# BENEATH THE RHETORIC: THE ROLE OF RIGHTS IN THE PRACTICE OF NON-ANONYMOUS GAMETE DONATION

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### ABSTRACT

The use of rights based arguments to justify claims that donor offspring should have access to information identifying their gamete donor has become increasingly widespread. In this paper, I do not intend to revisit the debate about the validity of such rights. Rather, the purpose is to examine the way that such alleged rights have been implemented by those legislatures that have allowed access to identifying information. I will argue that serious inconsistencies exist between the claim that donor offspring have a right to know the identity of their gamete donor and the way such a right is currently met in practice. I hope to show that in systems where non-anonymous donation is practised, an understanding of the proclaimed right of donor offspring to know their genetic identity is one composed of two different rights – the right to know the circumstances of their conception and the right to information identifying the gamete donor – can provide important insights into this important area of public policy.

The use of rights based arguments to justify claims that donor offspring should have access to information identifying their gamete donor has become increasingly widespread. In this paper, I do not intend to revisit the debate about the validity of such rights. Rather, the purpose is to examine the way that such alleged rights have been implemented by those legislatures that have allowed access to identifying information. I will argue that serious inconsistencies exist between the claim that donor offspring have a right to know the identity of their gamete donor and the way such a right is currently met in practice.

### INTERNATIONAL TRENDS

Internationally, the vast majority of countries continue to endorse anonymous gamete donation. However, in recent years there has been a discernible trend towards allowing children access to identifying information about their gamete donor. Sweden, Austria, Switzerland, Victoria Australia and Holland have all recently changed their laws to make gamete donation non-anonymous. New Zealand, Western Australia and Southern Australia are all in the process of reviewing the situation with a view to introducing non-anonymous donation.

Central to this move towards non-anonymous donation in several of these countries has been a focus on what is claimed to be the right of the child to have information about its genetic origins. In the debate about donor anonymity this has been expressed as the child's right to know the identity of its gamete donor. As Harvey has claimed, 'Increased knowledge and a gradual shift in attitudes has enabled us to acknowledge that in our contemporary culture young people have strong moral claims to know their genetic identities. It is now time for these moral claims to be converted into legal right.'<sup>3</sup>

The use of rights based arguments has been employed by various legislatures to support policies of non-anonymous gamete donation. Austria's Medically Assisted Procreation Act 1992 interpreted Article Seven of the United Nations Convention on the Rights of the Child, that includes the right to know one's parents and Article Eight of the European Convention on Human Rights, the right to respect for family life, to mean that sperm donation should not be anonymous as this would contravene such rights. In 1992 Switzerland incorporated a new article into its constitution, Article 24 novies, which recognises the child's right to know its biological lineage and entitles children to receive identifying information about their

<sup>2</sup> G. Pennings. The double track policy for donor anonymity. *Human Reproduction* 1997; 12: 2839–44.

<sup>&</sup>lt;sup>1</sup> Council of Europe. 1998. Medically assisted procreation and the protection of the human embryo comparative study on the situation in 39 States. Strasbourg. Council of Europe.

<sup>&</sup>lt;sup>13</sup> Parliament of Western Australia. 1999. Select Committee on the Human Reproductive Technology Act Report. Western Australia. Parliament of Western Australia: 194.

<sup>&</sup>lt;sup>4</sup> E. Blyth. 1998. Access to genetic origins information in donor-assisted conception – international perspectives. In *Truth and the Child 10 Years on: Information exchange in donor assisted conception*. E. Blyth, M. Crankshaw, and J. Spiers, eds. Birmingham. BASW: 69–77.

donors.<sup>5</sup> Two Australian states have recently reviewed their legislation on reproductive technologies and have recommended that donor anonymity should be abolished. Western Australia's Select Committee used the child's right to know its biological origins as one of the main reasons for recommending that donor offspring should have access to identifying information about their gamete donors, stating that, 'the right to know one's biological origins is a basic human right. And such a right must be enshrined and protected by state law.'6 South Australia has published a discussion paper that recommends that donor offspring have access to identifying information on the grounds that, 'legislative and regulatory conditions which presently ensure that a child conceived through the use of donor gametes is denied access to identifying information on the donor would seem to contravene Article 8 of the Convention [of the Rights of the Child] and need to be corrected.'7

Further, in the UK, under the recently enacted Human Rights Act 1998, a brother and sister conceived by donor sperm are bringing a test case to demand the right to know details of their biological father. They claim that a law banning disclosure of information about sperm donors contravenes Article 8 of the European Convention – the right to respect for privacy and family life.<sup>8</sup>

The source of such rights in current conventions is clearly contentious – most significantly because the conventions on child and human rights were not written with gamete donation in mind. The Council of Europe stated, 'it is not possible – at the present moment - to draw decisive arguments from the Convention for the Protection of Human Rights and Fundamental Freedoms either in favour or against the anonymity of donors.'9 The right to know one's parents clearly depends on the definition of 'parent'. In most countries the parents are defined as those who undergo the infertility treatment and are the ones

<sup>6</sup> Parliament of Western Australia, op. cit.

<sup>8</sup> C. Dyer. Offspring from artificial insemination demand father's details. British Medical Journal 2000; 312: 654.

<sup>&</sup>lt;sup>5</sup> M. Germond and A. Senn. A law affecting medically assisted procreation is on the way in Switzerland. Journal of Assisted Reproduction and Genetics 1999; 7: 341–343. And, Council of Europe, op. cit.

<sup>&</sup>lt;sup>7</sup> South Australian Council on Reproductive Technology. 2000. Conception by donor: access to identifying information in the use of donated sperm, eggs and embryos in reproductive technology in South Australia. Discussion paper of the South Australian Council on Reproductive Technology, April: 6.

<sup>9</sup> Council of Europe. 1989. Human Artificial Reproduction. Council of Europe Press: 27.

named on the birth certificate. Similarly, Article 8 of The United Nation's Convention on the Rights of the Child defines identity as, 'nationality, name, family relations as recognised by law.'<sup>10</sup> Again, this could simply grant the child a right to information on the couple who underwent the treatment rather than the gamete donor. However, despite such possible difficulties, what is clear is that rights based arguments have been a key motivating force and justification for recent international changes in policies on donor anonymity. It is the way that such rights have been implemented in public policy rather than the validity of such claims with which this paper is concerned.

## THE USE OF RIGHTS

In considering the role that rights play in the practice of non-anonymous donation it has been common to refer to one single, all-encompassing right: the right of the child to know the identity of its gamete donor. However, rather than see this as a single right I think that such a right is in fact made up of two, quite different, rights – it has two component parts. First, there is the right to know of the circumstances of one's conception. Second, there is the right to information identifying the gamete donor. The second right is clearly contingent on the first. Without knowledge of the nature of one's conception one cannot proceed to secure identifying information. I hope to show that analysing the role of rights in this way can serve to exemplify the contradictions that currently exist in the way that policies of non-anonymous gamete donation have been organised.

In the countries that have legislated for the practice of non-anonymous gamete donation the identity of the donor is held by a designated body that permits donor offspring access to the information. For example, in Victoria Australia the Infertility Treatment Authority has been established and this body holds information about the identity of donors and recipients of donated gametes. Donor offspring, at the age of 18, can contact the Authority and be given identifying information about their donor. In Sweden identifying information on the sperm donor is entered into a special registry and, when the child is sufficiently mature, it can have access to this information. <sup>12</sup>

 $<sup>^{10}</sup>$  United Nations. 1989. Convention on the Rights of the Child. Geneva. United Nations.

<sup>&</sup>lt;sup>11</sup> Pennings (op. cit.) recognises this point, see note 28.

J. Gunning. Oocyte Donation: the legislative framework in Western Europe. *Human Reproduction* 1998; 13, Supplement 2: 98–102.

However, in order for donor offspring to exercise their right to this information they have first to know that they were conceived from a donated gamete. Without being told, it is unlikely that such children would find out the circumstances of their conception. Most children would not think to question whether or not they were genetically related to their parents. Gamete donation is still also a sufficiently rare occurrence for children who suspect that they are not genetically related to one or more of their parents to not necessarily consider the possibility that they were conceived from a donated gamete. Despite this, none of the countries, which have adopted a policy of non-anonymous donation, have formalised a system for ensuring that children know how they were conceived; the decision to inform the child of the nature of its conception is left to the parents.<sup>13</sup>

Having distinguished between these two different rights, an extremely useful concept in helping us understand how they function in practice is to apply the distinction Feinberg draws between legal and moral rights. Feinberg defines a legal right as a claim that is recognised by some system of legal rules or regulations, whereas a moral right is a right that exists independently of any legal rules. <sup>14</sup> In relation to questions of rights and non-anonymous donation we can see that the right to have identifying information has been enshrined as a legal right whereas the right to know about the nature of one's conception only exists as a moral right. These two rights are both derived from a moral commitment but it is the way that they are enforced in practice that is the important difference between them.

If the children know the nature of their conception they are able to go to the relevant authority and are legally entitled to identifying information regarding their donors. In this sense, the child has a legal right to such information. But, as we have seen, the child has no legal right to be told about the nature of its conception. Neither the child's parents nor any state body is obliged by law to inform the child about the circumstances of conception. However, rights based arguments have not usually distinguished between two such distinct rights but have seen children as having a single, all-encompassing right: the right to know the identity of their gamete donors. This infers, if we divide the right into what I have suggested are its two component parts, that the child has both a right to information and a right to know about the circumstances of its conception. As the child has no

<sup>13</sup> Council of Europe, op. cit.

<sup>&</sup>lt;sup>14</sup> J. Feinberg. 1973. Social Philosophy. Engelwood Cliffs, NJ. Prentice Hall.

legal right to be told the truth about its conception I would argue that we must infer that, in such situations, he or she has a moral right to be told.

The existence of such a moral right clearly signifies the consequent imposition of a moral duty on others. <sup>15</sup> Under current systems this moral duty falls upon the parents. In Sweden, for example, where children are allowed access to identifying information, parents are told that they 'ought' to tell their children that they were conceived from donor sperm. This is a moral, rather than a legal 'ought' as no legal means exists to see that such telling is enforced. In practice, this means that a child's legal right to identifying information is contingent upon its parent's fulfilment of a moral, rather than a legal, duty. This clearly causes a potential conflict with the alleged right of the child to know about its genetic origins. With non-anonymous donation although claims are made in respect of the rights of the child, in leaving the duty of telling to the parents there is an implicit recognition that it is the parent's right to privacy, rather than the child's right to know, which is ultimately seen as having the greatest importance. <sup>16</sup>

This clearly has quite important implications for the extent to which a child's legal right to identifying information is actually realised in practice. The evidence suggests that parents are unwilling to tell their children that they were conceived with donated gametes. A recent study found that 89% of Swedish parents had not informed their donor offspring of the circumstances of their conception. A Dutch study found that 74% of DI parents planned not to tell the child how they were conceived. Soderstrom-Anttila *et al.*, reported that only 38% of

<sup>15</sup> This is not to say that rights are equivalent to duties, rather that rights are a sufficient reason for holding some other person(s) to be under a duty, see J. Raz, On the nature of rights. *Mind* 1984; xciii: 194–214.

<sup>16</sup> One of the main reasons given to justify not telling the child is that parents should have a right to privacy and if they wish to keep such information confidential that is their prerogative, I. Walker and P. Broderick. The psychology of assisted reproduction – or psychology assisting its reproduction? *Aust.Psychol* 1999; 34: 38–44. It has also been argued that to allow children knowledge is, 'an unthinkable intrusion into the privacy of family life.' J. Haderka. Artificial Reproduction in Czechoslovak Law, *International Journal of Law and the Family* 1987; 72: 85.

<sup>17</sup> C. Gottlieb, O. Lalos, and F. Lindblad. Disclosure of donor insemination to the child: the impact of Swedish legislation on couples' attitudes. *Human Reproduction* 2000; 9: 2052–2056.

<sup>18</sup> A. Brewaeys, S. Golombok, and N. Naaktgeboren, et al. Donor insemination: Dutch parents' opinions about confidentiality and donor anonymity and the emotional adjustment of their children. *Human Reproduction* 1997; 7: 1591–7.

couples who had received infertility treatment would tell their children how they had been conceived. 19

Further, the very nature of gamete donation makes it easy to hide the method of their child's conception. As the child is often the genetic product of one of the parents and there has been a pregnancy and a birth, it is possible to pass the child off as the couple's biological child. As Erica Haimes says, AID is accepted, 'because its deviant characteristics can largely be disguised. By distancing the donor, the appearance of the normal family is preserved.' The fact that telling the child about the nature of his or her conception is left solely to the parents can therefore act to reinforce such tendencies towards secrecy.

It is useful to compare this situation with the situation relating to adoption in states where adopted children are seen as having a right to know their genetic parents. The claim, that children have a right to know the identity of their genetic parents, is the same in both cases; however, the rights that adoptive children actually have in practice are quite different. This difference is based, I would argue, on the fact that for adoptive children, unlike donor offspring, the two component parts of their right to know the identity of their genetic parents – the right to know about the circumstances of their conception, and the right to information identifying their genetic parents – are both given legal status. The right to be told is not dependent upon the parents fulfilling a moral duty.

For example, in England, when children are adopted an Adoption Certificate – a legal document that records the child's adoptive status – is issued which, for all legal purposes, takes the place of a birth certificate. Further, when the child is 18 he or she is legally entitled to obtain a copy of the original birth certificate which will show the identity of the birth mother, and if the father was registered, the father. Although good adoption practice strongly emphasises telling the child about its adoptive status as early as possible, the child's access to both the adoption certificate and original birth certificate legally ensures – independently of the possible wishes of others – both its right to be told

<sup>21</sup> The Children's Act 1975.

<sup>&</sup>lt;sup>19</sup> V. Soderstrom-Antila, N. Sajanieme, and A. Tiitinen, et al. Health and development of children born after oocyte donation compared with that of those born after in-vitro fertilisation, and parents' attitudes regarding secrecy. *Humun Reproduction* 1998; 7: 2009–2015.

<sup>&</sup>lt;sup>20</sup> E. Haimes. Secrecy: what can artificial reproduction learn from adoption? *International Journal of Law and the Family* 1988; 2: 46–61.

about its adoptive status and its right to information identifying its birth parents.

This comparison between adoption and non-anonymous donation is important because it highlights the fact that although both sets of children supposedly have the same right to know their genetic parents, in practice this is not the case. In states where adopted children have the legal right both to be told about their status and the identity of their parents all adopted children are able to exercise the same rights. This is not the case with donor offspring born under systems of non-anonymous donation. As the right to be told the nature of their conception exists only as a moral, rather than a legal, right, only those donor offspring granted their moral right will be able to exercise their legal right to access identifying information. Donor offspring who are denied their moral right are effectively prevented from exercising any legal right to find the identity of their genetic parents. There is therefore clearly an important contradiction at the very heart of such a policy: the unequal application of a supposedly universal right.

I would argue that this difference in policy highlights some implicit assumptions that are held about the status of donor offspring in relation to their 'social' parents. Donor offspring are seen, in some sense, to be more akin to a naturally conceived child than an adopted child and correspondingly the couples' right to privacy is given more weight than it is in the case of adoption.<sup>22</sup> As Susan Golombok says, 'genetic unrelatedness has a different meaning for children conceived by gamete donation than for children in adoptive families or in stepfamilies.'<sup>23</sup> However, the purpose of this discussion is not to claim that such differential treatment of donor offspring is unwarranted, but to draw attention to such differences.

<sup>&</sup>lt;sup>22</sup> There has been much debate over how justified it is to make a comparison between gamete donation and adoption. Some argue that the two practices are very different and any conclusions about adoption cannot be applied to gamete donation, see for example F. Shenfield. Filiation in assisted reproduction: potential conflicts and legal implications. *Human Reproduction* 1994; 9: 1348–1354. Others would argue that such a comparison can be very useful, see Blyth *op. cit.* For a consideration of these debates see, Haimes *op. cit,* K. O'Donovan. 1989. What shall we tell the children? Reflections on children's perspectives and the reproductive revolution. In *Birthrights*. D. Morgan and R. Lee, eds. London. Routledge: 96–114, and M. Freeman. The new birth right? *The International Journal of Children's Rights* 1996; 4: 273–297.

### POLICY IMPLICATIONS

Given this understanding we now need to ask what implications this might have for the development of future policy in this area.

The most obvious solution, if it is felt donor offspring have a right to know their genetic origins, is to institute some formal mechanism which ensures that all donor offspring know the true nature of their conception. So far, the emphasis in this debate has almost solely been on how to ensure that the parents tell their child about the nature of its conception. This notion of enforcing telling is, understandably, seen as unduly intrusive into the family's private life and has understandably been rejected in all cases. As the South Australian Working Party said, '[we] have agreed that it is untenable to force parents to tell their children and that following this up would be very intrusive.'24 However, perhaps a better model to use is the one that operates with adoption in countries, such as England, where adopted children have the right to know the identity of their birth parents. Here, as we have seen, the child's right to information about both the circumstances of conception and the identity of its birth parents is ultimately guaranteed by the legal right to both the adoption certificate and original birth certificate. Following this example, if it is believed that donor offspring also have the same right to know the identity of their genetic parents, then they could be issued with both a birth certificate, that recorded the details of their 'social parents' (as they receive now) and, at the same time, a donor certificate that would record the details of their gamete donor. While good practice would obviously encourage parents to be honest with their children the availability of the information in this way would serve to ensure legally the child's rights.

Interestingly in the UK, the Warnock Committee, despite not thinking that donor offspring should have access to information identifying their donors did think that they had a right to be told about the circumstances of their conception. Warnock thought that an essential part of good practice should be, 'openness with the child about his genetic origins.' The Committee thought that this moral right to be told should also exist as a legally enforceable right and recommended that there should be a mechanism to ensure that the child was told. Their proposal was

 $<sup>^{23}</sup>$  S. Golombok. New families, old values: considering the welfare of the child. *Human Reproduction* 1998; 9: 2342–2347. Page 2344.

South Australian Council on Reproductive Technology, op. cit. p. 9.
 M. Warnock. 1985. A Question of Life: The Warnock Report on human fertilisation & embryology. Oxford. Basil Blackwell: 37.

that, in the case of artificial insemination, the birth certificate should have 'by donation' entered by the father's name and in the case of egg donation, if the parents wish, 'by donation' should be entered by the mother's name. This was seen as an essential measure to ensure that children were able to discover – independently of their parents if necessary – the circumstances of their conception. This recommendation was defeated in the House of Commons and not adopted in the 1990 Human Fertilisation and Embryology Act, perhaps as it was thought that it would cause the child embarrassment. A separate donor certificate, as has been suggested above, as part of a system where identifying information is provided, might, in future, overcome such an objection.

A different solution to resolve the contradiction in current nonanonymous donation policy has been suggested by Guido Pennings. Pennings argues that as we do not enforce telling under present systems then, 'the parents are given the right ultimately to decide whether or not to tell the child of the mode of conception.'28 As it is the parents who make the choice over what the child should be told, this means, as we have seen, that some parents will decide to tell and others will not. Donor offspring will have different rights depending on their parents' decisions whether to tell them of the circumstances of their conception. In light of this, Pennings argues that we might as well be quite open about this and allow couples to make their own choices about what kind of gamete donation programme they wish to participate in.<sup>29</sup> He suggests a policy that allows participants to choose between an anonymous or a non-anonymous donation programme. Under such a system, donors are able to choose whether they want to be identified and couples are able to choose between an anonymous and a non-anonymous donor. This approach already operates in Iceland, for example, where donors can choose to give anonymously or non-anonymously and couples can choose what type of donor to use.<sup>30</sup>

In terms of rights, the focus is quite different to that in other non-anonymous programmes. Rather than making reference to

<sup>26</sup> Ibid., pp. 26 and 38.

<sup>28</sup> Pennings, *op. cit.*, p. 2840.

<sup>30</sup> Council of Europe, op. cit.

<sup>&</sup>lt;sup>27</sup> D. Morgan and R. Lee. 1991. *Blackstone's Guide to the Human Fertilisation and Embryology Act 1990.* London. Blackstone Press Limited.

Pennings also justifies this argument on the grounds that there is little consensus on the issue and it is not clear which model of gamete donation, anonymous or non-anonymous, is preferable.

the child's right to know its genetic origins the emphasis is on the parent's right to choose. 'The only moral value involved is a person's right to organise his life in the way he sees fit.'<sup>31</sup> Although no claims are made about the rights of the child to identifying information, in practice it is possible that the results are likely to be similar to those systems where non-anonymous donation is uniform. Those parents who wish to tell their children will choose non-anonymous donors and those who do not want to will not.

While possibly accepting this point, proponents of current non-anonymous practices would probably suggest that one of the main aims of their policy is to help create a culture of openness and acceptance about the practice of gamete donation in which more parents feel able to tell their children how they were conceived. 32 As Blyth argues, 'through legislation, the creation of a culture that espouses 'freedom of information' and the commitment of social institutions and agents to probity and honesty, the state can provide the context in which openness and disclosure of the truth in donor assisted conception will be the norm.'33 Pennings' policy, in seeing both non-anonymous and anonymous donation as equally acceptable, would be unlikely to foster the same degree of possible change. It does, however, have the advantage that in practice it is consistent with the principles on which it is based. A fact which, as I hope to have demonstrated, is not the case for current practices of uniform non-anonymous donation which proclaim the right of donor offspring to know their genetic identities.

### **CONCLUSION**

I hope to have shown that in systems where non-anonymous donation is practised an understanding of the proclaimed right of donor offspring to know their genetic identity as one composed of two different rights – the right to know the circumstances of their conception and the right to information identifying the gamete donor – can provide important insights into this important area of public policy. Up until now, policy in

<sup>31</sup> Pennings, op. cit., p. 2839.

<sup>32</sup> K. Daniels and K. Taylor. Secrecy and openness in donor insemination. *Politics and the Life Sciences* 1993; 2: 155–170.

<sup>&</sup>lt;sup>33</sup> E. Blyth. Donor assisted conception and donor offspring rights to genetic origins information. *The International Journal of Children's Rights* 1998; 6: 237–253, p. 251.

this area has focused predominately on the identifying information that is provided about the gamete donor rather than considering mechanisms to ensure that children know the circumstances of their conception.

Whether in future we wish to develop some mechanism for ensuring that donor offspring are guaranteed the right to know both the nature of their conception and the identity of their donor; whether we think that a system where parental choice is given precedence is preferable; or if we think that donor offspring should have neither right, at least understanding the right to know one's genetic origins as one which incorporates the granting of two distinct rights can enable us to avoid inconsistencies and formulate policy in a more coherent fashion.

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