

SUBMISSION TO INQUIRY INTO ASSISTED CONCEPTION

My name is Emily [ok, so my name isn't *actually* Emily. I have changed all the names for privacy reasons]. My partner Benjamin and I are your average mid-thirties heterosexual couple. We have two cats and no kids. We are child-free by choice. Benjamin is a known donor to some friends of ours. My submission is to tell you my experience of being part of this known-donor, private, assisted-conception situation. This conception was done without any clinics, just a syringe of sperm, a few visits to the GP for screening, some strong communication skills and an ovulation chart.

Our situation is an example of how everything can work out like a dream come true for everyone. Hopefully our experience can help others and can help the committee put forward recommendations that would make private assisted conception a more accessible road for others.

I have put my views specific to the terms of reference at the end of this document. When preparing this submission I read about 90 of the other submissions.

Our Story

Benjamin and I are in our late thirties. We don't have or want to have any children of our own. Some friends of ours, a lesbian couple (Penny and Jo), asked Benjamin (and me) if he would consider donating sperm to them so they could have a family. The four of us discussed it a lot (over about six months). We went ahead with it, and now Penny and Jo are the proud parents of beautiful two-year-old Tom, and they have another baby due in January.

The decision to donate

Both Benjamin and I were very clear that we did not want children. I love children—other people's children. I liked the idea of being part of a child's life, to be a regular fixture in the long-term for a kid or kids. Having been involved in the lives of a few kids before (the kids of ex-partners) I knew that an 'Aunty' role was a lot like being a rockstar. The kids are always thrilled to see you. You give them all of your love and attention, and then go home and get 8 hours of uninterrupted sleep and days of quiet. It is like being a grandparent, without having to be a parent first. You get most of the good stuff and not much of the tricky stuff.

The fortunate byproduct of this rockstar role is that we can offer Tom's parents some down time and some emotional and practical support. We also offer them our undying awe and respect at how they manage to be parents--brilliant parents. Me and Benjamin get to feel like we are playing a small role in the 'village it takes to raise a family'. Our decision to donate was not completely altruistic – although that was a large part of it. We get a lot out of the situation and we are grateful to Penny and Jo for giving us this opportunity. I think this aspect of being a known donor and being part of the immediate family of a known donor should be valued a lot more. There is this idea that being a known donor is completely generous and altruistic; while this is an important aspect and should be primary, it should also be emphasised that being part of this situation is something that everyone gets a lot out of, and society gets a lot out of.

Penny and Jo did not want a donor who wanted to be a 'father' but they did want a known donor. And Benjamin did not want to be a 'parent'. Benjamin's motivations for saying yes to Penny and Jo were perhaps enhanced by my enthusiastic rockstar argument, but he was also interested in playing a supporting role in his offspring's life. From the very beginning the four of us focused on being open and honest with each other about our feelings and our fears. And this was key. It meant that we were sure that our desires and motivations were compatible with each other's from the start. We all agreed it was about expectations. If we were all clear and open and honest about

the expectations that we held, the chance of things going awry were minimised. And this has so far proved to be the case.

Penny and Jo did a lot of hard work researching assisted conception, lesbian families, donors and so on, and prepared a draft memorandum of understanding [attached]. This MOU has been crucial. The four of us have redrafted and reinforced and updated it as we move through the process. It will never be a finished document, and since Tom came along we have not redrafted it much. But it was very helpful in guiding our discussions.

The mechanics of private assisted conception

My partner Benjamin was tested for relevant transmissible diseases, as was I, and Benjamin's sperm were assessed and deemed to be numerous and active (Penny and Jo reimbursed us for our costs). Penny and Jo lived in the flat upstairs from us at the time, so arranging the conception was logistically simple. They told us when birth mum (Jo) would be ovulating and we delivered the fresh sperm up to them on those days and they inserted it.

While we were prepared that it might take some time to conceive, Tom was conceived after only three (I think?) ovulation/donation rounds; and Tom's sibling-to-be was conceived in the first ovulation/donation round.

Our current relationship to Tom and his parents

Both Benjamin and I play a role in Tom's life—a role that is perhaps akin to the role of grandparents or aunt and uncle (Tom has plenty of actual aunts and uncles and grandparents on both parents' sides, but none that live in Canberra). We were the first of Penny and Jo's friends/relatives to see Tom after he came into the world. We see Tom about once a week. We are confident (if not wildly enthusiastic about) changing nappies. We have a babyseat in our car. Benjamin sometimes minds Tom without me, and I sometimes mind Tom without Benjamin; sometimes we mind him together; and sometimes all five of us hang out together. Sometimes the five of us go on holidays together. And it will probably be Benjamin and me who will look after Tom when Jo and Penny go to the birthing centre to have their second baby. And my rockstar scenario has worked out perfectly according to my cunning plan: Tom thinks we are absolutely great.

The key to success

The whole process has been a lovely and positive experience. In my opinion, the key to having it all work out favourably for everyone is:

- For all parties to communicate clearly and continuously with each other (verbally and in writing)
- To have complementary desires regarding roles in the child's life—if possible.
- To have clear, agreed-upon, honest expectations of the roles everyone will play.
- Try to anticipate potential areas of conflict and change and discuss them before they occur.

MY RESPONSE TO THE TERMS OF REFERENCE

The past and present practices of donor conception in Australia, with particular reference to: (a) donor conception regulation and legislation across federal and state jurisdictions.

Consistency

Laws should be the same throughout all jurisdictions. It is clear that there is great confusion and hardship caused by the current situation of different laws in different states.

Discrimination

- Marital status, sexual preference or income should not have a bearing on access to assisted reproduction. Access to Medicare rebates and other financial support should be available to singles and homosexuals.
- Something should be done to make assisted reproduction more financially accessible so that people are not economically discriminated against. Perhaps through making private, non-medicalised donation simpler and safer (legally and physically).
- People donating gametes should *not* have a say in the marital, political, geographical, economic or sexual preference status of who their donation goes to. People donating embryos or gametes should not be able to stipulate that their gametes go to any particular ‘type’ of family.

I read Tonia’s submission (submission no. 7) about how her and her husband wanted the embryo they donated to go to a ‘normal heterosexual family’. I applaud Tonia and her husband for being honest about their wishes in their submission because I think this is an issue that needs to be aired and discussed. I understand Tonia’s feelings of ownership over her gametes and that she wants some control over who her embryo goes to, but a donation is a donation and what she is suggesting is discrimination.

No doubt Tonia’s wishes for her gamete to go to a family ‘like hers’ was because she and her husband want the best outcomes for any child that might come of her gamete. If you really care about the wellbeing of the child that your embryo will become, then having that child raised in a planned family (as all assisted conception is) means that that child is very likely to have a wonderful stable and loving life. So you are already donating your embryo to ‘a family like yours’ – a family that desperately wants a child that they can love and care for and a family who has thought about it and planned for it. And I include single people when I say ‘family’ because they are probably already part of a family (grandmothers, aunts and uncles, close friends etc), and a new baby will enlarge that family.

A child raised in a ‘normal heterosexual family’ is much more likely to have bad outcomes (such as sexual abuse, psychological abuse, neglect) than any child raised by parents who wanted that child so much they went through the hassle of donor conception. ‘Heterosexual’ or ‘single’ has no bearing on the outcomes for donor-conceived children; although there is strong evidence to suggest that donor children brought up by lesbian parents are better adapted than children brought up in ‘normal heterosexual families’ – see the [National Longitudinal Lesbian Family Survey](#) and [ABC RN Life Matters](#).

Statutory body

I believe there needs to be a federal statutory body that will have responsibility for:

- Creating and managing a mandatory private and secure database of donors and donor-conceived children and siblings—past, present and future
- Enforcing laws (to be enacted—relating to privacy, rights, discrimination, pricing, disclosure, recordkeeping, counseling, informed consent, medical screening, number of families using one donor etc) and regulations in relation to fertility clinics and other forms of assisted reproduction
- Providing information and advice regarding assisted reproduction—including raising public awareness about issues relating to assisted reproduction
- Helping donors, donor-conceived children and their families make contact with each other in appropriate and sensitive ways.

Education and awareness

I believe there needs to be a wide and thorough public education campaign about assisted reproduction, for two reasons:

- 1) To educate the public:
 - About donor-conceived individuals and their families: to show how many different varieties of family there are and what a positive and normal experience it is; to limit stigmatisation, discrimination and misinformation.
 - About the value of being a (known) donor, about how rewarding it is, so as to encourage anonymous donors to come forward and to encourage more people to donate.
- 2) To ensure the rights of people involved in assisted reproduction:
 - to make sure they have access to clear, accurate, reliable and up to date information about all aspects of assisted reproduction;
 - to increase the number of parents who disclose to their donor-conceived children;
 - to increase the number of anonymous donors who come forward to be known to their offspring.

This could be done through things such as:

- A comprehensive website, including videos or radio podcasts of the stories of people involved in all the variations and roles of assisted reproduction.
- Information kits

(b) the conduct of clinics and medical services, including:

After reading most of the submissions to this inquiry I was appalled at the stuff-ups and deceptions that have (allegedly) been perpetrated by some clinics. There should be strict laws and rigorous recordkeeping to prevent such stuff-ups.

I also believe the committee should look at issues relating to the screening of gametes for genetic diseases such as cystic fibrosis (as was mentioned in one submission), Downs syndrome and other disabilities -- versus screening for what are medical or psychological ‘predispositions’ or socially or personally ‘unfavourable’ characteristics. We need to be aware of the delicate balance between real concerns about bringing someone into the world to face a life of pain and suffering and/or a severely shortened life in a family unable to cope with that; and the slippery slope toward a Brave New World of designer babies, a class of tall, blue-eyed, ‘perfect’ children paid for by wealthy parents. There needs to be a balance between:

- not stigmatising disability, not de-valuing difference;
- minimising avoidable pain and suffering of children and their parents;

- and not creating a class of designer babies.

(i) payments for donors

There needs to be a balance between the need to have more donors (payment would increase the amount of donors) and the need for donors to be known (for the welfare of the donor children especially, but also for all parties).

Personally, I do not have a strong feeling against donors being paid; I think that with careful consideration, it could work for everyone. But: currently gamete donors are not paid, and there is strong resistance to changing this situation from people who have a lot more experience in this area than I do. So, I think donors should not be paid, but I think they should be reimbursed for any costs and for their time (although I do not know how that could be quantified). At the very least it should be made as convenient and easy as possible to donate – ie donors should be able to make appointments with clinics outside of business hours if preferred etc. Donors should be treated with the utmost respect for performing such a valuable and altruistic role.

There should be advertising or some kind of information or awareness-raising campaign to educate people about the value of being a donor and about how being a donor is not simply altruistic—it can be rewarding for everyone—to increase the number of donors. I think this kind of thing would be valuable for everyone in society: something showing the positive experiences of being a known donor, and something that dispels the fears that people might have surrounding their donation. Again, having people tell their stories would be the ideal way to do this.

Children used to be born to younger parents, they had young grandparents and they had more siblings and aunts and uncles. Now, with people choosing to have children later, often grandparents are not able to be as involved in their grandchildren's life for as long. Children's worlds, and the family resources that parents can call upon, have shrunk. There are also a lot more people like Benjamin and me who have decided not to have children, and we can play a role in children's lives. And I think this could be an argument to encourage people to donate, and to encourage the donor's family to come onboard with it.

(ii) management of data relating to donor conception

There should be a national, mandatory, private and secure database of all donors, siblings and donor children born, so that donor children can find out who their siblings and donor parents are. This would also guard against donors contributing to several fertility clinics. Private donors should also have to be on the database.

All donor children should have the right to identifying info when they are 18 – and younger if both parties agree. I think this should be retroactive. Donor children should have the same rights to know their genetic heritage that adopted children have. I think the rights of donor children over-ride the rights of donors who donated expecting to be anonymous. Having said that, donors who wish to be anonymous should be able to have a say in the timing and processes of the revelation of their information and should be given adequate counseling. It should be a heavily mediated and sensitive process. Perhaps in some instances, donor children might be satisfied with the amount of information that the anonymous donor is willing to offer. There could be negotiations through a third party to achieve this.

If the law is not made retroactive, then every effort should be made to try to sensitively convince the donor to provide the donor-conceived child with at least some of the information they require. Perhaps it could be compulsory for the anonymous donor to disclose medical history and known siblings and other salient non-identifying information.

It seems that most donor children would be satisfied with a certain amount of information from their donor about siblings, medical and family history, a photo, a written answer to some questions posed by the donor child. The donor could remain anonymous in that situation as the interaction could be mediated. I think donors have unrealistic fears about donor children wanting to move in with them or become part of their family or get money from them or something. If these fears are addressed through education and counseling, donors who wish to remain anonymous might be more amenable to having their identity revealed to their donor children.

In the future, donors should provide a lot of information when they donate (family tree, reasons for donating, medical history, physical description, letter to potential child, personality description) in case they become untraceable or die. This way the donor child will be assured of knowing their medical and genetic family history.

(iii) provision of appropriate counseling and support services;

Definitely, for donors, parents and donor children, whether they are doing it privately or through a clinic. On donation and on disclosure and at any time in between or thereafter.

I feel that donor children have a right to know their genetic heritage and that it is very wrong for parents to hide this from them. I imagine there is no way to absolutely ensure that parents tell their children from an early age the truth about their conception, but the bare minimum would be to make it part of the counselling process: to educate parents about the value of being honest with their children about their background. As part of the process it would be good to expose potential parents to the stories of donor children who have known their genetic heritage from the start—which seem to be overwhelmingly positive stories—and compare this to situations where the child has not been told or has been told when they are an adult or teenager—which seems to be mainly a negative experience.

(c) the number of offspring born from each donor with reference to the risk of consanguine relationships;

There should be a limit of 5 families *per donor* worldwide and no limit on the number of offspring born. It should be *per family* not *per person*. That way, a same-sex family can feel safe that, if they decide to have a second or third child with the same donor, they can. Having no limit on the number of offspring in this situation would mean that any one donor child would still be unlikely to have more than 10 to 15 siblings.

(d) the rights of donor-conceived individuals.

Donor-conceived individuals should have the right to access identifying info about their donor retrospectively. These children's rights over-ride the rights of donors who thought they were doing it anonymously. This could be helped by informing, counseling and preparing anonymous donors.

Birth certificates

I believe all birth certificates should have the maximum amount of information, to account for heterosexual couples, same-sex couples, single-parents, assisted conception, IVF, surrogacy, and adoption. I suggest that birth certificates should include:

- Parent
[being a person who will be legally, socially, emotionally and physically responsible for child]
- Parent
[being a person who will be legally, socially, emotionally and physically responsible for child]
- Birth mother
[this would account for surrogacy where the birth mother might be different to the parent(s) and/or genetic parent]
- Genetic male parent
- Genetic female parent
- Siblings
[should include all ‘half’ siblings]

The category ‘Parent’ should be foregrounded strongly against the other categories on the certificate. It should be made clear in the law that the/a ‘Parent’ is the legal guardian and that the other categories hold no legal sway in their own right but are there as part of the donor-conceived individual to know their background. All categories should be filled out even for the garden-variety heterosexual couple. There should be no mention of the method of conception.

The argument that the choice of providing information about parentage should not be taken away from parents is a specious argument. The evidence is overwhelming that it is in the best interests of donor children (and probably to everyone else involved as well) to know their genetic heritage, and ensuring all information about their parentage is on their birth certificate will ensure donor children’s rights, even if parents do not disclose to their children.

In response to the argument that donor children will be discriminated against if this information is on their birth certificate, I would say:

- If society sanctions secrecy and shame in relation to assisted reproduction (by not encouraging people to be open and honest with each other and by catering to people’s prejudices), that stigma and discrimination will remain.
- Your birth certificate is actually not required to be presented for many things, especially not many things that are open to discrimination.
- Any discrimination against people on the basis of their parentage is illegal anyway, so recourse (hopefully) can be got through the law if someone is discriminated against.

Private arrangements

Any obstacles put in the way of people being able to do it privately (in a safe, legal and positive way) should be minimised. It can be a very rewarding, non-medicalised and straightforward way to go about it. However, there should be more guidance, information and counseling available to parties involved in private assisted conception—such as how to go about it, what things to discuss, what medical screening to undertake and how, what documents to think about, what outcomes to contemplate, the roles to be played etc. Some kind of kit could be made available to people contemplating assisted conception – perhaps including several case studies and a template for a memorandum of understanding to prompt people to think about all the issues they may encounter and to help people find a way to communicate with each other positively about it.

Benjamin and I are available to appear before the committee if asked. Penny and Jo wanted to put in a submission but did not have time to put one together.

This submission reflects my experience and a little of Benjamin's experience. Although Penny and Jo read this submission and were happy for me to submit it, clearly their experience is very different and they are more involved in this issue than either me or Benjamin.

Emily.