Submission
No 14

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

Organisation: Fertility Society of Australia

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Submission to the NSW Parliament Legislative Assembly, Law and Safety Committee "Inquiry into managing information related to donor conception" on behalf of the Fertility Society of Australia and its sub-committees

- **The IVF Medical Directors Group**
- **Scientists in Reproductive Technology (SIRT)**
- **The Australian and New Zealand Infertility Counsellors Association (ANZICA)**
- **The Fertility Nurses Association (FNA)**

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All responsibility for the opinions expressed in this submission lie with the Board of the Fertility Society of Australia

[redacted]

Terms of Reference

That the Committee inquire into and report on the management of information related to donor conception in NSW, with particular regard to:
a) whether people conceived by donor conception prior to January 2010 should have access to donor conception information, including information that identifies their donor and donor conceived siblings.
b) which agency should manage donor conception information and provide services related to the release of this information.
c) what counselling or support services and public education measures are necessary to support people who are seeking access to donor conception information.
d) any other relevant matter.

Executive Summary

The Fertility Society of Australia (FSA) is the peak national body that represents health professionals and consumers in the field of reproductive medicine and fertility. The FSA regulates clinical practice in ART units in NSW by accreditation with the Reproductive Technology Accreditation Committee (RTAC) Code of Practice (COP).
The FSA welcomes the opportunity to submit to the Legislative Assembly Law and Safety Committee "Inquiry into managing information related to donor conception." We would like to make the following points in relation to the Terms of Reference

a) The FSA strongly supports the rights of donor conceived people to have access to identifying information about their genetic origins. Where donor conception has occurred prior to the establishment of current regulatory practices, the FSA supports the following models to facilitate exchange of information between donor conceived adults and their donors with the consent of all parties
   - The establishment and promotion of voluntary donor registers (by ART Act and clinics)
   - Community education re donor conception
   - Outreach to donors by clinics in a sensitive manner

   However the FSA is strongly opposed to compulsory retrospective registries as this would be a violation of agreements entered into, in good faith, with sperm donors who have made an altruistic donation to help other families have children.

b) The FSA does not hold a strong view regarding which agency should manage this information in NSW. However experience in Victoria suggests there are efficiencies in giving one body ownership of all aspects of the donor conception information management process. The effective placement of an agency to best manage the donor registry ultimately relates to the resources made available to the agency, particularly in regard to managing enquiries sensitively with provision of consent for all parties.

c) The existing frameworks for practice pertaining to ART Units in NSW reinforce the need for counselling as an essential component in managing information related to donor conception. (NHMRC “Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research’ June 2007 and FSA Reproductive Technology Accreditation Committee (RTAC) Code of Practice (COP) for Assisted Reproductive Technology Units”. The “ANZICA Guidelines for Professional Standards of Practice: Donor linking Guidelines” provide guidelines for a framework for practice of donor linking in clinics. Public education measures are also necessary to promote registries and provide information for donors if they are to reconsent to the provision of information.

Responses of the FSA to the list of questions raised by the Inquiry are as follows

Question 1: Should donor-conceived adults have retrospective access to doors identifying details?

The FSA recognises that it is very important for some donor-conceived individuals to have the opportunity to know their biological parentage. Our society and its members, over many years have worked with prior patients, fertility clinics, governments and the NHMRC to:

- Progressively remove anonymity in all treatments involving gamete donation
- Establish retrospective registers retaining information regarding donors, recipients and offspring
- Provide community education and support in this area
- Provide specific assistance and counselling to individuals involved in donor conception.

However there are residual circumstances where donor conception has occurred prior to the establishment of current regulatory practices and the principles of non-anonymity. The donors who took part in fertility programs at that time, donated their gametes in good faith and with the understanding and assurances from relevant health professionals, that anonymity would be guaranteed.

To make available information about these donors without their consent, would constitute a fundamental breach of privacy and further would constitute a breach of the doctor-patient relationship. Our society considers this untenable. It is indeed notable that no Australian state or territory has legislation that allows retrospective access to donor information because the privacy issues involved are issues of fundamental law.

The FSA recognises that there are alternate models of managing information related to donor conception with the consent of all parties.

- The FSA supports the establishment and promotion of voluntary donor registers as mandated by the ART Act 2007, and also functioning in some ART clinics. Such registers have the potential to manage the different levels of information (identifying or non-identifying) that donors may wish to provide and donor conceived adults may wish to receive.

- The FSA supports the NHMRC recommendation to “use forums for public information to encourage people who were donors… to contact the clinic and register their consent to being contacted by their genetic children…” (NHMRC Guidelines on the use of ART in Clinical practice and research, June 2007 6.1.3 p26) This further highlights the need for ongoing promotion of voluntary registers to encourage donors to come forward and indicate their consent to the exchange of identifying or non-identifying information.

- The FSA supports donors being contacted in a confidential and sensitive manner by their clinics with a request to provide identifying or non-identifying information, similar to the process outlined in the Infertility (Medical Procedures) Act 1984 (Vic). This also provides a mechanism for donors to to decline further contact depending on their wishes. Indeed many of our Society work actively to forge voluntary and sensitive links between donors and donor conceived individuals. The FSA notes this is also the recommendation of the NHMRC, the peak research and ethics body in Australia (NHMRC Guidelines on the use of ART in Clinical practice and research, June 2007 6.13 p29).

  The “ANZICA Guidelines for Professional Standards of Practice: Donor linking Guidelines” (attached) describes this practice model for donor linking with consent of all parties. This has been shown to be successful in clinical practice and we would recommend resources be directed to this mechanism of donor/offspring linkage as the primary means by which donor conceived individuals can be helped to trace their biological origins.

The FSA recognises that parallels have been drawn with adoption, where legislation has been amended to grant retrospective access to pre-adoption birth certificates. However the existence of parallels does not imply that the adoption model can inform the policy response for managing information related to donor conception. There are significant differences in the two practices that pertain to the rights of all parties. There is no fit with the role of a donor in the adoption models where birth parent(s) had legal rights prior to consenting to adoption.

Question 2: If retrospective access were granted what conditions should apply?

The FSA does not support any models granting retrospective access to donor’s identifying details without the consent of the donor.

For example, the veto model proposed by the Victorian Law Reform Committee Report 2012 is inadequate in providing protection to donors. The donor’s information would have to reside, without their consent, with a third party and therefore be subject to, and at risk of, further alterations to policy in the future.

The FSA supports the view that retrospective legislation is unfair and deprives the donor of their right to confidentiality and privacy as existed at the time of the donation. Moreover the Society is concerned that retroactive laws in the context of gamete donation may jeopardize the whole practice by destroying the trust of candidate donors and recipients. (Pennings, G., “How to kill

gamete donation: retrospective legislation and donor anonymity” Human Reproduction journal, attached).
The right of the child to know its genetic origins is supported in current practice but past practices cannot be corrected by depriving the donor of privacy and confidentiality.

Question 3: What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required?

As previously stated, the FSA strongly opposes the granting of retrospective access as this would be a violation of agreements entered into, in good faith with sperm donors who have made an altruistic donation.

The model endorsed by the FSA and documented in the “ANZICA Guidelines for Professional Standards of Practice: Donor linking Guidelines” is the professional model of practice utilised in most ART clinics in Australia. Provision of counselling is central to this mediation model of practice which allows exchange of non-identifying or identifying information only if all parties consent.

Question 4: Which agency is best placed to manage the register of donor conception information (donor registry)? Is the current management of the registry adequate?

Dept of Health has a strong record in management of confidential information and the Registry of Births, Deaths and Marriages has relevant experience in working with adoption cases. There is also the potential for utilising an existing organisation such as the Post Adoption Resource Centre to sub-contract the management of the donor registry. However the Law Reform committee enquiry in Victoria recommended that counselling previously subcontracted to FIND be returned to the Victorian Assisted Reproductive Technology Authority (VARTA). This suggests that a stand alone model is the desirable alternative in that state. There are obvious efficiencies in giving one body ownership of all aspects of the donor conception information management process that will benefit stakeholders and the community.

The placement of an agency to best manage the donor registry ultimately relates to the resources made available to the agency, particularly in regard to managing enquiries sensitively. The critical needs are for privacy, and for staff who are sufficiently trained and experienced to take a sensitive view to these exceptionally personal issues.

The current management of the NSW donor registry is primarily administrative. Concerns of members of the FSA in NSW relate to the absence of any resources, advisory body or tribunal of persons experienced in ART to manage the complex and sensitive matters arising from legislation. The management of the registry needs to allow flexibility to manage the unique needs of each donor conceived adult and donor with the provision of information. Furthermore, there remains a need in NSW for the provision of public education and resources for professionals and the community on fertility, and issues related to assisted reproductive treatment. It is noteworthy that such advisory bodies exist in Victoria (VARTA) and in Western Australia (the Reproductive Technology Council) to the benefit of both consumers and clinics.

Question 5: Should a stand alone body be established to manage the register? What other areas could it have responsibility for?

Following from above, the establishment of a stand alone body with appropriate resources would provide an efficient and professional service to manage the register. Other areas for which it could have responsibility are

- Promotion of the register
- Provision of public education re fertility, including promotion of the need for recruitment of donors
- Development of resources for donor conceived families e.g. “Time to tell” program (VARTA)
- Letterboxing service connecting donors and donor conceived adults
- (Possibly) the retention of records if a clinic closes

FSA recommends the establishment of an agency or tribunal with resources to meet the needs of consumers and clinics, to provide public education and the flexibility to respond to sensitive consumer needs, encompassing both the NSW ART Act 2007 as well as birth registration. Incorporation of an advisory body consisting of key stakeholders to the agency is also recommended.

Question 6: Should counselling and support services be offered to those seeking donor conception information from the register?

Yes. Counselling is integral to service provision for those seeking donor conception information. Current practice (refer RTAC COP and ANZICA Donor Linking Guidelines) models outline service provision to those seeking donor conception information which is inclusive of counselling. Furthermore NHMRC Guidelines 6.13.3 stipulates that “acceptance of counselling services should be encouraged as part of the preparation for the release of identifying information.”

Question 7: Are there other types of support that could be offered?

VARTA provides an excellent model of an agency that provides a spectrum of support for donor conceived persons and their families. Other types of support include

- Educational resources for parents on how to tell
- A website with podcasts of personal stories, literature and information pertaining to donor conception
- Research to better inform professionals and families
- Letterboxing service connecting donor conceived adults and their donors
- Support group for donor conceived young adults

Question 8: How would support services be funded? By the government, the individual seeking the service or by ART clinics?

Services could be funded by a variety of models incorporating a basic level of government funding, private counselling, but with minimal costs for counselling of young adults who are financially disadvantaged. The Victorian and Western Australian models for funding counselling both provide feasible models for consideration of their application in NSW.

It should be noted that the majority of ART clinics in NSW are privately funded and currently demonstrate flexibility in costs associated with donor linking. However it is not appropriate for clinics to fund the donor register.

Question 9: How would such a service be provided? By referral to the department of Family and Community Services (as with adoption) or by a stand alone body (as has been recommended in Victoria)?

The FSA has a preference for a stand alone body for which VARTA provides an appropriate model.

Question 10: How long should ART clinics be required to retain records?

FSA recognises that existing guidelines for the retention of records are effective.

The RTAC COP requires that ART clinics comply with

- ◊ the NHMRC Guidelines that stipulate “provision to keep records indefinitely (or at least for the lifetime of any persons born) “ (10.1.1),
- ◊ relevant state legislation i.e. ART Act 2007 that requires minimum retention of 50 years

Question 11: What should happen to records if a clinic closes?
There may be circumstances where a clinic closes and no other clinical organisation is taking over that clinic. Providing appropriate legal safeguards are in place, a stand alone body managing the donor registry could take responsibility for retention of the records of the clinic that is closing. Legal safeguards would have to accommodate the donor’s consent at the time of donation. The rights of the donor conceived adults under the ART Act 2007 also need to be protected.

Question 12 How can we ensure the integrity of records? For example ensuring that they are not destroyed or tampered with?

The integrity of records held by clinics accredited by the RTAC COP is guaranteed by compliance with this accreditation process.

ANZICA GUIDELINES FOR PROFESSIONAL STANDARDS OF PRACTICE: DONOR LINKING COUNSELLING

Introduction

The 2007 NHMRC Ethical Guidelines on the Use or Assisted Reproductive Technology in Clinical Practice and Research state that,

'Persons conceived using ART procedures have a right to know their genetic parents (Part B, 6.1:25)'

'Voluntary exchange of information between persons conceived using donated gametes, gamete donors and gamete recipients, with the consent of all parties, is desirable. …. Access to further information may occur only with the consent of all parties involved or as specified by the law.' p25

If the consent form does not include permission for release of identifying information (because the donation was made before the introduction of these guidelines and the gamete donor has not come forward in response to the public information campaign outlined in paragraph 6.1.3), the clinic should make an appropriate effort, consistent with the original consent document and the privacy rights of the donor, to contact the gamete donor and obtain his or her consent to the release of information.' 6.13.1

Definition of Donor Linking:

These guidelines pertain to requests for exchange of information between a donor-conceived adult or recipient parent and their donor, as well as between donor-conceived half genetic siblings and recipient parents who have used the same donor. These exchanges may or may not lead to direct contact depending on the wishes of the parties involved.

Guiding Principles:

As always counsellors will be guided by client individual need. These are guidelines and not regulations. This document aims to provide guidelines for professional standards of practice which will reflect the spirit of the NHMRC guidelines and both respect the interests of donor-conceived adults, recipient parents and donors as well as individual's sensitivities regarding privacy by utilising a model of mediation and facilitation.

The clients including the enquirer and the subject of the enquiry (donor conceived person, donor or recipient parent) should:

- Provide confirmation of their identity
- Be provided with clear information
- Be offered the opportunity for discussion
- Be treated with respect
- Be assisted with the process and in their adjustment to the outcome
- Be clearly informed of the choices available to them
- Have control over the pace of the steps involved
- Make informed decisions about each step taken

The donor linking counsellor:

- Takes on the role of the mediator
- Does not become the advocate for one party over another but supports both the client who wishes to find information and the subject of the enquiry throughout the process.
- Supports the principle that people affected by donation may have an interest to request information or make contact with their donor, genetic offspring, or genetic half-siblings, and such interest in information or contact is to be treated as normal and responded to positively
- Is respectful of an individual's right to privacy. Information must not be released to another person without the consent of the individual concerned
- Maintains confidentiality at all times.
- Provides information about other mechanisms for donor linking e.g. NSW Health Voluntary Register, Donor Sibling Registry, Victorian Donor Registers

Suggested Procedure/Protocol:
Figure 1. Process Map Donor Linking Counselling

1. Initial Enquiry

Provision of written information by clinics regarding policies and protocols for exchanging identifying and non-identifying information is optimal.

The donor linking counsellor is the person appointed by the ART clinic to manage these cases. All initial inquiries and communication should be referred to the donor linking counsellor. The counsellor will need to work closely with staff of the ART clinic who have direct access to the donor records.

At the time of the initial inquiry, the specific information needs of the client should be established. If their needs are not clear or there are issues needing further discussion an appointment for counselling should be offered.

2. Non-identifying information request (when information is available from clinic records.)

Counselling should be offered with requests for non-identifying information. The request should be made in writing with verification of the identity of the enquirer (driver's license suggested). A search of clinic records should then be made to establish whether there are any records pertaining to the request. If no records are able to be located, the enquirer should be advised and counselling should be offered. In cases where information is available, after searching appropriate records information is to be provided by the counsellor in writing. Follow up counselling should be offered.

3. Identifying information and non-identifying information request requiring consent from the other party.

If the request is for identifying information or further specific non-identifying information not included in the records, an appointment for counselling should be arranged before any further steps are taken.

4. Counselling session with party requesting information (enquirer)

The counselling should address the following:

- Confirmation of the identity of the enquirer (e.g. driver's licence check)
- Clarification of the specific request for information/contact for that person including their motivation and clarification of their needs and expectations of the possible outcome of the enquiry i.e. what specific information do they wish to know e.g. medical, do they want to exchange emails/letters/meet?
- Understanding the context of other life issues including the impact of the search to people close to the enquirer
- Clarification of the legal rights of all parties
- Discussion of the anticipated steps involved
- Discussion of possible outcomes of pursuing the request including case scenarios of positive and adverse outcomes e.g. where donors and donor-conceived individuals have exchanged information or made contact , the possibility the other party does not consent to provide information,
- Consideration of the possible implications for the other party and the possible impact to those close to them.
- This session assists the client to develop a clear understanding of their needs and motivation, and whether they wish to proceed.

If the enquirer has decided after counselling to progress with the request, the following steps should be followed:

5. A formal (written) request should be made by the party wishing to initiate contact/information exchange.

The client should also provide in writing the information that they want communicated by the counsellor if/when contact is made with the outreached party, and ideally how they would like to proceed if the subject is willing to exchange information/have contact. The subject of the search is likely to ask the counsellor about the reasons for the enquiry (e.g. motivations, specific information requested, interest in ongoing communication exchange/contact, non-identifying information about the person making the request).

The only information that should be passed on is that which was consented to by the client. Also establish in writing what the client wants the counsellor to ask the subject of the search. This is particularly important as the subject may not agree to further contact but may be prepared to answer some questions.

6. A search is initiated for the contact details of the subject of the outreach. This can be done by accessing the electoral roll, or enlisting the assistance of an organisation experienced in searching e.g. VANISH in Victoria. It may be possible to locate the party via the internet but extreme care needs to be taken that the correct person is identified before any attempt is made to contact them.

7. If the subject of the outreach is not located, the client is advised and further counselling may be necessary.

8. If the subject of the outreach is located, inform the enquirer and re-establish whether the client wishes to proceed before any attempt is made to contact the other party. Some clients may have second thoughts as the possibility of contact moves closer to reality. This contact with the enquirer also prepares them that a response from the subject may occur in the near future.

The counsellor then adopts the role of **mediator/facilitator**.

9. The counsellor then may contact the subject requesting that they contact the counsellor. If by letter, it should ideally be sent by person to person registered mail and should contain information that will enable the person to recognise what it is about. However it should not give out detailed information in case someone other than the subject reads the letter. See sample letter Appendix A

10. If the letter is received but there is no response The counsellor could try sending a further letter, or making contact in any other appropriate way.

11. When contact is made with the outreached party, information may be passed on to the subject by the donor linking counsellor as authorised by the inquirer. The subject should be invited to attend counselling.. The counselling session assists to clarify the subject's feelings, thoughts, expectations, and wishes in relation to the enquiry and implications for themselves and those close to them. Would they be prepared to exchange information? If so, what information would they be prepared to pass on to the enquirer, would they be prepared to exchange emails/letters, would they be prepared to meet etc? During the counselling session, information may also be provided to the counsellor to pass on to the enquirer

Information, whether it be identifying or specific non-identifying, should only be exchanged with consent given by the person it pertains to.

12. The counsellor continues to act as a mediator between the two parties until either an agreement is reached to exchange further information or it becomes clear that an agreement cannot be reached. *When this has occurred the counsellor assists to establish the first contact between the parties and then steps out of the mediating role so the clients can establish their own relationship independently if they* *have agreed to do so.* The counsellor may agree to provide a **letterbox service** in which letters are forwarded confidentially by the counsellor between the parties so that the two parties can write to each other without having to give identifying details about themselves. This can provide a safe mechanism for parties to get to know each other. This may continue for some time or the parties may choose to include identifying details in correspondence and discontinue using the letterbox exchange.

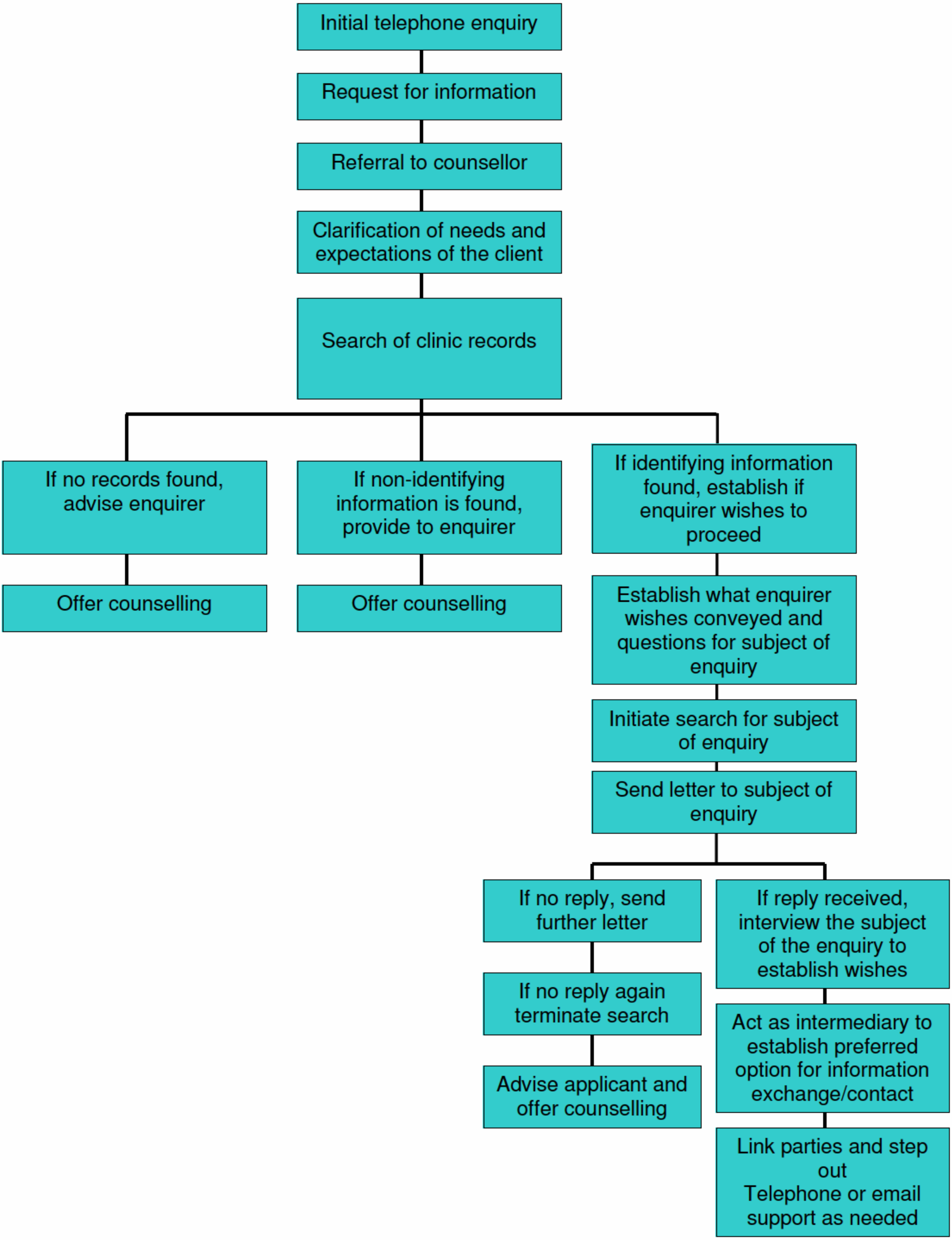
13. Further counselling may be required by either party depending on outcomes and emotional reactions. The needs of others in the immediate families of each party should also be considered. It is likely that issues that were salient at the time of the treatment or donation will resurface and will need to be dealt with (e.g. marital conflict, dealing with infertility, grief etc). Disclosure issues are also likely to need to be addressed if people close to either party are unaware of the donation.

See over for:

- Figure 1 - Process Map of Donor linking counselling.
- Appendix A - Sample outreach letter to donor

ANZICA would like to acknowledge the original authors of this document, Jenny Blood and Helen Kane, who pioneered donor-linking counselling practice in Australia. These guidelines have been updated in January 2012 by Kate Bourne and Liz Hurrell.

FIGURE 1. PROCESS MAP- Donor Linking Counselling Process



Appendix A: Sample outreach letter to a donor

Date xx/xx/xx

X

Dear **x**

Around **(insert date)** you very kindly assisted with a project which was run at **(insert name of hospital).** There are a few questions that have arisen which you may be able to assist us with and hence this letter to you. If you were willing to consider helping us with these enquiries, I would be very happy to talk with you by telephone at a time suitable to you. You could contact me on **(insert telephone number)** which is a direct line to my office. You are not obliged to contact me however it would be much appreciated if you choose to do so.

Thank you for considering this request.

Yours sincerely,

Name of counsellor

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human reproduction OPINION

How to kill gamete donation: retrospective legislation and donor anonymity

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ABSTRACT: Victoria (Australia) is considering retrospective legislation on the abolition of gamete donor anonymity. Retrospective legislation evokes many negative emotions mainly because it is considered unfair. It also makes it impossible for citizens to organize their life with reasonable certainty of the consequences. Introduction of this law for donor anonymity is defended by the right of the child to know its genetic origins. Against this law, people appeal to the right to privacy and confidentiality of the donor. This paper analyses the arguments for and against a retrospective law on donor anonymity by looking at the conditions that should be respected when two principles (the donor's right to privacy and the child's right to genetic information) have to be balanced. It is concluded that the justification for introducing retrospective law is lacking: the conditions are not fulfilled. Moreover, retroactive laws in the context of gamete donation may jeopardize the whole practice by destroying the trust of candidate donors and recipients in the government.

Key words: donor anonymity / ethics / gamete donation / justice / retrospective legislation

Introduction

In 2011, the Senate Legal and Constitutional Affairs References Committee of Australia issued a report on the practice of donor conception in Australia. In that report, the Committee introduced the question of whether information on the donor should be provided to children born before the law that required donor identifiability. About a year later, the Law Reform Committee (LRC) of Victoria, which advises the Parliament on new legislation, recommended that the law should be retrospective. The Victorian Government has 6 months from March 28 to respond to the Committee's report. If this recommendation becomes law, gamete donors in the past, who donated in the understanding that they would remain anonymous, will become identifiable. The legislation in Victoria has maintained complete donor anonymity for donors before 1988. For donors who donated between 1988 and 1997, the identity can only be released to the offspring if the donor consents. Donors after 1998 have to provide identifying information to their donor offspring.

Many people consider the proposed retrospective abolition of donor anonymity as an unacceptable violation of the donor's rights. In this paper, we will analyse and evaluate the arguments for and against retrospective legislation on gamete donation.

Retrospective legislation

Generally speaking, there is a widespread antipathy against retrospectivity in law (Sampford, 2006). The reason for this attitude is that retrospectivity violates the rule of law, i.e. the conditions that have to be respected by lawmakers in order for law to guide conduct in a democratic society (Murphy, 2005). When lawmakers fall short of the rule of law, for instance by introducing retroactive legislation or by contradicting themselves, citizens feel resentment, based on a sense of fairness and justice (Woozley, 1968). Perhaps the most fundamental reason why retroactive legislation is viewed suspiciously stems from the principle that 'a person should be able to plan his conduct with reasonable certainty of the legal consequences' (Hochman, 1960). As a consequence, one needs a strong justification to introduce a retrospective law.

What reasons can be given to introduce retrospective legislation? Retrospective legislation may:

(i) rectify a slowly grown discrimination or inconsistency. The different steps of the Victorian law on donor anonymity indirectly lead to different rights for the donor children born at different times.
(ii) demonstrate the growing conviction that things done in the past are unacceptable. Lawmakers in countries that have abolished donor anonymity may come to believe that the steps taken in previous legislation can no longer be justified. In other words, too many rights were accorded to the gamete donor in the past compared with the rights of the donor offspring.

Why is retrospective legislation about donor anonymity morally wrong? Several reasons can be given. Retrospective legislation is:

(i) unfair; the government comes back on a previous agreement, unilaterally. This decision can be seen as abuse of power.

(ii) ungrateful; donors donate to help others and they do so within a context in which there is a balance between costs and benefits. Instead of being grateful for their help, the government now significantly increases the costs to a point where it can be expected that the majority of the donors would not have donated if they had known. In a way, they have been cheated into donating.

(iii) inconsistent; donors are counselled so as to enable them to make a well informed decision. When they have done so, the conditions on which the decision was made are changed. The retrospective changes inherently deny the donor's autonomy, because he (or she) has not given informed consent within the amended situation.

(iv) disrespectful; closely related to the previous reason, it can be argued that retrospective changes imply that the donor is used solely as a means to serve someone else's interests. The only way the donor can be respected is by requiring prior consent to the release of the information.

Solving conflicts between principles

There is no obvious reason why all retrospective legislation would be wrong. Whether or not such law is justified depends on the balancing of the principles involved. The two main principles for our discussion are the right of the donor to privacy and the right of the child to know his or her genetic origin. The parties who believe that retrospective legislation is acceptable argue that the donor's right to privacy and confidentiality is overridden by the child's right to know its genetic origin (Allan, 2011; Law Reform Committee, 2012). They are convinced that not being able to know one's genetic origin causes great harm to the child.

When two conflicting principles have to be balanced, six conditions should be respected: '(i) better reasons can be offered to act on the overriding norm than on the infringed norm; (ii) the moral objective justifying the infringement must have a realistic prospect of achievement; (iii) the infringement is necessary in that no morally preferable alternative actions can be substituted; (iv) the infringement selected must be the least possible infringement, commensurate with achieving the primary goal of the action; (v) the agent must seek to minimize any negative effects of the infringement, and (vi) the agent must act impartially in regard to all affected parties.' (Beauchamp and Childress, 2001).

Let us consider these conditions consecutively.

There must be better reasons for the overriding rule

Obviously, both sides believe that they have better reasons. Reasons should refer to morally relevant aspects of the situation, and it is clear that both sides can refer to harm and to violation of rights. When we look at harm, the evidence about the harm to the child when no identifying information is available is weak (Broderick and Walker, 2004). It mostly amounts to anecdotal evidence from donor conceived offspring. The evidence pointing to 'no (major) problems' is much stronger and based on scientific research. This also explains why the majority of the countries maintain donor anonymity. The data are reassuring for the welfare of the children for both secrecy and anonymity. Firstly, the studies up to date indicate that children who do not know about their donor conception are doing as well as non donor conceived children (Golombok *et al.*, 2006; Murray *et al.*, 2006). Secondly, children who are informed about their donor conception early in life are curious about their donor but do not suffer from any major problems from not knowing their donor (Vanfraussen *et al.*, 2001). The wish to know more about the donor in children who were informed about their donor conception neither has an effect on the child's well being nor on the quality of the parent child relationship (Vanfraussen *et al.*, 2003). Much more can be said about the different elements of the 'need' of the child to genetic information, but the overall conclusion is that the strong justification needed to break the rule against retrospective law is lacking.

The evidence on the harm to the donor in a strict sense is also weak. It is not known at present how much harm will be caused to donors and their families by such legislation. Presumably, many of these older donors have not told anyone about their donations. When their social environment is informed, highly problematic situations may be caused. Whether this harm will outweigh the harm to the child is undecided. Still, harm comes in many forms. When fewer donors present themselves because they no longer trust the government, the infertile couples will have to wait longer or will have to look for treatment abroad, where identifiability is frequently not offered. This balancing of harms and benefits tends to become a highly complex discussion and we need the other elements to break this tie.

When we look at rights rather than harm, Allan argues that the right to privacy of the donor is outweighed by the manifest injustice against the children (Allan, 2011). As I pointed out above, there is no manifest injustice against the children. The argument largely depends on the comparison one makes. Defenders of the right of the child mostly refer to adoption. This is a revealing view, since it leads to the conclusion that gamete donors are like people who give up their child for adoption and have the same obligations as birth parents. However, several analogies can be made, leading to different conclusions. One might, for instance, refer to the millions of children conceived by 'natural' donation, i.e. after adultery or unfaithfulness of the mother. Moreover, if we accept, for the sake of argument, that there is an injustice against the child, the solution would not be to commit an equally manifest injustice against the donor. The donor, in good faith and backed by society, performed an act to help people to have a child and now may suffer serious consequences for it. This message about the protection through the rules of the moment can be illustrated by the statement of the Human Fertilization and Embryology Authority (HFEA) regarding the rights and duties of the donor: 'If you donate through an HFEA licensed clinic, you will not be legally responsible for any child born as a result of your donation.' (http://www.hfea.gov.uk/egg and sperm donors.html). This statement is clearly inspired by the growing tendency to look for donors outside the official circuit. The HFEA is warning the potential 'grey' donors about the dangers of leaving the regulated practice. Indirectly, the HFEA gives the message that they are safe and that their rights and duties are fixed within the law. Retrospective amendments of legislation, even when outside the UK, unsettle all that.

The moral objective must have a realistic prospect of achievement

The moral objective of the compulsory retrospective donor identifiability is to enable every donor child to obtain the name of his or her donor. However, this goal is clearly not achievable. The most important barrier for this goal is the secrecy by the parents: children who do not know that they are donor conceived cannot ask for the name of their donor (Janssens *et al*., 2011). It could also be argued that the objective is that every child who asks for the name of the donor should receive the name. This would very severely limit the number of children who would benefit, since most of the children conceived at the time will not be aware of their donor conception. Moreover, this goal is problematic because it accepts discrimination and one goal emphasized in the report of the LRC is non discrimination among children born at different time periods. The LRC does not argue that all children should be contacted to tell them about their donor conception, regardless of what the parents think about this. By not doing so, it allows discrimination, not between those before the new law on donor identifiability and those conceived afterwards, but between those children who were told and those who were not. To their credit, the LRC does try to force the parents to tell by giving donors the right to request identifying information about their donor offspring. This is interesting in itself, since this means that the donor children might be informed about their conception in the worst possible circumstances: when they are over 18 years old and by a state agency.

Retrospectively lifting donor anonymity must be necessary

Several alternatives have been presented as morally preferable. The Fertility Society of Australia, for instance, has recommended in reaction to the report that 'donors be contacted in an extremely sensitive, confidential and respectful manner and asked their wishes in relation to this'. This solution would respect the donor's autonomy. Moreover, if he consents to the release of identifying information, he will be better prepared, will be more likely to accept contact if requested (thus preventing harm to the donor offspring) and will be able to inform his partner and/or children in a way he/she considers appropriate. Obviously, this means that one should accept refusal but especially in those cases the revelation of his donation may cause irreparable damage to his family. A second solution would be to provide non identifying information considered useful by the child. However, the absolutism about the right to know one's genetic origin seems to block the consideration of this solution. If non identifying information would satisfy the curiosity that the donor children have about their donor, there would be no need to breach the donor's privacy. Empirical research should establish which information would be most useful for the children.

The retrospective law must be the least infringement possible of the donor's right to privacy and confidentiality

The LRC (2011) seems to believe that the negative effects to the donor and his family can be minimized by giving the donors the option of lodging a contact veto. This balance, euphemistically speaking, is skewed. This concession to the donor is so small that it cannot qualify as a compromise. Moreover, it should not be made easy for the donor to obtain a contact veto since, in the mind of the LRC, it has 'the effect of constraining people's ability to freely associate with certain other people' (p. 80). This formulation reveals the assumption that the donors should have long term relationships with their donor offspring. Identifiability means much more than just revealing the name of the donor. The LRC believes that donors should build friendships and other relationships with the offspring and they even seem to regret the fact that the state cannot compel people to do so (p. 63). But they would make it difficult for the donor to refuse such contact. Therefore, the contact veto has to be renewed every 5 years and the donor should lodge a separate contact veto for every donor child who requests information (which may be up to 30 or more). As a final concession to the donor, they grant that if the child plans to make unwanted contact, he can always apply for a personal safety intervention order against the child (p. 81). Imagine being a donor: would you feel reassured?

The government must make sure that the negative effects are minimized

The LRC seems to believe that counselling will do much good. How would counselling prevent that the partner of the donor feels betrayed by his/her partner's donation? Moreover, the trust they put in counselling seems to be selective since if it would indeed work that well, why not solve the children's problems through counselling? The most evident way to minimize the negative effects is by inserting a step which requires the donor's consent. If, as they point out, many donors have either changed their minds, have always had no desire to be anonymous or have come to realize that donor children need this information, why not trust them and give them the possibility to consent? If all these arguments were true, then donors would already have come forward and registered with the voluntary registers that were installed years ago.

A second important point regards the feelings of the social parents. They too may feel betrayed when they were told at the time of treatment that their children could not make contact with their donor. They might have made a different decision about telling or not telling about the donor conception if they had known about the new situation. Moreover, for single women and lesbian couples, the legal status of the donor may be unclear and a demanding donor may threaten the family unit (Cameron *et al*., 2010).

The government must act impartially

Impartiality demands that the interests of every person should be considered in the same way. The balancing of the LRC is window dressing, since the result is known in advance. Throughout the LRC report, it is emphasized that the interests and rights of the donor children are paramount and should override the interests and rights of all other people involved. This position has no theoretical foundation. On the contrary, it violates some basic ethical rules like equality and impartiality. The 'interests of the child are paramount' is moral demagogy appealing to the general intuitive weakness of people for children. It is clear that the rights and interests of vulnerable groups should be protected, but that does not mean that their rights should take automatic precedence.

Trust

Apart from the violation of the original contract, the main effect of retrospective legislation is the loss of trust. Uncertainty and distrust are lethal for a practice that may have far reaching implications for a person's private life. Once one rule is changed retrospectively, what should stop the legislator from coming back on other points? In a few years time, the legislator may decide that it is impermissible to transfer parental rights and duties (Weinberg, 2008). That would mean that the donor might also be forced to take up parental obligations for the donor children. If it is judged to be in the best interests of the child, the donor might be obliged to provide child support for the child and eventually to adopt the child. Some already argue that a child has a right to be raised by his or her genetic parents (Somerville, 2010). The same arguments as those used now to justify retrospective legislation regarding donor anonymity could be used to impose parental rights and duties on the donor. Given the extended time period during which retrospectivity may have an impact (the whole life span of the donor) and given the increasing tendency to attribute an extremely high value to genetic links, a donor should be willing to accept the worst case scenario. Unless a donor is willing to become the parent of the child, he or she should not donate.

Some people may believe that this is a far fetched argument. However, I would advise reading the report of the LRC. I will give just one example of how they look at gamete donation. At a certain point, they present a discussion on the donor's access to information and state the following: 'For example, the Committee hears from Mr. Ian Smith, a pre 1988 donor, who is the biological father of nine children, seven of whom were donor conceived'. It is extremely rare to find a similar description of a donor's family in other documents. On reading the report and many of the documents produced by the defenders of the child's right to know, the idea that gamete donors may one day become legally responsible is not far fetched. It may even be closer than one thinks.

This report of the LRC is a collection of anecdotal evidence from self selected donor conceived people who present their wishes and whose wishes are directly transformed into needs to be fulfilled. It shows where attaching absolute value to genetic relationships in gamete donation leads us. Numerous counselling sessions are suggested for the donors, the donor siblings, the non donor conceived children of the donor, the partners and family of the donors, the recipients, the family of the recipients, the donor conceived children, and all that, over a long time period. Intricate stepwise procedures are developed to provide information and to support people in every step. It makes one wonder where the counsellors will come from to do all this work and who is going to pay for this organization. It also demonstrates the dynamics of this movement. The members of parliament in Victoria, Australia, are no longer talking about identifiability: they talk about long term contact, large family networks, implicit and explicit obligations to form relationships etc. Finally, the report expresses a totally different culture. For decades now, the Australian and New Zealand culture has emphasized the importance of genetic relationships for psychological well being (identity) and social networks. In doing this, they culturally induced and reinforced the wish to know one's genetic origin and thus indirectly caused the problems that are seen now. There is little doubt that, in a society that tells a person that she cannot know who she is if she does not know her genetic parents, she has a high(er) risk of developing psycho social problems if she cannot find her genetic parents. This opens a familiar debate: should we do something about the desire (i.e. make sure that people do not need to know their genetic origin to form an identity) or should we do something to increase the chance of fulfilling the desire? Given the context of past gamete donation, it seems far more logical to do something about the need for genetic information.

Hidden agenda

A strategy of some people who oppose a certain practice is to shift focus when their original arguments do not convince the others. They then focus on a different aspect of the practice that carries greater consensus. Some opponents of embryo research moved from the status of the embryo, not very successful since highly contentious, to the argument of exploitation of women in oocyte donation (Mertes and Pennings, 2010). For certain types of embryo research, such as somatic cell nuclear transfer, one has to create embryos. To create embryos, one needs oocytes. By blocking the availability of oocytes for research, they indirectly prevent therapeutic cloning. A similar strategy seems to underlie the present discussion on donor anonymity. Some people are opposed to gamete donation because it contradicts their normative conception of the family. This argument is not very successful, since it conflicts with the increasing acceptance of pluralism in family forms. Instead of pursuing the old line, they shift strategy by emphasizing the importance of genetics for the identity of the child. Children's rights can always count on much sympathy. Even if this does not lead to a prohibition on gamete donation, it will surely make things more difficult. An additional effect is that it renders family building hard especially for same sex couples, another violation of these opponents' beliefs of what families should look like. Like the feminist argument against oocyte donation is meant to block embryo research, the child's right to know his or her genetic origin argument serves to discredit gamete donation. For this movement, the goal is reached when the child is raised by his or her genetic parents and when social parents become foster parents. Moreover, a retrospective change of law is one of the most damaging steps imaginable for the practice of gamete donation. Why would any donor from now on trust the clinic or the government? Destroying this trust will make it much harder to recruit donors.

Conclusion

Retrospectivity in the law needs a strong justification. This justification is lacking as far as legislation on donor anonymity is concerned. Moreover, retrospectivity in matters of gamete donation jeopardizes the whole practice. By granting a child an absolute right to know his or her genetic origins, thereby ignoring the rights and interests of the other parties, very little benefit will be obtained and a lot of damage will be caused.

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