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Committee Secretary
Legal Affairs and Safety Committee
Parliament House
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Committee Members

INQUIRY INTO MATTERS RELATING TO DONOR CONCEPTION AND INFORMATION

I write to you to address the following items of the inquiry:

- a. Rights of donor-conceived persons, including to know their genetic origins;
- b. Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors;
- c. Access to historical clinical records and implications of retrospectivity;
- d. Access to support and counselling for donor-conceived persons and donors;

It is from the perspective of a person that does not have access to their biological or genetic information that I write to the Committee. I am not a donor conceived person, I am an adopted person and while adoption carries a myriad of other issues with it, I am speaking to you only on the issues raised above in relation to the rights of information. The correlations between the two circumstances of donor conceived and adoption are equal and undeniable in terms of the denial of information and the impact of such.

Rights of donor-conceived persons, including to know their genetic origins:

Can I begin by saying that the system and process of donor conception is designed to meet the rights of the parent. All parties, donors, prospective parents, medical staff are working toward the goal of making 'parents'. What they are actually making is a child, a person with limited right to their genetic information. No matter how honourable the intentions of the prospective parent are there may be little consideration of the child's right to their knowledge of who they are. In this respect the rights of the parent are being put before the rights of, not only the child, but the adult that child becomes.

It is a person's innate right to know where they come from. Medical technology has taken that right away from donor conceived people under the guise of a loving family. To refer to a person's information as 'genetic information' demonstrates an objectivity that delineates misunderstanding. Genetic information is not a tangible record for the person missing it, it is the nature of their being, it is 'who I am'.

Under the *QLD Human Rights Act 2019 section 15 (1)* it is stated that *every person has the right to recognition as a person before the law*. While the intention of Parliament here might be to align with the rule of law we can, in this context, define ‘person’. Does a ‘person’ include the knowledge of who they are? The responsibility of the State and relevant legal institutions is surely to advance the equality of all people before the law regardless of the nature of their conception. Therefore the knowledge of a person’s genetic being must fit with the definition of a ‘person’ for the purpose of the Act. If we then apply this to a legal right to genetic information, all persons must be equal before the law in this respect. That would then entail a legal right to knowledge of genetic information and the question becomes whether there are any extenuating circumstances to justify limiting that right.

We cannot support a legal situation where, on the one hand all people are equal before the law, and on the other, all people are equal before the law except if they are donor conceived. The law provides a system of births, deaths and marriages that allows children and adults access and knowledge of their parentage. If, for example in a non donor conceived scenario, birth certificate information is incomplete or incorrect then it is between the parent and child to work through such situation. We might term this a consequence of life. Donor conception is not that. It is State controlled conception and therefore must carry all legal rights as pertained in any human rights instrument.

If we consider the *International Convention on the Rights of the Child*, particularly [Article 3](#), it is the States Parties responsibility to have the best interests of the child as the primary consideration. So we need to explore the best interests of the child. As mentioned earlier if we have a system that is set up to meet the rights of parents to conceive a child, then the State and parents must acknowledge and be responsible for the position they have put the child in. This position must recognise the child’s right to their whole being including their genetic information, hence the definition of a *person*. It is the States Parties responsibility to undertake and ensure care

“as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures”

It is therefore the State’s responsibility to ensure adequate, equal and just measures to meet the needs of a donor conceived person.

These concepts are also reflected in other legislative instruments such as the *QLD Human Rights Act 2019 section 26 (2)* and the *Family Law Act 1975 (Cth)*. Again, we must consider what is ‘the best interests of the child’, not the parent, but the child who will become an adult with a missing piece of their personal identity. Is it in the best interests of the child to be denied clear and detailed information of who they are? If we make the best interests of the child the primary concern then this would entail a legal obligation for donors and prospective parents to consent to a donor conceived persons having right to their genetic information prior to any IVF process.

Let me come at the issue from a more subjective perspective. For many of us that do not have access to our genetic information it becomes a life long issue and often a never ending quest that we had no say in. [REDACTED]

“I know who I am, but I need to know who this is” (tapping his body).

It is our innate right to know and understand ‘who’ we are rather than ‘why’ we are. It is not enough to naively believe that family will subjugate the need for understanding who we are

as an individual. I am sure the psychological submissions to the Committee are able to better explore this concept with relevant research, I am merely explaining the notion from first hand perspective.

I could not have been bought up in a more loving family where the best interests of the child were always at the fore. [REDACTED] are all stable, educated, contributing adults although we were denied our genetic information by the State, and, when reform occurred the information has been subject to many constraints. Each one of us have at various stages during our life needed counsel and access to as much identifying information about our biological being as the law has allowed. At times this has been a struggle and all of us have had to grieve the reality that we will never know our genetic identities.

The consequences of life leave us in many family situations but we cannot continue to make babies without considering the consequences of birth. With all the State's knowledge and resources this situation is simply unacceptable in modern society. It is therefore the State's responsibility to provide a right of passage to such information should a donor conceived person wish to proceed with the pursuit of their genetic information. This knowledge should be open and transparent and the institutions involved need to ensure accountability. It is therefore up to the State to direct the adherence to such practices.

[Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors;](#)

For all the reasons discussed above, a person should have the right to their full genetic information. This cannot merely be a description of the physical. We know that genetics is much more than just our physical being. Genetic information can help explain what makes us unique, understand physical traits, medical history, how to stay healthy, and so on. At the deeper level it gives us identity and this, for some people who do not know their genetic history, cannot be derived from a clinical description. The extent of the identifying information should be driven by the donor conceived person. For all the reasons mentioned under part (a) of this submission, the donor conceived person is the one with the least amount of power in the situation. They did not choose the position they are in therefore should be given the right to self determination of the amount of information accessible.

If a person donates genetic material that will make a human being, then, by nature of the donation they must be willing to be responsible for the consequences of that donation. These consequences must take into consideration the inherent needs of the child/adult produced. Again, when a system is set up to protect and serve the all but the child that is produced we need to rethink the consequences of our actions. The State must direct this good intention and be clear to all stakeholders the needs and rights of the subsequent child. To '[take into consideration the right to privacy of donors](#)' negates the right of the child. It is simply unjust to produce children that have no or limited rights to their genetic information, all stakeholders have to be ready to accept their role, when and if the time comes, of a donor conceived person needing to know their information.

[Access to historical clinical records and implications of retrospectivity;](#)

Any law reform must be retrospective. If we are to assert that all people are equal before the law we cannot have a class of individuals that merely, by the timing of their birth, are denied the rights attributed to others.

The State must address the issues arising and offer structures of support for those in the retrospective category.

Access to support and counselling for donor-conceived persons and donors;

One only needs to look at the popularity of genetic testing for ancestry research. Note that many people do this to understand their ancestral history, identify with the passage of time. A person who does not know their genetic history often uses this method as a way of expanding their genetic information. In fact is actively advertised as a method of genetic discovery for people without a genetic history on by companies such as Ancestry.com (Ancestry, 2014), X23andMe (Kirkpatrick, 2020) Results are pot luck and it is unjust that people without genetic information must resort to commercial carriages for such deeply personal identifying information. These tests are unlikely to provide meaningful clinical information, can provide false sense of reassurance, can turn up a myriad of unexpected biological relatives putting both sides of the relationship at risk and so on. (Matloff, 2018) The consequences of finding such critical information in this manner can be devastating for individuals.

The responsibility of counsel must lie with the State to ensure equitable benchmark and accessible support. This opportunity has existed in the adoption context whether State provided or delegated for free access to those affected. In my experience this has been a positive opportunity for great learning and sharing under a respectful and controlled environment.

Should such counselling be compulsory for those seeking access to information, or other stakeholders impacted by the issue? At the bare minimum it must be controlled to protect all parties and provide support structures throughout the process. No doubt the psychological reports tendered to the Committee would inform this process.

To conclude this submission I would ask that:

- The Committee learn from the past and acknowledge the correlation of the importance of understanding genetic history with adoption practices.
- The State cannot continue to support a system where the parents' rights to a child outweigh the child/adult rights to knowledge of who they are.
- The State ensure all stakeholders are aware, accountable and readily accept the consequences of donor conception in terms of the rights of the child born, and their quest for information.
- The State produces regulation that is retrospective.
- The State be responsible for the funding and standard of counsel required to support stakeholders.

Many thanks for considering this submission.

Helen McKenzie