy if they were able to get some response from the donor giving them information — maybe not contact, but information. That would enable them to complete their identities, or the bits of their identities they have been struggling with. But I see that as an interim measure moving towards complete openness, maybe in a period of seven years.

I make the point that I think the real issue in this field is not donor insemination, it is the secrecy. For a donor who has not told his partner and not told his kids, it is going to be a massive issue. They are going to need a lot of help with that, and the law will be a clumsy instrument to try to bring change about unless there is a cultural change as well as a psychosocial one.

Mr NORTHE — Professor, you speak in your submission about the fact that we have a contact veto. That is okay, but you would like to see counselling as maybe a progression to the next step?

Prof. DANIELS — Yes. If somebody is saying, 'I want to put a veto on my records', then I think they should be seen by a counsellor, who would talk through the reasons for that so that those reasons could be passed on to the offspring. An offspring will be much more accepting if they know that the person — they are still going to be unhappy about it, but they are likely to be more accepting if they know that this person is really scared or anxious or whatever. That is the proposal I have. I do not think a veto should be forever.

The CHAIR — That was my question. We have had one example of somebody — a child — who sought information and got no response, and the person who was helping her was told, ‘We cannot just keep harassing them if they have ignored us’. In a situation where somebody has taken that step and put on a veto, after what sort of length of time would you say that they should be asked again if they want to remain on the veto list? Should it expire after five years or two years?

Prof. DANIELS — I suggested the veto should expire after 7 to 10 years. I would love it to be five years, but I think I am being influenced there by our experience in adoption in New Zealand, where — I think it might be the same here in this country — you had a veto for 10 years or something.

Ms GARRETT — In New South Wales and Queensland there was, in adoption.

Mrs PETROVICH — In the case, Ken, of circumstances — we have heard this a number of times — where there is a hereditary medical condition, should the right of veto still apply?

Prof. DANIELS — You see, if it is a medical condition, it is probably information that is needed, not actual contact. It is information about the family history that is missing and is critical. Again, I am sorry to be anecdotal, but it kind of adds a personal flavour to all of it. I worked with a family who had a 12-year-old whom they had never told about the donor conception. She was seriously ill in hospital. The parents were there and the doctors were there, and the doctors were saying, ‘We have no idea what’s wrong. Can you tell us about the family history?’. They were confronted with a dilemma. Do they disclose the DI by saying, ‘We only know half of the history’ and then create problems for the daughter, or do they play dumb, as it were, and she might die? What an awful dilemma to be in.

The CHAIR — As far as your submission goes, is there anything further that you wanted to add?

Prof. DANIELS — Yes. Yesterday I was presenting some research, and I am involved in two pieces of research about donors and their views. In one particular study which looked at donors we had recruited through King’s College Hospital in London we were able to go back to the records and see what their views were about openness or anonymity. When we went back 18 years later we found that 37 per cent of them had changed their minds and 75 per cent of that 37 per cent had been towards openness. The reasons that they gave for changing their minds were that they were older, that they had children of their own, that there had been a whole lot of media coverage and that they could understand the needs of offspring more. Again, it goes back to this issue of who we are recruiting, because their attitudes are going to flow through.

The second piece of research is one that has not been published yet; it is under review. It is the largest study of donors undertaken in the world — 164 who joined up with the Donor Sibling Registry. These were all donors who were recruited anonymously, and now 94 per cent, I think it is, from memory, are willing to be open and contactable. There is a trend, and I suggest that a lot of those donors in the past are not necessarily as closed as the one who is illustrated in case 3 in your report. When I look at some of the reasoning he gives for taking his position, there are a whole lot of issues in there that really need to be discussed with him. Of course this is moving into the counselling area in part, but he has taken a view that is quite irrational in parts and not accurate — but that is how he feels. You have to acknowledge that; that is where he is coming from.

Ms GARRETT — We have had a number of donors give evidence, and you would have to say that the vast bulk have said that it really is about the child — ‘Whatever is necessary. It may have impacts on my life that I am not necessarily enamoured with, but it is about the child’.

Prof. DANIELS — In a recent connection I made between a young woman who was 22 at the time — a university student — and her donor, the donor had been guaranteed anonymity. The hospital got in touch with him and said, ‘Somebody is expressing interest. Would you be open to Ken Daniels getting in touch with you to talk about this?’. So we had a talk about it. They live in Dunedin, 400 kilometres south from where I am. Anyway, I met with him and his wife, and their greatest concern was about how to tell their kids, who at that stage were 15 and 16. I had to spend quite a lot of time facilitating that process.

Then I was there when the two — the donor and the offspring — met, and it was a lovely occasion. The similarities between the two of them were just absolutely amazing. There is not a lot of ongoing contact, but this young woman now feels as if she is complete; an issue that was there has been overcome. We did that without any law, but I think that is because in New Zealand we have a much closer relationship with the doctors. The doctors are much more accommodating and much more supportive. They will do whatever they can, because they have a commitment to the interests of the children as well.

Ms GARRETT — On the evidence before us there is a reasonably significant number of children who were born in that period when anonymity was guaranteed. We do not have exact records, because it appears that in private clinics there was an amount of activity going on that we will probably never know about, but most of it appears to have been done through major clinics that kept records. What is also clear is that the vast bulk of donor-conceived people probably just do not know, because there have been a limited number who have been in the public. In your wealth of experience around the world and in terms of encouraging parents to have that conversation with children, what advice would you give or can you give about what helps that prompting?

Prof. DANIELS — There is a lot of fear out there, so it is the fear that has to be dealt with first. I think the issue about how you actually get in touch with those people — it is one thing to advertise, but parents who have been keeping secrets are probably not going to respond to an advertisement or publicity. They need something which is much more reassuring to them. I think that may well mean there has to be some going back to those parents, very cautiously and very gingerly, and saying, 'We wish to make available to you, if you would like, the opportunity to come and talk with somebody'.

I do not know whether I have time for this, but I have to say that I had a disastrous situation where I was writing to one parent, and she had a 14-year-old daughter who was conceived by DI and a son who was conceived naturally. She wanted to tell the daughter and had been communicating, and I was arranging to go visit them. I had said to her beforehand, 'How will I communicate about it?'. 'Just write me a letter'. I said, 'Are you sure that's going to be safe?'. She said, 'Oh, yes, that will be fine'. So the letter arrives with the University of Canterbury on the outside and she is at work in the evening as a nurse. She rings the son and says, 'Any mail today?'. He replies, 'Yes, there's a letter here'. She asks, 'What's on it?'. He replies, 'The University of Canterbury'. She was studying at Massey University, extramural, and thought it was a letter from Massey University. She said, 'Just open it and read it to me'. Here is this boy finding out that his sister is only his half-sister. We have to avoid those situations. There must be mechanisms to avoid that. It is just too dangerous.

Mr NORTHE — What are they then, Ken?

Prof. DANIELS — I think it is probably the phone call in the first instance, and that is a huge job — trying to track people down. We had an example at the conference over the last two or three days of a GP who had been a donor who had been discovered — found, as it were. Professor de Kretser, the ex-Governor, was the doctor concerned and he talked about the fact that he wrote to this GP and said, in whatever year it was, 'You were involved in some research that we were undertaking and it would be very good if you could get back in touch with us about that'. So there are ways of doing it, but you have to be pretty inventive, I think.

Mr NORTHE — I am interested, Ken, in extrapolating a little bit further. Who would have carriage of that? I guess there are examples you have seen around the world. Is it a body like an ITA that would have carriage of coordinating all of this, or Births, Deaths and Marriages? How do you see that playing out?

Prof. DANIELS — No. Certainly VARTA. Births, Deaths and Marriages in our experience in New Zealand are great at record-keeping. This is not about record-keeping, this is about facilitating contact, which involves a lot of psychological, social and ethical issues. That is why I think it needs to be in a service which has a welfare health mode of operating rather than a legal record-keeping one.

The CHAIR — Finally, what about the issue of donors who want information about their offspring? Should they have rights?

Prof. DANIELS — I have always believed that this should be driven by the offspring. I have concerns that donors could get in touch. I have had one situation that has gone disastrously wrong in terms of a contact. That was a person living in Australia who had been donor to children in New Zealand. His needs were such as to potentially damage the offspring. That is all I need to say. Unfortunately I had not been given enough background by the referring doctor to be aware of this until we were suddenly in a situation and it blew up.

Mr CARBINES — Out of the conference that you attended, were there any other observations you drew out of the discussions there? Some of us were not able to attend, so I was interested, as it was held in Melbourne, to know if there were any observations or general discussion points that came out that might be worth sharing.

Prof. DANIELS — The major observation would be the reinforcement, if you like, that we in this part of the world are world leaders in terms of children and families and concerns about these issues. In New Zealand we are more advanced than you are. Sorry, I did not mean to be — —

Ms GARRETT — That is an outrageous thing to say! I was going to start talking about unions, but I will not do that either.

Prof. DANIELS — What has happened in New Zealand is that we take a very family-oriented approach to this. I think in other places they take a child-oriented approach or a medical-oriented approach. For me it is about the families that are formed or built in this way and how we enrich that. There were lots of examples over the last two or three days that reinforced the advances that are being made, both in Australia and New Zealand.

Wendy Kramer, who set up the Donor Sibling Registry in the States, was here and she said to me on one occasion that her mind was blown by what we were doing here. At one point I said to Professor van Steirteghem, who is the editor-in-chief of *Human Reproduction*, which is the no. 1 medical journal in the world, 'How are you finding all of these sessions about openness?'. He said, 'My mind has been blown'. He was actually seeing the people who had resulted from the treatments rather than just focusing on the treatments. It is at the family end that the crunch comes.

The CHAIR — Thank you very much, Ken. That has really been very helpful.

Prof. DANIELS — I hope so.

The CHAIR — It was very opportune that you were in town and able to come and talk to us.

Prof. DANIELS — I wish you well with your struggles and dilemmas.

Ms GARRETT — Have a safe trip home.

Prof. DANIELS — Thank you. I shall look forward to seeing what comes out of the inquiry.

Witness withdrew.