Submission
No 2

INQUIRY INTO INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS

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Date Received: 18/11/2011

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Friday, 18 November 2011

The Hon Mr John Barilaro MP,
Committee on Law and Safety
Parliament House
Macquarie St
Sydney NSW 2000
Fax: (02) 9230 3309

Dear Mr Barilaro,

Re: Inquiry into inclusion of donor details on the register of births

1. Introduction

Thank you for the opportunity to make a submission to the enquiry. I have had a long term involvement in this issue, including having been deputy chair of the Australian Health Ethics Committee that in 2007 revised the National Health and Medical Research Council *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice* and a member of an expert panel advising the Victorian Assisted Reproductive Technology Authority. I have also had a long term association with the Victorian Parliament on this issue including having been an adviser to several Ministers of Health in relation to both the 1984 Bill and the 1995 Bill.

The views in this submission are my own and not necessarily those of the Institute nor of any of the government agencies with which I am involved.

2. Overview of the Needs of Donor Conceived People and their Families

2.1 Donor Gametes and Embryos

The choice to use donor sperm, eggs or embryos is a difficult choice for couples and many choose to remain infertile rather than to bring someone else into their relationships in this way with all the difficulties created for the child and the family of creating a matrix of parental relationships. That other person also becomes a parent to the child as a genetic parent. Parenthood then becomes separable into genetic, gestational and social or nurturing. For the child, that involves a fragmentation of parenthood, raising questions about who really are the child's natural parents, whatever the law may say in terms of recognizing the birth mother or the genetic mother, depending on the jurisdiction and whatever has been contracted between the parties. Using donor sperm or donor eggs is problematic for both the couple and the child because it involves including another person as a genetic parent of the child.

In practice this fragmentation of the parental roles into genetic, gestational and social or nurturing parents has implications for the child. Psychologists often refer to the issue of genealogical bewilderment as children, perhaps later in life, seek to discover their origins and to identify their own identity in circumstances in which the genetic parents may be completely unknown to them or become known to them at a later stage. The relationship between a child and his or her parents is complex. So much of our sense of identity is based upon that relationship. When it is fragmented, that can be hurtful and confusing.

Prior to when it became clear that anonymity could not be guaranteed by the clinics, it had been the practice of the clinics to undertake not to voluntarily to release information about gamete or embryo donors. It is that group that is the major issue at this time.

What is significant about the previous arrangemens was that they were an arrangement that involved the person conceived, the donor or donors, the infertile couple and the IVF clinic, but the person conceived was excluded from those arrangements. An agreement that principally involved the interests of the child was made seemingly without regard to the interests of the child and certainly without anyone to represent the interests of the child. Undertakings for secrecy and anonymity that breached the children's rights to know and to have access to their parents ought not be regarded as morally binding.

An important element of the arrangements at least since the 1984 nationally uniform revision of the *Status of Children Act* 2004 is that if a woman gave birth to a child using reproductive technology and she was single or had a partner who did not consent to being considered the parent of the child, then that person has no father according to the law, even though there was always a genetic father in existence. That seems particularly egregious. That there is a genetic father but a structure has been put in place to prevent the donor conceived person from being able to identify that person clearly breaches that person's right to know and have access to both their mother and father.

2.2 Surrogacy

The New South Wales Parliament passed the Surrogacy Act 2010. That creates another set of record-keeping issues for donor-conceived persons because not only is there a need to keep records of those who donated sperm, there are now other categories of people who may have made a parenting contribution including the surrogate mother and her partner and anyone else who has been in a parenting role to the child via a surrogacy arrangement, whether or not the contract was actually fulfilled.

Surrogacy sets up, to the detriment of families, a division between the physical, psychological and moral elements that constitute those families. The woman's capacity to bear a child is implicitly separated from her role as mother to that child and any other children she may have. She must deny any affections she has for the child she carries.

In that respect, the treatment of the surrogate is problematic because it does not recognise the motherhood that exists in becoming pregnant and nurturing the child until birth. The surrogate is implicitly treated as an object, and her body is used as a mere incubator rather than as the child's mother. As the child's mother she is linked to the child physically, emotionally, cognitively and spiritually and that reality ought not be denied. To enter into a contract to the contrary by which her connectedness is to be rejected is essentially false.

The surrogate may be genetically a stranger to the embryo because the latter has been obtained through the union of the gametes of "donors;" or she may use her own egg fertilized through insemination with the sperm of a man other than her husband or of her husband. Either way, she carries the pregnancy with a pledge to surrender the baby once it is born to the party who commissioned or made the agreement for the pregnancy, who may or may not be the donors.

Surrogate motherhood represents a failure to meet the obligations of maternal love, marital fidelity and responsible motherhood. That is to say, carrying a pregnancy involves a unique relationship to the child in which the woman becomes the child's mother. As the mother of the child she has obligations to nurture the child.

The issue now is whether the child will be able to obtain identifying information about not only those who provided gametes, but also the birth mother. The practice of surrogacy is problematic in that it severs the child's relationship to the woman who carried pregnancy and gave birth. That relationship is of great significance even if the woman is not genetically related to a donor conceived person. Similar issues apply in those circumstances for a donor conceived person to know and have access to that person who figured so significantly in their lives.

In itself surrogacy contracts offend the dignity and the rights of the child to be conceived, carried in the womb, brought into the world and brought up by his own parents. These rights are recognized by the United Nations in the Convention on the Rights of the Child, which upholds the child's right:

- to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference (art. 8);
- not to be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child (art. 9);
- not to be separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's best interests (art. 9):
- to rely on the common responsibilities of both parent for the upbringing and development of the child, and their primary responsibility for the upbringing and development of the child on the basis of the best interests of the child (art. 18);
- that in adoption decisions the authorities shall ensure that the best interests of the child shall be the paramount consideration (art. 21).

It is important that donor conceived people are able to identify their origins including the gestational or birth mother and any donors.

The current surrogacy legislation makes provision for *parentage orders* as a way of dealing with the surrogacy arrangements. That leaves some flexibility about the parenting possibilities so that people may come and go as social parents in the life of the child. The same issues of being able to identify and access those people who have had a parenting role in their life as child would seem to apply for donor conceived people.

3. Issues arising if records of those who make parenting contributions were maintained

The main issue to be raised is access to identifying information about those involved in a parental role in the origins of donor conceived persons conceived using gametes donated before it became clear that anonymity could not be guranteed. Parental roles include the donors of gametes, birth mothers in surrogacy arrangements, and anyone who fulfilled a social parental role and relinquished, whether or not they were genetically related to the child or related to the child as a birth mother.

There are practical issues about the storage of data before there were requirements to maintain the records, such as required by the 2004 NHMRC *ART Guidelines*. It is a question of how accurate the data was especially as there had been a practice of mixing donor sperm with the husband's sperm and whether it has been kept in a way that can be readily accessed.

Second, there is the issue of the clinics having given an undertaking not to voluntarily relinquish identifying information. As discussed earlier it was an undertaking that they had no right to make given that it was an undertaking that breached the rights of the donor conceived person to know and to have access to his or her parents. *Prima facie*, in those circumstances the rights of the donor conceived person would seem to override a claim to anonymity. However there could be extraordinary circumstances in which a person who is a genetic parent, a birth mother or relinquishing social parent to a donor conceived person but is now in vulnerable circumstances such as mental illness.

In those circumstances it might be appropriate for a legislative process to be established which allows for application to be made and an objection lodged by the person about whom identifying information is sought. In the same way in which the Courts have powers to make parentage orders, they could also have the task of determining whether extraordinary circumstances of vulnerability applied. The legislation would need to clearly define the way in which the criteria of vulnerability were to be applied.

Legislating to require the information to be kept by a government agency and that agency having responsibility for releasing the information and providing counselling to those receiving information and those about whom the information is to be released would seem to be important as it would then remove the liability from those clinics who undertook not to voluntarily release identifying information.

The National Health and Medical Research Council's ethical guidelines on the use of assisted reproductive technology in clinical practice and research strongly support the rights of persons conceived using ART procedures to know their genetic parents[1]. The guidelines also insist that that for gametes that were donated prior to the guidelines, both gametes not be used unless consent to identifying information being given to the child has been obtained. The guidelines have not addressed the issue of identifying information about persons in other parenting roles, such as a relinquishing birth mother, relinquishing substitute parent, or relinquishing social parent.

However the principles of a child having a right to know and have access to his or her parents, expressed in the UN Convention on the Rights of the Child, would seem to apply to all of the parenting roles in the origin of a donor conceived person. There would not seem to be a need to obtain consent from those who held parenting roles in the origins of a donor conceived person. They have parental obligations because they were in parenting role. The law should not ever have countenanced circumstances in which they could be allowed to be anonymous parents. To maintain the anonymity now for those who were given undertakings would continue the injustice to those who were donor conceived. As discussed earlier commitments have that kind cannot be morally enforceable because they affected someone who was not a party to the commitment to that person's detriment.

Where records do not exist is obviously problematic. However what does need to happen is that whatever records do exist should be transferred to a government agency to be administered as well as they can be given whatever state they are in.

There is a need to put in place a government administered system. One of the strange aspects of all of this is that NSW has a Registrar for Births Deaths and Marriages, but that agency has never been used to store information about the genetic origins of children conceived through the use of reproductive technology. Instead the information has been kept by the clinics. Yet the obvious agency that has responsibility for issues of this nature and has the capacity to provide these services that are needed of verification of identity and counselling is the Registrar for Births Deaths and Marriages. The obvious step to take would seem to be to legislate to require all the information about those who have parenting roles in the origin of the child, (including the genetic parents, the gestational or birth mother, and relinquishing social parents or relinquishing substitute parents), to be supplied to the Registrar. As suggested earlier, where there is not consent to identifying information being provided to a donor conceived person, then the person about whom information is sought should have a statutory right to object subject to that objection being upheld by a Court. The legislation would need to specify the criteria for upholding an objection on the grounds of extraordinary vulnerability.

In future donor programs consent to the release of identifying information will already be required as it is under the current legislation and under the National Health and Medical Research Council *ART guidelines*. The issue is the impact, prior to the change to arrangements which prohibited guaranteeing anonymity, on those who were given an undertaking that the clinics would not voluntarily release the identifying information.

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[1] National Health and Medical Research Council *Ethical Guidelines on the Use of Assisted Reproductive Technology Clinical Practice and Research* June 2007, section 6.1

Many of those people would pose no objection. However there may be some who are vulnerable and the above proposal would provide some protection for them. There may be others who have been very frequent donors. In earlier enquiries into this matter there has been some indication that clinics did not restrict the number of times that a single donor could be used to parent children. It has also been suggested that medical students were often approached to be donors and even that doctors in the clinics have been donors. There is potential for embarrassment if matters are not handled sensitively. Once the information is made available to a donor conceived person then there is no practical restriction on who might have access to that information subsequently.

There does not seem to be any way around this issue. There is a natural moral obligation that a person takes on in deciding to be a genetic parent to a child or in being a birth mother or social or substitute parent. The child is vulnerable to decisions being made by others and the state has a *parens patriae* obligation to protect the best interests of the child. That obligation would seem to extend to include donor conceived people in relation to decisions made when they were children to which they were not a party at which so severely affected their interests. The undertakings should never have been given and they ought not now be upheld.

Bringing parity to the interests of donor conceived people compared to people who were adopted is an important step. The latter have had a service provided by a government agency that has not been available to people conceived through the use of donor gametes. The impact for donor conceived people is that it would give them some confidence in the record-keeping and the accessibility of information that is often so important to them.

Yours sincerely,

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