

# Mum's the Word: Donor Anonymity in Assisted Reproduction

*Josephine Johnston*

Traditionally, assisted human reproduction by gamete donor<sup>1</sup> has been a secretive, even anonymous, procedure. The very fact that an individual was conceived by assisted reproductive techniques was hidden from that individual, and strict donor anonymity ensured that both donor offspring<sup>2</sup> and their birth parents<sup>3</sup> would never know the identity of the donor(s). In fact, some fertility clinics would mix the sperm of more than one donor before inseminating a woman, so that no one would know which of the donors had a genetic link to the resultant child.<sup>4</sup> As a result of this secrecy, donor offspring have often assumed, or been led to believe, that they were the genetic child of both their birth parents. And even if they had been told of their donor origins, few have ever been able to gain access to any information, particularly identifying information, about their gamete donors. This history has led to an apparent presumption in favour of secrecy in assisted reproduction by donor ("ARD"). However, over the past 20 years this presumption has been challenged by a call for greater openness in ARD, with particular emphasis being placed on donor offspring having information, including identifying information, about their gamete donors.

Canada has responded to this call in cl. 18 of Bill C-13.<sup>5</sup> Unfortunately, this response is inadequate. Although cl. 18 guarantees donor offspring access to health information about their donors, it stops short of complete openness by providing that identity information can only be passed on to donor offspring with the written consent of the donor. Allowing donors to withhold their identity from their donor offspring is particularly surprising given the Standing Committee on Health's recommendation that donors be required to consent to subsequent release of identifying information before they make a gamete donation.<sup>6</sup>

A call for complete openness in ARD is not to ignore the important arguments that are often given in favour of secrecy. Rather, it is to say that because a choice must be made between secrecy and anonymity on the one hand and openness and honesty on the other, the presumption should be in favour of the latter policies. Similarly, where a choice

must be made between the interests of birth parents and donors and the interests of donor offspring, the presumption should be in favour of donor offspring. Arguments for secrecy in ARD state that anonymity and secrecy are necessary to protect the birth parents, the family unit, the donor, and the donor offspring. For instance, it is said that society disapproves of ARD and that secrecy is necessary to protect both the birth parents and the donor offspring from perceived societal disapproval and stigma.<sup>7</sup> Another commonly cited justification is that secrecy protects the feelings of the infertile birth parent (usually the man) because, as one commentator noted, "[o]ur society has unfortunately equated virility with fertility in men."<sup>8</sup> However, as fertility services are accessed by more and more people, it seems likely that the public will (if it has not already) become much more sympathetic towards the use of ARD and the cause of infertility in general, and so fears of public disapproval should be lessened.

It is also often argued that openness in ARD would create a shortage or complete lack of donors (particularly sperm donors).<sup>9</sup> It is supposed that donors will be discouraged from donating if they know that their donor offspring could one day contact them. However, unwillingness among donors to being subsequently identified to, and perhaps contacted by, donor offspring may not be as prevalent as first assumed. A New Zealand study found that 68% of sperm donors surveyed were agreeable to their identity being made available to their donor child<sup>10</sup> and Australian studies have reported similar findings.<sup>11</sup> In Sweden, the profile of sperm donors changed from young students to mature family men when a law was passed to give donor offspring access to identifying information about their gamete donors, and despite an initial drop, donor numbers did not suffer an overall decline.<sup>12</sup> If the number of donor offspring created using each donor's gametes is limited, as it is in the United Kingdom under the Human Fertilisation and Embryology Regulations,<sup>13</sup> and if donors are not considered legal parents, then the prospect of identification and contact may not be as daunting as it once was. In any case, it is questionable whether the practical concern that donor identification will

create a shortage in donors is sufficient moral reason for denying donor offspring information about their genetic heritage.

Finally, it is often said that secrecy protects the interests of donor offspring themselves. An English study found that 70% of birth mothers of donor insemination children justified the decision not to tell their children of their mode of conception on the ground that secrecy would protect the child.<sup>14</sup> In addition to saying that such secrecy would shield the donor offspring from social stigma and preserve the bond between the child and the infertile birth (in this case) father, the women surveyed felt that it would be devastating for the child to find out that his or her birth father was not his or her genetic father. The same survey recorded that birth parents were concerned that the child would be distressed by the absence of any information about the donor parent, and thought it therefore better not to tell the child anything at all. Similarly, a New Zealand study found that birth parents who had not discussed the fact of ARD conception with their donor offspring were prevented from doing so because they did not know the best way to discuss the issue with their children, although this study did note that the parents believed that disclosure *per se* was not harmful to the child.<sup>15</sup>

Although knowing what birth parents believe would be in the best interests of their children is certainly important, these beliefs do not necessarily represent the actual best interests of donor offspring, particularly adult donor offspring. There is some evidence to suggest that donor offspring told of their donor origins from an early age are not harmed by the knowledge. Some writers believe that if children grow up knowing of their donor heritage they actually perceive the information as “no big deal.”<sup>16</sup> And according to attachment theory, children develop attachments to those who respond to them as parents, rather than to those who are merely their biological relatives,<sup>17</sup> so knowing from an early age that their birth parents are not their genetic parents need not result in donor offspring rejecting their birth parents. On the other hand, some writers report that the secret of ARD can create tension and division within families and that an eventual discovery of this deception may cause great damage to family relationships.<sup>18</sup> As years of secrecy in adoption have shown, secrets in families regarding genetic origins and genetic relatedness can have a very negative effect on children, both in childhood and later in life. So, far from protecting donor offspring, ARD secrecy may actually harm both them and their birth parents.

But even if it is misguided or speculative to think that secrecy protects donor offspring, a focus on the interests of donor offspring in ARD is a step forward in a system

developed in response to, and driven by, a desire to create children for childless couples. Infertile individuals and couples have traditionally been the ‘patients’ in the fertility context, and much of the focus in ARD and other forms of assisted reproduction has been on them, with the interests of the resultant child receiving less attention than one might expect. When decisions have required striking a balance between the interests of birth parents and donors on the one hand, and the interests of donor offspring on the other, the presumption appears to have been in favour of the former. But because of the vulnerable nature of children (a fact recognized by family law and the United Nations Convention on the Rights of the Child) it would, in fact, be proper to give primary weight to the interests and rights of donor offspring when setting laws and policies in assisted reproduction.<sup>19</sup>

A focus on the interests of donor offspring also recognizes that donor offspring are the only participant in the ARD matrix without any effective agency, ‘finding’ themselves surrounded by secrecy they had no opportunity to avoid. Although there is truth in the claim that infertile individuals or couples do not always make a truly ‘free’ choice to use ARD, on a fundamental level both users of ARD and gamete donors are voluntary participants. On the other hand, donor offspring have no control over the secrecy about either the mode of their conception or the identity of their gamete donor(s). They are, in effect, at the mercy of their birth parents, their gamete donors and the ARD system when it comes to knowing about their genetic heritage. Given donor offspring’s reliance on others for knowledge of the existence and identity of their donors, it seems appropriate to consider donor offspring’s interest in accessing this information as being of particular importance when formulating laws on this topic.

So what do ‘best interests of donor offspring’ arguments say against secrecy in ARD? A major objection to secrecy is that it is wrong to keep both the fact of ARD and the identity of gamete donor(s) secret from donor offspring because this information is personal information about the donor offspring that she or he has a right to access. This argument is premised on the idea that because genetic relatedness is of, at least some, interest and value to donor offspring, they should be told that one (or both) of their birth parents is not their genetic relative, and they should be able to identify their gamete donor(s). This claim is sometimes criticized as being an example of genetic essentialism, because it is taken to say that knowledge of one’s genetic parents is of vital importance to each individual and that social parents are not as important as genetic parents. This, however, is a misinterpretation of the claim. To say that every donor offspring should have the right to know both that they were conceived by donor and the identity of that donor(s) is to

claim that donor offspring should have the right to assess the importance of this information for themselves. It is not to impute this information with any particular level of importance in the individual case, although we know that for some individuals this information is of considerable medical and personal value.

The importance of knowing one's genetic heritage for health reasons, particularly in light of the growing focus on genetic causes of disease, is less often contested than its relevance and importance in terms of social and identity issues. But even on the latter, it seems fairly clear that genetic relatedness is of varying importance to different people. For some, finding that they are not genetically related to a birth parent, or meeting someone they are genetically related to, can be a very important part of their identity formation.<sup>20</sup> And even those donor offspring who do not appear to attach a great deal of importance to genetic relatedness, still appear to desire some information about their donors.<sup>21</sup> The problem with secrecy in ARD is that donor offspring are never given the chance to assess for themselves the importance of knowing people with whom they share a genetic, as distinct from a familial, association. The decision as to the importance of this information is made for donor offspring by their birth parents and by a system that facilitates, or even imposes, secrecy.

The second main argument against secrecy in ARD claims that secrecy is both morally wrong and practically harmful. Philosopher Sissela Bok has commented that “[w]hen the freedom of choice secrecy gives one person limits or destroys that of others, it affects not only his own claims to respect for identity, plans, action, and property, but theirs.”<sup>22</sup> Secrecy's inherent paternalism means that donor offspring are never given the choice to know about some of their genetic relatives and in this way secrecy (and the secret keepers) actively disrespects donor offspring's autonomy. But secrecy is not only normatively problematic, it may also have a negative impact when it exists between family members, both on the individual family members and on the family unit as a whole. The strain caused by secrets in families is thought to build as time goes by,<sup>23</sup> and many writers believe that children can sense the presence of a secret in their family, even if they cannot divine what the secret is.<sup>24</sup> As one commentator has reported:

Child psychiatrists and psychoanalysts' clinical experience shows that every secret hanging upon a child is in fact a lie and produces a pathogenic

effect. The child will realise that something is kept secret, but not what it is. Thus he will no longer distinguish between true and false statements and suspicion will grow and destroy the relationships the secret was meant to protect.<sup>25</sup>

In addition, trust within the family could be irreparably damaged if donor offspring do one day learn, perhaps from someone other than their birth parents, of the truth of their conception.<sup>26</sup> Given the possible negative effects on families and family members of secrecy about ARD, it certainly seems that openness should be preferred, unless such openness can be shown to cause donor offspring more damage than secrecy may do. Yet as has been canvassed above, there is no consensus in the literature that secrecy is actually necessary for the welfare of donor offspring. On the contrary, many writers have argued that secrecy can be harmful to both donor offspring and their families, and therefore they have called for a reversal of the presumption in favour of secrecy.<sup>27</sup>

Canada has responded to the call for greater openness in ARD in several clauses of *Bill C-13* dealing with information collection, use, and transfer in the course of assisted reproduction. In particular, cl. 18 deals specifically with disclosure of health related and identifying information between gamete donors, donor offspring and birth parents. Clause 18(2) would allow any of the three groups to request “health reporting information” about each other, being information about identity, personal characteristics, genetics and medical history, but states that this request will only be met with the written consent of the person whose information is requested. Clause 18(2) effectively gives each party the right to veto the transfer of their identity and health information to one other. In the case of gamete donors this right of veto is curtailed in cl. 18(3) where information about a donor is sought by the potential birth parents, the donor offspring, or their descendants. In such a case, all information about the donor will be disclosed *except* the donor's identity, unless the donor gives written consent. Effectively, cl. 18 means that while donor offspring are assured access to a certain degree of information about their gamete donor(s), they can only access the donor's identity with that donor's consent. Although the bill seeks to remove much of the secrecy that has traditionally shrouded ARD, some secrecy is unfortunately still preserved.

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While *Bill C-13* must be commended for recognizing donor offspring's interest in accessing health information about their gamete donors, the response does not go as far as it could to ensure complete transparency and access to full information for donor offspring. If the interests of donor offspring are given primary weight, as I believe they should be, then the bill should be amended to ensure that donor offspring can know both that they were conceived by ARD and the identity of their gamete donors. Access to this information should not be subject to possible veto by gamete donors. Given the apparent reluctance of some birth parents to tell their children of their donor origins,<sup>28</sup> it may be necessary that a notation be made on each donor offspring's birth certificate to the effect that the person was conceived using donor gametes.<sup>29</sup> To ensure that donor offspring have access to identifying information about their donor origins, the bill should require that all donors consent to the release of their identity to any resultant offspring, before gametes are collected. These amendments cannot rightly, or practically, be retrospective, but should apply to all future ARD donations and ARD births in Canada. The interests of donor offspring require that neither their donors, nor anyone else, hold the power of veto over complete and full information about their genetic ancestry.

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1. The term 'gamete donor' refers to the donor of either sperm or an egg used to conceive a child in an assisted reproduction procedure and it is used interchangeably with the term 'donor.' The word 'parent,' as in 'genetic parent,' or 'donor parent' is intentionally avoided because it too easily connotes the possibility of a greater social role than is usually carried out by a sperm or egg donor.
2. There are many different terms used to refer to a person who was conceived using donor gametes. I generally avoid calling this person a 'child' because in the context of creating a legal right to information about gamete donor(s), the donor offspring may well be an adult rather than a child.
3. The terms 'social parents' and 'legal parents' are arguably equally appropriate when referring to the individual(s) who gives birth to and raises a child conceived using donor gametes. 'Birth parents' is used for consistency and because it captures the individual(s) who made the decision to use donor gamete(s) to conceive a child and who then raise that child (although it is acknowledged that these functions are separable). The case where donor gametes are placed inside a surrogate mother is not specifically considered here.
4. This practice was called artificial insemination by combination, usually referring to the combination of a donor's sperm and the husband's sperm. D. Clapshaw, "Legal aspects of artificial human reproduction: can the law afford to play ostrich?" (1982) 4 *Auckland University Law Review* 254 at 254.
5. *An Act respecting assisted human reproduction*, 2d Sess., 37th Parl., 2002 (1st reading 9 October 2002) [*Bill C-13*]. *Bill C-13* was originally introduced in Canada's House of

- Commons on May 9 2002, as *Bill C-56*, but died when Parliament was prorogued in September 2002. However, it was re-introduced into Parliament pursuant to an Order made October 7, 2002, in the same form as *Bill C-56, An Act respecting assisted human reproduction*, 1st Sess., 37th Parl., 2002 (1st reading 9 May 2002).
6. The Standing Committee on Health. *Assisted Reproduction; Building Families* (Ottawa: House of Commons, 2001) at s. 8.
7. R. Landau, "The Management of Genetic Origins: secrecy and openness in donor assisted conception in Israel and elsewhere" (1988) 13 *Human Reproduction* 3268 at 3268; National Bioethics Consultative Committee, *Access to Information: an analogy between adoption and the use of gamete donation* (Canberra: National Bioethics Consultative Committee, 1988) at 15 [NBCC].
8. R. Rowland, "The Social and Psychological Consequences of Secrecy in Artificial Insemination by Donor (AID) Programmes" (1985) 21 *Social Science and Medicine* 391 at 393.
9. L. Furth, "Gamete donation and anonymity: The ethical and legal debate" (2001) 16 *Human Reproduction* 818 at 822; P. Patrizio, A. C. Mastroianni & L. Mastroianni, "Disclosures to children conceived with donor gametes should be optional" (2001) 16 *Human Reproduction* 2036 at 2037.
10. A. J. Purdie *et al.*, "Identifiable semen donors - attitudes of donors and recipient couples" (1992) 12 (Feb) *New Zealand Medical Journal* 27 at 27.
11. NBCC, *supra* note 7 at 20.
12. *Ibid.* at 25; K. Daniels & O. Lalos, "The Swedish Insemination Act and the availability of donors" (1995) 10 *Human Reproduction* 1871 at 1874.
13. Clause 6.7(d) of the UK's *Human Fertilisation and Embryology Act's* Code of Practice states that normally no more than 10 live births should be achieved with the gametes of a single donor. There is currently no provision in *Bill C-13* limiting the number of live births one donor's gametes can be used in, although this sort of limit is the kind of matter that may become the subject of regulations made pursuant to the Act: Human Fertilisation and Embryology Authority, *Code of Practice*, 5th ed. (London: HFEA, 2001) online: Human Fertilisation and Embryology Authority <<http://www.hfea.gov.uk/Downloads/CodeOfPractice/CodeOfPractice2001.pdf>> (last modified 11 April 2002, date accessed: 11 November 2002).
14. R. Cook *et al.*, "Disclosure of Donor Insemination: Parental Attitudes" (1995) 65 *American Journal of Orthopsychiatric Association* 549 at 553.
15. A. Rumball & V. Adair, "Telling the story: parents' scripts for donor offspring" (1999) 14 *Human Reproduction* 1392 at 1398.
16. *Ibid.* at 1397.
17. S. Golombok, "New Families, old values: considerations regarding the welfare of the child" (1998) 13 *Human Reproduction* 2342 at 2343.
18. A. McWhinnie, "Gamete donation and anonymity: Should offspring from donated gametes continue to be denied knowledge of their origins and antecedents?" (2001) 16 *Human Reproduction* 807 at 812; A. J. Turner & A. Coyle, "What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and

- the implications for counselling and therapy” (2000) 15 Human Reproduction 2041 at 2044.
19. United Nations General Assembly, *The Convention on the Rights of the Child*, 1989, arts. 3, 8; as one 42-year-old woman said: I long to know who my biological father is, and to meet and speak with him at least once. I search for my half-siblings in other people’s faces. I want to know the missing part of my family history, but more than anything I need to know the other half of my ethnic background”; McWhinnie, *ibid.* at 812; see also Turner and Coyle, *ibid.* at 2046-2047.
  20. In 1964 H. J. Sants described adopted children as suffering from “genealogical bewilderment” on account of having no knowledge of their genetic parents and he concluded that each person needs to have knowledge of their genealogical heritage for adequate mental health. H.J. Sants, “Genealogical bewilderment in children with substitute parents” (1964) 37 *British Journal of Medical Psychology* 133.
  21. Government Employees Health Fund “Donor dads step out of the shadows,” online: Government Employees Health Fund <<http://www.gehf.com.au/content/showpagenum.asp?Page=2781>> (date accessed: 11 November 2002).
  22. S. Bok, *Secrets: on the ethics of concealment and revelation* (New York: Pantheon Books, 1983) at 26.
  23. K. W. Ruyter, “The Example of Adoption for Medically Assisted Conception” in D. Evans, ed., *Creating the Child: The Ethics, Law and Practice of Assisted Procreation* (The Hague: Martinus Hijhoff Publishers, 1996) at 177-194.
  24. Sants, *supra* note 20 at 140; J.-M. Thévoz, “The Rights of children to information following assisted conception” in D. Evans, *ibid.* at 201; Ruyter, *ibid.* at 187.
  25. Thévoz, *ibid.* at 201.
  26. Landau, *supra* note 7 at 3269.
  27. Rowland, *supra* note 8 at 396; V. Söderström-Anttila *et al.*, “Embryo donation: outcome and attitudes among embryo donors and recipients” (2001) 16 *Human Reproduction* 1120 at 1127; McWhinnie, *supra* note 18 at 816.
  28. Cook *et al.*, *supra* note 14 at 553; Purdie *et al.*, *supra* note 10 at 28; C. Gottlieb, O. Lalos & F. Lindblad, “Disclosure of donor insemination to the child: the impact of Swedish legislation on couples’ attitudes” (2000) 15 *Human Reproduction* 2052 at 2054; Söderström-Anttila *et al.*, *ibid.* at 1126.
  29. The practical implementation of this aspect of openness in ARD may be at a provincial level and therefore be carried out differently from one province to another. Differences in the exact mode of recording that a birth is as a result of ARD need not be of any concern if the overall effect is the same across the country.