



VARTA

Victorian Assisted Reproductive Treatment Authority

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Submission to the Law Reform Committee of the Victorian Parliament
Inquiry into Access by Donor-Conceived People to Information about Donors
Victorian Assisted Reproductive Treatment Authority
August 2011

The Victorian Assisted Reproductive Treatment Authority (VARTA) provided a submission to the Inquiry into Access by Donor-Conceived People to Information about Donors in August 2010. All terms of reference for the review were addressed in that submission with the exception of (f). This submission addresses that item.

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

The donor registers were formally transferred from the Infertility Treatment Authority (ITA) to the Registry of Births, Deaths and Marriages (BDM) on 1 January 2010. Counselling services related to the donor registers that were previously provided by the ITA have been provided by Family Information Networks and Discovery (FIND) since this date.

Following implementation of the *Assisted Reproductive Treatment Act 2008* (Act), some issues have arisen for applicants to the donor registers, the person contacted as a result of the application (the subject of the application) and the agencies providing services to the donor registers. These issues are outlined as follows:

Issues related to donor registers service provision under the current Act

- There is no provision in the Act for counselling for the subject of an application to the Central Register. If the subject of the application is a donor-conceived person there is a risk that they may find out they are donor-conceived through a letter from BDM. This, and a lack of available counselling support, may have long-term impacts on the donor-conceived person's mental, emotional and social wellbeing.
- There is no provision in the Act for BDM to release information about the application to counsellors at FIND. As a result, FIND counsellors receive no information prior to a counselling session about the content of an application, including whether the applicant is a donor, donor-conceived person or recipient parent.
- FIND counsellors are unable to relay information provided by an applicant to the subject of the application (even with an applicant's consent). This means the subject of the application has no information upon which to base their decision to give, or not give, consent to the release of their identifying information.
- FIND is unable to give information to BDM regarding the outcomes of counselling. If the person counselled has particular wishes as to how they would like information exchange or contact to proceed, FIND cannot provide this information to BDM.
- Due to the Act's restrictions on information release, a letterbox service that enabled secure transmission of non-identifying information from one party to another under the *Infertility Treatment Act 1995*, no longer operates. This method was a highly popular way for parties to begin to communicate with each other and has been used widely as a communication method in the adoption reunion field.

- No follow-up support is available for those who are unable to access information from the donor registers or for those who are initiating information exchange or contact.
- Services provided to those affected by donor conception are minimal compared to services provided to people affected by adoption yet there are significant complexities in donor conception practice due to the number of families created by one donor (up to ten).
- Donor-conceived people, donors and recipient parents need to navigate between several government agencies to obtain information and counselling.
- The Act does not provide for the ability to share information about potential genetic diseases or genetic abnormalities from donors to the people they helped to conceive and vice versa. VARTA considers this to be a gap in the legislation as this lack of information can have serious health implications for donor-conceived people.

Further detail in relation to issues

Counselling provisions within the Act

While applicants to the Central Register are provided with counselling, parties affected by the application, (whether they are a donor, parent or donor-conceived young adult) are not. While counselling for parties affected by an application is not specified in the Act, there are risks to the health and welfare of donor-conceived young adults, parents of donor-conceived children and donors if information about an application is not provided within a counselling environment.

Information exchange between BDM and counsellor at FIND

Under the Act, the capacity for information exchange between BDM and FIND under the Act is quite restricted.

For example, BDM may be required to seek consent from a donor-conceived young adult on receiving an application from a donor for identifying information. This young adult may not be aware that they are donor-conceived and so learn they are donor-conceived as a result of the application. In seeking consent from the donor-conceived person to release information to the donor, BDM is not in a position to provide counselling support to assist the young adult to come to terms with the revelation that their Dad (or Mum) is not their biological parent. The donor-conceived person will also need information regarding the reasons and wishes of the donor in making the application. Under the existing service model, there is also no capacity for BDM to refer the young adult to FIND for discussion and support about the application and potential issues associated with providing consent.

As a result, there is no clear pathway of support for a donor-conceived young adult. They may not be able to discuss issues with their parents and community counsellors have little experience in dealing with these issues. This puts the donor-conceived person in a difficult position.

Role of counsellor and inability of FIND counsellor to relay information to the subject of an application

As a result of changes within the new Act, the counsellor's role has changed from an intermediary facilitative and mediative role in which the counsellor works with each party to achieve a mutually acceptable outcome, to that of giving the applicant broad advice which is not specific to that person's particular situation. Therefore, the person who is contacted as a result of the application (e.g. the donor who is contacted as a result of a

recipient parent's application) has no information on which to base their decision of whether to consent to the release of their identifying information.

In the ITA's experience of managing the donor registers, understanding why the applicant wanted information was crucial to the decision-making of the person who was contacted. The request for consent to release identifying information was usually quite unexpected and came as a shock. While the applicant may have deliberated about making an application, the person contacted as a result of the application might not have thought through the implications of giving consent to their information being released. To make such a decision, they usually wanted to know the motivation behind the application, the short and long-term goals of information exchange or contact and how the applicant wanted to begin this process.

The intermediary role played by the counsellor is common in the adoption reunion field. The ITA's model of service provision was based on evidence-based success of this practice model. An average of two counselling sessions per linkage was required. The role of the counsellor was to establish the ground rules for information exchange or contact. The counsellor assisted the parties with the first steps of contact and then withdrew, allowing the parties to communicate with each other. If either party was experiencing difficulties they could request further support from the counsellor. Telephone or email contact was usually sufficient.

Without information about the applicant's motivation for making an application, the person who was contacted might not give consent for release of identifying information. If the person chooses to give consent, both parties are left to navigate contact without an indication of the other party's wishes. They have no capacity to protect their privacy other than refusing consent.

Restrictions on information release – letterbox service

While operating under the *Infertility Treatment Act 1995*, the ITA provided a letterbox service which allowed parties to write letters to each other, while not exchanging identifying information. The ITA would forward the letters to the respective parties. Under the new Act, there are restrictions on information that can be passed from the applicant to the subject of the application and on the information BDM and FIND can exchange. Therefore, a letterbox service is no longer in operation.

With the letterbox service, if both parties were uncomfortable releasing identifying information immediately, they were able to exchange information in a safe and protected way. This exchange of information enabled parties to make a more informed decision about whether to release contact details or to meet in person. Some people preferred to keep their identity private for some time, while others included identifying information in a letter. Many of the applicants to the donor registers were parents of young children who usually had concerns about protecting their children. Similarly, donors and donor-conceived young adults had concerns about giving private information to someone they didn't know. This service was well utilised. Letterbox services are also popular within the adoption reunion field.

Support for parties unable to access information

Applicants to the donor registers who are unable to access information do not receive counselling support. Applicants may be unable to access information because:

- information does not exist
- there is no corresponding link on the Voluntary Register
- the donor declines to consent to the release of identifying information.

Lack of available information is usually a very disappointing outcome and can be devastating for a person. They may not have discussed their application with anyone else as it is a very sensitive issue. Community counsellors do not have experience in this specialist field and may not be able to provide the required support.

Navigation between several government agencies

Services related to the donor registers and related public education is currently provided by three government agencies – BDM, FIND and VARTA. This may present difficulties for the service user in navigating between these agencies and for the agencies to ensure that there are no breaks in the chain of service. The process means that the applicant may seek information from BDM or VARTA by phone or website. On making an application to BDM, counselling would be provided by FIND and contact would be made again with BDM in relation to the release of information. If the parties require assistance with telling family members about donor conception they might then contact VARTA.

There is no allowance in the Act for government agencies to exchange information regarding an application. In addition, BDM does not have a counsellor on staff to discuss with service users the implications of making an application to the donor registers. Service users often have to discuss these sensitive matters with a number of staff in different agencies.

A more integrated service model would include counselling regarding the application (both pre-application and during the process). Counselling would help the applicant to navigate the wishes of the other party around information exchange or contact. The service model would also incorporate supporting people to talk to family members about donor conception. As Victoria leads the world in providing donor registers and linking services and little is known about the outcomes of donor linking worldwide, a research element could also be built into the service provision model to evaluate application outcomes.

Comparison with services provided for people affected by adoption

Many of the issues raised here concerning access to information for donors and donor-conceived people and their families are common to the field of adoption reunion. Under the terms of the Act, the services that can be provided to people affected by donor conception are substantially inferior to those provided to people affected by adoption. A comparison is provided in Table 1 below.

ITA donor linking service model	FIND service model for adopted persons or birth parents	FIND service model for applicants to donor registers
Mandatory Counselling offered and provided to applicant to donor registers.	Mandatory counselling provided to applicant prior to receiving birth certificate information and identifying information.	Mandatory counselling provided to applicant to donor registers on referral from BDM.
Support offered and provided by counsellor to person affected by an application; advice on how to tell children or a young adult that they are donor-conceived if required. Reason applicant wishes to seek identifying information is discussed to inform decision-making (per linkage, average of two counselling sessions provided face-to-face, with some brief email or telephone follow up).	Counselling support offered if required to birth parent or adopted person affected by an application for information.	No counselling provided to the person affected by the application.
Letterbox service available for secure information exchange between two parties to enable trust to be developed prior to direct contact being made.	Letterbox service available for information exchange between two parties to enable trust to be developed prior to contact being made.	Counselling does not include any specific non-identifying information from the donor registers.

Further complexity for donor-conceived families and donors

Yet, people affected by donor conception have the additional element of complexity that it is common practice for ten families to be created from one sperm donor. It is possible that a donor-conceived person has up to 20 genetic half-siblings in addition to any children the donor may have themselves. A donor-conceived person's parents may have used more than one sperm donor to have their children. These donors may have provided consent under different legislative periods. As disclosure to donor-conceived children has only become more common in recent years there are many donor-conceived people who are likely to be unaware they were donor-conceived. Late disclosure usually raises many issues for the donor-conceived person regarding their identity.

Donors may be unaware that any children have been born as a result of their donation, may not have informed their partner or children about donating and may be approached by a number of donor-conceived people they helped create. They are often confused as to their role and whether the donor-conceived person has a legal claim on their estate or whether they owe a legal responsibility to them.

All parties are usually anxious about beginning contact even if they initiated the application. All parties are usually unclear as to what is appropriate or the correct 'etiquette' between donor-conceived people, donors and recipient parents. Usually, a small

amount of early support is sufficient to reduce this apprehension and give guidance as to appropriate roles and boundaries for each party.

Heritable diseases and abnormalities

In recent months, VARTA has been informed of three cases where important information about a genetically inherited disease has affected a donor-conceived young adult and a donor. Two cases came from a clinic which has since closed down. There has also been notification from a recipient parent that her young child has been diagnosed with a condition which has a genetic link.

There is currently no requirement in the Act for information about heritable genetic diseases or genetic abnormalities to be passed on to people who may be affected by this information. For example, if a donor informs BDM that he or she has learnt of or been diagnosed with a condition that may have a genetic link, BDM is not able or required to contact the people born as a result of his or her donation, or their parents. This is an important issue that needs to be addressed as it has significant health implications for the people concerned.

Summary

Changes to the service system related to the transfer of the donor registers from the ITA to BDM under the Act have raised a number of issues for donor-conceived people, their parents and donors. These need to be addressed to improve services for all parties involved in donor conception.