CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne — 10 October 2011

Members

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Witnesses

Ms K. Toohey, Acting Commissioner, and

Ms S. Rose, Senior Legal Advisor, Victorian Equal Opportunity and Human Rights Commission.

The CHAIR — Welcome everybody. My name is Clem Newton-Brown; I am the Chair of the Law Reform Committee. Jane Garrett is the Deputy Chair and Russell Northe to my right and Anthony Carbines. Also Donna Petrovich, who is not here, but will probably turn up sometime during the course of the afternoon.

This Inquiry is a cross party inquiry from both sides of Parliament and we are gathering information to provide a report to Government which would then consider what changes are necessary in this area.

You are protected by parliamentary privilege of anything you say here but not outside the room. You can say what you like here but if you are asked questions outside this room you do not have that protection outside the room.

Basically we ask you to talk through your submission and we will ask questions as we think of them. If you would start by stating your full name and address and the organisation you are representing.

Ms TOOHEY — Thank you Chair. Karen Toohey, I'm the Chief Executive Officer and currently the Acting Commissioner at the Victorian Equal Opportunity and Human Rights Commission. The address is 204 Lygon Street, Carlton. I might ask my colleague to introduce herself.

Ms ROSE — Skye Rose, I am the Senior Legal Advisor also with the Commission.

The CHAIR — And the same address?

Ms ROSE — Yes.

Ms TOOHEY — Skye has done most of the work on our submission, which is why she is here as technical back up. So certainly any of the technical questions I will be directing to her.

Chairman, I want to thank you for the opportunity to present to the Committee today and the opportunity to provide a submission. We have got some talking points to start with but obviously we are quite happy to take questions on the submission and the talking points.

We are clearly coming from the position of the Charter of Human Rights and Responsibilities in Victoria and that is really the focus of our submission, about how the Charter provides a framework with which the Committee could consider the issues that come before it as part of this inquiry.

The Commission is of the view that the status quo of the current legislation does not strike the right balance between the rights of donors and donor-conceived people and the Charter will provide a framework for identifying the rights and considering those rights, balancing the rights and finding what we would hope is the least restrictive solution to the human rights issues raised by the subject matter of the inquiry.

For the Act to be truly consistent with the Charter our view is that the data which gametes and samples were donated with assurances of anonymity at that time should not be the only consideration as to whether information should be disclosed to donor-conceived people. Reform is needed as we see it to address the impact of withholding information from donor-conceived people and to consider the limitations on the rights in this inquiry.

Our submission deals with, as we said, using the Charter as a framework to consider these issues and we appreciate there might be some questions about that.

The Charter in our view provides a framework that public authorities must work with, both when preparing laws but also in implementing them and making decisions under this, so it does affect both the framing of the legislation but clearly also the implementation. We see that that has been one of the benefits that the Charter has brought to the legislative processes in Victoria over the last four or five years.

Recent amendments have been made to the legislation introduced shortly after the Charter commenced. When the Charter was in its infancy and perhaps when you were approached about balancing rights was not necessarily as well understood or explored as it is now and perhaps the understanding of the rights that come into play with these issues were perhaps not as well understood.

The Act currently places, as we see it, unnecessary limitations on the rights of donor-conceived people and we see that this is an opportunity for this Committee to make recommendations to address some of those limitations.

Assurances of anonymity, as we know, have led to what we would see as a donor-centric law which protects the donor's right to privacy but does not recognise or adequately protect the rights of donor-conceived people.

The CHAIR — The donor's rights to privacy, do you consider the Charter to protect that as it addresses the child's rights?

Ms TOOHEY — As we said, I think the Charter is a tool for analysis around those rights, so we are not saying the Charter takes away the right to privacy. What we are saying is that those rights need to be considered in an equal way and there needs to be a balancing process around those rights. At the moment the framing of the legislation clearly seems to give primacy to the right to privacy. We appreciate that that was appropriate or at least was what was decided at a point in time, but clearly that was quite a long time ago and certainly our understanding of the rights of donor-conceived people have come some way since then.

In summary the overview of our recommendations is that there are various alternatives to the current regime that would be less restrictive on the rights of donor-conceived people. Our proposal and we have varied it slightly in terms of how we describe the options in the submission to I guess how we are presenting it today.

Our proposed model would provide greater protection and recognition of the protection of the rights of donors and donor-conceived people. Subject to safeguards, all those born through donor conception should be able to obtain some information about their donors, irrespective of when the gametes were donated and whether consent was obtained.

A responsible body should be empowered to manage requests for the disclosure of information related to a donor and upon receiving a request for information that body should be required to make all reasonable efforts to contact the donor and seek their consent to the release of that information.

If consent cannot be obtained, that body should at least release all non-identifying background information held or release identifying information perhaps subject to a contact veto where disclosure would be shown to be in the best interests of the donor-conceived person and there were appropriate support mechanisms in place.

If consent is not provided, our view is that there should be a release of only non-identifying information. If consent is obtained obviously we would see that the release of that information is appropriate.

We see that that body should have the power to seek an individual’s consent to the release of information and seek additional information where that information was not subject to the initial restriction and where it is appropriate.

The collection, storage and disclosure of information would need to be subject to appropriate safeguards to ensure that information is collected, stored and disclosed of appropriately.

We have also noted the comments recently of the Privacy Commission about need for consideration of the accuracy of that data and we appreciate that that is also something that that body should have responsibility for.

The safeguards could include and should include the provision of counselling and strict processes to identify and verify the individual’s identity and therefore their right to access that information.

Our view is that consistent with the rights of the child, children should be able to apply for access to information at an age of sufficient maturity appropriate to their needs.

The rationale, as we said, for our recommendation is that the existing framework as it currently sits is too donor-centric and it does not sufficiently recognise the rights of people conceived with gametes donated prior to 1988, it provides limited recognition of those rights for people conceived between 1988 and 1996.

We appreciate that introducing retrospective application of access to donor information would bring donor conception into line with other laws but does provide some difficulties, as we understand it, for people who entered into agreements pre-1988 on particular conditions.

We also note from some of the information that has been provided in other appearances before the Committee that there does not seem to have been an enormous reaction to that process of making that information available.

We do note that changes of this nature and the establishment of such a body if it were a new body or increasing the responsibilities of existing bodies would require careful planning and would need to be accompanied by safeguards in order to minimise the impact on the rights of donors and donor-conceived people.

Again, our view is that the Charter provides an analytical tool by which the rights of all people involved in these decisions can be identified, assessed and considered and we would hope that the legislative process that follows on from this inquiry uses the Charter in that way so that people are clear about how those rights have been both engaged, but also been considered and balanced.

As I said, we were hoping to open with a very short statement with a view that we anticipated questions from the Committee. If there is anything particular in the submission you would like us to address, we are very happy to do so.

Mr NORTHE — Karen, just in terms of, as mentioned to us a few times, an outside responsible authority. Do you have any ideas about who that might be? Who might form a responsible authority in terms of accessing such information, being a controlling body?

Ms TOOHEY — I have to say that I do not see that as our area of expertise, because we do not practice in this area. Clearly it would need to be an authority that was governed by the Charter; so it needs to be a public authority of some nature to ensure that those rights are protected.

We do note that there have been a number of suggestions in other appearances ranging from VARTA to the Births Deaths & Marriages Registry. As I said, I do not think that that is our area of expertise, unless Skye has got a different view.

Ms ROSE — No.

Ms TOOHEY — Clearly our view would be, given the nature of the information, it clearly must be a body that is covered by the Charter to ensure that those rights are protected.

The CHAIR — What about the rights of the donor father to get information about his offspring? Does the donor have rights as well under the Charter?

Ms TOOHEY — I think our view would be again because you are balancing rights around privacy of the donor-conceived child and the rights of the donor, our view would be that similar terms would apply, which is the donor should be able to have access to information about the donor-conceived child. That does not need to be identifying information unless there is consent.

The CHAIR — As far as consent goes, when contact is being made with the family, the parents of the children if they are under 18, to seek their consent?

Ms TOOHEY — As we understand it, yes. Clearly that would need to be done with appropriate counselling in place, appropriate safeguards around that process.

Again, as we have seen from some of the other transcripts, there are people with a lot of experience in how this actually plays out in practice. I do not think we purport to have that expertise, but what we do say is that clearly as we understand it, certainly the donor does have rights to some information. Clearly the donor-conceived child and the family of that child have a right to privacy and the Charter is a way of balancing those rights and recognising those rights.

That process for obvious reasons needs to be very well supported. There are other examples, say adoption, where that is happening appropriately in the current framework by which people access that information and we would support those mechanisms being available.

The CHAIR — But does the Charter actually assist in the balancing question though? It sets out the various areas which you have put in your submission but it does not actually assist with how you balance, does it? I suppose it recognises these are a set of rights and there is nothing in there to assist with that?

Ms TOOHEY — Unfortunately it does not have a volumetric weight attached to it but it does provide a methodology and I think that is the important thing. There are tests and those tests are established in law, as well as in administrative practice. Certainly we would say while we cannot say we get to a particular answer at this point in time, it does provide the process by which that will occur.

The CHAIR — Skye, did you want to say something on that?

Ms ROSE — I just think that given that there are perhaps less restrictive options available, which is the fifth element in terms of the section 7(2) analysis within the Charter, I think that really provides us with significant guidance on what the options might be — I guess strike a better balance in terms of balancing those.

Ms GARRETT — With respect to the first recommendation that a similar approach is adopted in this situation as with adoption and that donor-conceived children are given retrospective access to identifying information; just a couple of questions on that. The first is — I know you refer to attempting to get consent from the donor in your later recommendations if the first one is not adopted — would you envisage that that process would include the donor being alerted to the fact that the donor-conceived child has sought identifying information or would that be separate? How would you envisage the donor's rights being managed through a retrospective access process?

Ms ROSE — I think it would be certainly appropriate to try and notify a donor that a request has been made. Obviously safeguards would need to be put in place to ensure that they were notified in a way that would ensure that their identity was verified, as well as providing potential counselling to that individual so that that contact is done in a way that is respectful of their rights as well.

Ms GARRETT — On that point I guess what would the safeguards be should the donor say: Well, I mightn't have a legal right to say no, I don't want my identify known but I don't want contact. Do you have a view of how that should be managed?

Ms ROSE — I think in terms of adoption law in New South Wales other people throughout the public hearings have highlighted how contact vetoes have worked in other jurisdictions and have not posed particular problems to date.

Ms GARRETT — Would that be the model you would recommend here?

Ms ROSE — I do not necessarily think that we would want to lock ourselves into a model. I think really what we are trying to do here is highlight that there are many alternatives available that would strike a better balance.

Mr NORTHE — If I could just add a little bit to what Jane says. I am just trying to think from a practical viewpoint through my mind about this. If the Act was amended to what was suggested under recommendation 1 and the donor was adamant that: No, I don't want anything to do with this, I'm sorry. Where do you turn from a practical viewpoint with that when you say the donor would be required to give some form of disclosure? Do you envisage penalties might apply for the donor not providing information? How would that actually work from a practical viewpoint?

Ms ROSE — I think again as Karen mentioned, we have perhaps moved slightly away from the two options that we identified within the submissions and have come up with a variety of models that could strike a better balance in terms of protecting all of the rights that are engaged in this process. Would you mind repeating your question?

Mr NORTHE — I guess I am saying if I am a donor and a request for information has been put forward to me, mindful that under your recommendation the Act has been amended to say that it is a requirement but if I say, still as a donor, for whatever reason say: No, I don't want to have anything to do with this. I am just not sure at that fork in the road what happens, particularly under the Charter for the protection of the donor at that point, if that donor still says: No, I'm sorry, there is a requirement of me under the Act but I still don't want to participate in this. What happens from that viewpoint I guess is what I am saying?

Ms TOOHEY — I think it is an issue around what is identifying information versus non-identifying information. I would also have to say, having read a number of the transcripts to date, there are clearly people who practice in this space with far more practical hands-on experience than we do. So we acknowledge we are coming at it from a framework perspective, rather than people who do this on a day in/day out basis. Certainly in our minds non-identifying information should be able to be provided and that goes to issues around the rights of the child, rights of identity. There are a lot of rights of the child that I guess are engaged in the provision of that information.

In terms of identifying information, it would be difficult I think for me at the moment to come up with a reason why that would be essential, but if it were essential I think that is where the reserve position around having an independent body or an independent mechanism to determine that comes into it. Certainly it is a decision-making process that someone needs to go through as to whether that information is essential for some reason. If it is, in our view that needs to be properly considered by an authority of some description and we suggest either a board or a body be involved in that process.

Ms PETROVICH — My apologies for my lateness. I hope I have not missed too much. One of the things that I am interested in is how do we deal with those people who are not aware that they are donor-conceived and if changes were allowed that enable access to identifying information for those donors and donor-conceived people, how can we best ensure that their rights are protected and particularly there are some safeguards around how do we protect the rights of those people who do not know they are donor-conceived?

Ms TOOHEY — Again, I think certainly there are people who work in this space who have much better experience than we do of the practicalities of that. There are a number of mechanisms that we have drawn attention to around the contact vetoes and things like that which other people can be provided information, we have now an agreement that they do not contact people where it is not appropriate to do so or where there has been no voluntary participation in that process.

Certainly if the child — and Skye might have a different approach to this — but if the child has not sought that information until that point, I think the argument would be that their right to privacy and their right to identity as they understand it needs to be protected. Obviously we have had quite a lot of discussion internally about our position on this.

Mr NORTHE — Just on page 11 of the submission the recommendation to the Committee to permit the donor-conceived people to access information about their donor independent of their parents at an age of sufficient maturity, but no later than 18 years.

Would you have some sense of how that might work in a practical viewpoint in terms of the age of the donor-conceived person?

Ms TOOHEY — I think our experience is that there are a number of other jurisdictional frameworks where children’s rights are recognised by the fact that they can exercise their rights at an earlier age based on the assessment of their capacity. The Family Law does that, Child Protection does that. There are a range of areas where children who are not expected to reach a particular age on the basis of age discrimination, on the basis that they cannot make a decision about something until they are of a particular age. Certainly our view would be that there needs to be — if the child wants to access that information, there needs to be appropriate support for them available to them around the potential impact and consequences of that prior to reaching 18 but there are clearly a number of frameworks and conventions on the rights of the child, as with the Charter, it recognises that children should be treated equally as to their capacity and maturity rather than necessarily arbitrary age cut offs.

I think there are a number of other models that, as I said, certainly the Family Law; where that is recognised.

Ms GARRETT — Clearly the evidence we have had to date shows that often there is a number of siblings that have resulted from donations. Do you have a sense, in a sort of balancing of rights, where you would see a donor-conceived person's rights to gain information about siblings or how that would work?

Ms TOOHEY — I think again, coming from a rights of the child perspective but also in the best interests perspective, identity is complex and it does relate to not just who our parents are but who we are related to generally. I think certainly again a number of the transcripts reveal that people had a great sense of harm and distress that there were other siblings out there that they were unaware of.

Our view would be I think, again, while there is a balancing around the privacy, providing that process was managed appropriately through counselling, particularly people understanding the consequences of contacting people out of the blue really about some of these issues, that the right to identity and the best interests of the child suggest that people have an entitlement to understand all their circumstances, not just necessarily who their parents were and that would include identification of siblings and access to information about siblings.

Ms GARRETT — I guess to follow up from Donna's point, that really takes you into uncharted territory where people who are donor-conceived do not know it. If you were a donor, then you know you were a donor and while you may not know that children came of your donation, it would not be a complete surprise if they did; whereas if you were one of eight siblings and had no idea, in terms of safeguards around that, access to retrospectively identifying information of siblings, do you have anything to add on that?

Ms TOOHEY — It is a complicated situation and again, I think our expertise really is looking at where the rights arise and we are using the analogy that if one of these matters went to Court and we had to intervene, what would our role be? It really is around the analysis of where the rights sit. I think probably if you think about the evolution of it all from 1988 to now, we can see that people's understanding of what is identity and how important it is to people has evolved.

Again, based on the information that we have seen in the transcripts, we certainly see that there does need to be a process around siblings and we would suggest the problem is now getting to a point to include grandchildren, where people in this age have grandchildren. So there is a complex analysis that needs to be done there but we also go back to the notion, as with adoption and some of the other models, that a person's right to their identity and the notion of the best interests of the child do encapsulate not just who they are living with at the time but that genetic connection to a fuller set of people.

Ms GARRETT — Dr Koops, can I ask you a question?

Dr KOOPS — Yes, okay.

Ms GARRETT — Just in terms of the background, has there been to your knowledge a concerted effort or is there significant and direct support for parents who have raised the child and who have not told the child they are donor-conceived?

Dr KOOPS — Only anecdotal I think but the evidence is that most donor-conceived children do not know that they are donor-conceived.

Ms GARRETT — And there has never been a campaign I suppose like there was around — —

Dr KOOPS — I am not sure.

Ms GORDON — There was the Time to Tell campaign run by VARTA.

Ms TOOHEY — Certainly our experience with particular communities is that the practice — there is a practice obviously of telling people now but there may not have been for the people most affected by this.

Ms PETROVICH — This might have already been covered, I am not sure, but on the privacy rights in the case of a medical condition which is hereditary or congenital and it is discovered by the donor that he may have passed on a condition through perhaps some genetic material, is it possible to override these rights on the basis of the individual's health?

Ms TOOHEY — I think our view is that the rights of the child are not absolute, which is why the Charter does provide that limitations clause, but also there is a mechanism by which you must balance the rights out. So we do not see that the right to privacy for the donor is absolute. We do see that certainly it is complex in terms of how that information is conveyed and disclosed. Medical information, again from what we have seen in the evidence is clearly a priority for many people because of the flow on effects and I think it is not that the Charter overrides the privacy right, but the privacy right in and of itself is not absolute from the legislation.

The CHAIR — Thank you very much for attending today, it has been very helpful.

Ms TOOHEY — Thank you very much.

Ms ROSE — Would it be helpful for us to table our speaking notes from today?

The CHAIR — Yes.

Witnesses withdrew.