

Please accept this submission to your inquiry into the issues surrounding information regarding donor-conceived people. I was unaware of the inquiry until very recently, so my submission is necessarily brief and schematic. I would welcome the opportunity to make a further submission, or in some other way contribute to the discussion, on these very important issues.

My submission focuses largely on (f): the impacts of the transfer of the donor registers currently held by the Infertility Treatment Authority to the Registrar of Births, Deaths and Marriages. Although it may also have implications for (g), the questions pertaining to the Charter, I don't have any expertise in this area and cannot comment.

I believe that the impact of the transfer of the management of records from the ITA to the Registry has had, and will have many further, detrimental effects. In this submission, I would like to briefly outline first, the policy reasons for this assertion, and second, the personal reasons which bear these out.

The transfer of the donor registers to the Registry of Births, Deaths and Marriages recommended by the VLRC was not underpinned by sound policy logic but was, rather, a matter of streamlining systems that *appeared* to be well-suited to being merged.

First, this appearance of suitability was based on a misrecognition of the functions of the Registry. These are important functions, but amongst them is *not* the recording of information about genetic parenthood or heritage; however, this often surprises people, who assume that this is indeed its primary function in the registration of births. The major policy question that is buried time and time in these debates is this one: should the Registry be recording *genetic* information when it records information about births, or should it be recording the names of the people who nominate themselves as parents of a child just born?

Under the current system, anomalies (which amount to forms of discrimination) arise precisely because these functions are confused. The Registry records the information supplied to it about parentage in some situations and refuses to do so in others.

So, for example, if a man and a woman sign an application to register the birth of a child conceived through donor sperm and sign the application as the mother and father of the child, the Registry accepts those parents as the legal parents of the child. If a woman and a woman sign an application to register the birth of a child conceived through donor sperm and sign the application as the mother and 'parent' of the child, the Registry does not simply accept those parents as the legal parents of the child.

My first major encounter with the Registry on these matters occurred in when my daughter was born. My partner was not at that time legally able to

apply for parental status. I applied on my own, therefore, for the certificate. I provided my details and declared the father 'unknown'. I was asked to clarify this, and did: the name of the father was unknown to me and I therefore could not provide it. I was then asked to provide a letter from the clinic where the child was conceived to confirm that the child was conceived by donor. I refused to do so. This refusal was not done lightly, but my partner and I believed it was not in the best interests of our child to provide this information. Our reasons were several.

First, we considered our daughter's privacy. We do not intend to withhold any information from her about the circumstances of her conception or the identity of the person who helped us to make her. We did not wish, however, for that information to be available to third parties at the discretion of anyone else for reasons over which we (and subsequently she) had no influence, and the Registrar is empowered to give access to our daughter's records to third parties. Second, the request was discriminatory, because we were only asked to provide that letter because we did not nominate a father on the registration form. Had I done so (in other words, had I been in an opposite-sex relationship and conceived through donor sperm) I would not have been asked for such a letter. Indeed, the Registry would not have known, at that time, that the child had been donor-conceived. Third, the consequences of this discrimination led to further discrimination: that the circumstances of our daughter's birth by donor conception could be made available to third parties, while the circumstances of other children so conceived would remain private because they had a 'father' nominated on their birth certificate and therefore were not required to provide the letter revealing their donor conception.

The Registry refused to register the birth without the letter from the clinic and I refused to supply it on the grounds I have outlined. Eventually my partner and I engaged a lawyer, a very senior lawyer in the field very familiar with the issues involved. This lawyer made identical arguments to those I had made to the Registrar. Where my voice did not result in a birth certificate, the letter our lawyer wrote did, although her arguments were the same as ours. It was only a lawyer's letter that enabled the registration of our daughter's birth. We did not supply the letter from the clinic .

In my view, this behaviour of the Registry was scandalous, not to mention in contravention of the rights enumerated under the International Convention on the Rights of the Child. The birth certificate finally arrived in the post with no acknowledgement that the Registry had reversed its decision and no apology. I wonder whether the Registry amended its practices or whether it just put us in the 'too-difficult-to-deal-with' basket. This story underscores the necessity to separate such human rights issues as the issuing of birth certificates from the very complex and difficult issues of donor conception. The Registry withheld the issuing of a birth certificate for no other reason than that they would not take my word, even though supplied on a statutory declaration, that I did not know the name of the man who helped up to make our child. They wanted somebody else's word for it.

In my view, the Registry made several mistakes here, and I hope I have made the discrimination issue clear. The other mistake, to which I have already alluded, is to fail to make a distinction between a function of ensuring that genetic parentage is recorded and that of the accurate recording of details of parents. The Registry is not the gatekeeper of genetic information. It is fanciful to think that it records genetic parentage: it records the names of people who nominate themselves as parents of a child just born. This may or may not reflect the genetic facts, but the Registry does not investigate as a matter of course the veracity of this connection. There would have to be a radical overhaul of it if it were to take on that function, and that it tries to take on that role with respect to *some* births *but not all* is clearly discriminatory, not to mention nonsensical.

Do we want the Registry to record genetic parentage on a birth certificate? If we do, then clearly there must be statutory declarations, or more invasive still, DNA testing of all people nominating themselves as parents, to ensure this function. If we do not, then what is it that the Registry records when it records the details of the parents of a child on a birth certificate?

If the answer is that it records the names of the people who nominate themselves as parents and hopes that, if there's no evidence to the contrary, those are the genetic parents too, then we cannot rely on that system to provide the children of this country with their genetic details. So the registration of information about birth has to be seen as a *separate* system to any system that records genetic information. In my view, the birth certificate records parentage: that is, it records the names of the people who are in the position of parent, whether or not they are genetically related. It leaves, as I believe it should, the matter of the genetic connection between those people to the family members themselves to disclose. But to accept this limited function would be for the Registry to accept that it had no right to pursue people on the basis of getting more information about genetics from them.

There is one type of reproduction where this cannot be left to the individual families involved and that is reproduction through state-assisted donor conception. It is precisely because the state is involved and has a duty-of-care to all the people participating in the system that it must also be involved in how the information pertaining to this is stored, disseminated and handled.

There is no necessity that the Registry does this work; as I've outlined above the functions of the Registry with respect to gathering information about birth and parentage are distinct from this particular issue. The decision of the Registry to mark some children's records with a note that there is further information available provides *some* children with more information, but not all.

The question is, then, why the Registry rather than the ITA should manage the registers. What are the compelling arguments for this to occur? I don't know of any, but I know of compelling arguments why they should not.

One of the great benefits of the ITA handling the registers was that its staff, its CEO, its board, were peopled by experts in relevant fields: infertility counsellors, lawyers in the fields, reproductive medicine specialists, infertility nurses, etc. They are familiar with the issues, and the issues are nowhere more complex,

more emotive and more misunderstood in the general populace than in this field. Nowhere is the impulse to judge quicker; nowhere is it less underpinned by logical analysis. The ITA was capable of handling inquiries with tact, delicacy and compassion as well as with a view to what could be done. My encounters with the Registry have been the antithesis of such qualities.

In a recent encounter with the Registry, I approached them for information about applying for identifying information about the man who helped us to have a child. We know, from the information we received at the time of conception, that he is more than willing to provide this information; indeed, that he regards a child's access to that information as a right. MIVF asked us to contact the Registry to see if he was on the voluntary register, so I did that. It was a very offensive experience.

I was told, in the course of several distressing conversations with the Registry staffer, quite a few startling pieces of misinformation and was, ultimately, disgusted and dismayed by the way my inquiry was handled. Again, this is in my view a systemic problem, produced by a profound confusion of roles which has, at its basis, the misunderstanding of the Registry's proper function as well as a profound lack of education about why these situations, of people applying for information about the genetic parenthood of their children, should not be treated as just another bureaucratic job. The Registry ethos is to attempt to protect itself from any questions, indeed perhaps any conversation with the public. I think this is borne out in my encounter, detailed below.

I was told by this staffer that MIVF was not legally able to continue to provide information about donors (which turned out not to be true). I was told that the way the reproductive centres handled these requests for information was morally wrong. In my view, it was the way the Registry handled my inquiry that was wrong.

I waited 6 weeks from the time I put in a request for information from the Voluntary Register. Finally, no answer forthcoming, I rang to ask the outcome of my application, to be told that I had not filled in the form properly. When I pointed out that I had, indeed, filled the form in properly and that I had already been through this with her I received an apology. I asked, then, to be given the information immediately, as I had waited a long time for something that should take five minutes. I was told that information couldn't be given over the phone. I asked why not and was told, because it can't be. I asked to speak to a manager. I got the information immediately. I asked to be given a copy of the letter that would be sent to the donor requesting identifying information. I was told I couldn't be given a copy of that letter. I asked why not. Because that's private. I asked to speak to a manager. I was given a copy of the letter.

I don't say these things to denigrate the particular person concerned: she was no better or worse informed than any other person working in a similar capacity in a government office. And that's my point. This is not just any information: in fact it is not just information, as the discussion held in the Legislative Council about this issue acknowledges. We are speaking about people's lives, their connections with other people through genetics and the question of what each one so conceived will and can make of that. This is what the ITA and its staff know and

will always know because of their education and involvement in the field. They are close to it, and they know how complex it is. They are not perfect; they make mistakes too, but they are far more prepared than the Registry can be for the day-to-day running of these incredibly important registers and for the day-to-day policy questions that arise in running them. I don't say this because of any personal loyalty to them, but rather because, over the course of many years involvement both as a researcher in the area and as someone personally affected by the issues, I have seen the way they work.

Finally, we contacted MIVF, who, after the mandatory counselling session, contacted our donor for us, who was delighted to provide us with so much identifying information that we are assured that we will never have to deal with the Registry on this difficult issue again.

I regard it as one of our responsibilities as a family to be on the Voluntary Register: so that all the members of my daughter's generation, including the children of the man who helped us to make our daughter, can see and perhaps know who their genetic siblings are. If the Registry continues to be the agency handling the records, I predict that less and less people will register unless they have to, and this will mean that information that could go to people, and go to them early, will not. Because my sense of responsibility is stronger than that, I will do it, but I am not looking forward to my next encounter with them. I can imagine that other people will find it so offensive that they don't apply.

I would like to say, in closing on this particular set of issues, that having children with the assistance of donors is a very remarkable and startling area of human life: the people who help others bring children into the world are often people of remarkable generosity and considerable courage. They have taken risks on both their own behalf and their partners and families. They deserve to be treated with a similar generosity: with tact, sensitivity and decency. The Registry can't do this: its staff are simply not in the right position either through education or profession to do that work. In entrusting this function to the Registry we are dismissing the experience and education of the many professionals in this area who had these records in their care and were doing a very good job of handling all the many complex issues that surround them. The care and management of the Registers is not simply a bureaucratic function that can be undertaken by any bureaucracy. It involves much more than that. We leave it to the Registry at its great peril, and people's lives will be affected as mine and my family's have been.

I will finish the main argument of my submission there. I regret that I had to write it in such a hurry, and would welcome the opportunity to produce another submission in the next phase of the inquiry. But I would like also to raise one more issue, which may be outside the terms of your inquiry but which is relevant, I think, not only to this field in general but also to the question of whether the transfer of the records to the Registry should be reversed.

The Registry does not deal well with same-sex couples: at the policy level, my experience is that they are usually considerably behind best-practice in this area. Our story of trying to register our child's birth is one such example. Another is the way the birth certificate has been designed for same-sex parents. In my view, this is a discrimination action waiting to happen. Why? If an opposite-sex couple

with a donor-conceived child registers the birth of the child, the woman is called 'mother' on the form and a man is called 'father': they are given the titles there by which they are designated socially and which are turned into diminutives such as 'mum' and 'dad'. If two women register for the status of parents in this way, one is called 'mother' and one is called 'parent'. The Registry appears to have decided that the term 'mother' should not be used for the non-biological parent of a same-sex couple but that the term 'father' can be used for the non-biological parent of an opposite-sex couple. Surely this is discriminatory? Is a woman who is not the biological mother of a child not a mother? She is if she conceives through donor ova and gives birth to a child; in these circumstances she can register as a mother on a birth certificate. How is it that a non-biological mother in a same-sex relationship cannot do the same?

Many same-sex couples we know use various diminutives of 'mother' in daily life and their children know them by these names. What is the reason for not reflecting this social reality on the certificate? Is it because, in the Registry's view, a child cannot have two mothers? Where is the policy document supporting this view? I would be very surprised if there was one, but if there is I would like to see it made public on the Registry's website. The Registry is not good at transparency on these issues, so nowhere is it clear how this decision was made: it is as if the public has no investment and no role in the names by which we are called, names which opposite-sex couples can enjoy without question.

I hope these brief points and arguments can contribute to your policy deliberations and recommendations for your interim reports.