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Eric Blyth

Adoption & Fostering 1999 23: 49

DOI: 10.1177/030857599902300108

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Secrets and lies Barriers to the exchange of genetic origins information following donor assisted conception

Until the Warnock Report of 1984, the veil of secrecy surrounding donor assisted conception in the UK went more or less unchallenged. Starting with a look at the Report and subsequent legislation, **Eric Blyth** explores the main arguments for and against releasing information about their genetic origins to donor assisted offspring. Factors contributing to the debate include increasing public awareness of the importance of genetics in defining identity, the significant shift in attitudes towards openness in adoption which has taken place in England and Wales since the early 1990s and reluctance on the part of semen donors to be known to their offspring. Different attitudes in different parts of the world are also examined, as are the limitations of human rights legislation at both national and international levels.

Eric Blyth is Reader in Social Work, School of Human and Health Sciences, University of Huddersfield

Key words: donor assisted conception, genetic origins information, children's rights

Introduction

Measures to overcome involuntary childlessness have been known to humankind for millennia. In Genesis we read:

And Sarai said unto Abram, Behold now, the Lord hath restrained me from bearing: I pray thee go in unto my maid; it may be that I may obtain children by her . . . and Sarai . . . took Hagar her maid . . . and gave her to her husband Abram to be his wife. (ch 16, vv 2–3)

Further on in Genesis (ch 30, vv 3–5), there is a second reference to what would now probably be regarded as a surrogacy arrangement, involving Jacob, his wife Rachel and her maid Bilhah.

Other forms of assisted conception involving both a third party and professional intervention (ie semen, oocyte [egg], embryo donation and IVF surrogacy) have a more recent pedigree, oocyte and embryo donation and IVF

surrogacy becoming readily available only since the 1980s.

As the most commonly practised¹ and, after surrogacy, the longest established form of donor assisted conception, donor insemination (DI) has set the pattern for information exchange in donor assisted conception. In the UK at least information exchange is more extensive in oocyte and embryo donation and surrogacy than in DI. In the first recorded use of donor insemination using human semen in the United States in 1884, the procedure took place without the knowledge of either the recipient or her husband. Although it appears that the recipient was never told of her insemination (which had been performed while she had been anaesthetised), the doctor carrying out the insemination did subsequently tell her husband (Gregoire and Mayer, 1964). Novaes (1998) notes that this was not an isolated incident and that instrumental fertilisation had been 'practised discretely' in Europe earlier in the nineteenth century. Religious and moral objections concerning third party intrusion into the sanctity of the marital relationship, charges of 'interfering with nature' and the stigma accompanying male infertility in particular appear to lie behind the secrecy characterising donor insemination up to the present time. In 1960, a committee appointed by the UK government to enquire into human 'artificial insemination' dismissed semen donation as 'an activity which might be expected to attract more than the usual proportion of psychopaths' (Feversham Committee, 1960, p 59), reason enough, one would have thought, for anyone engaged in DI to keep their involvement a closely guarded secret. Furthermore, the Committee argued that 'in the interests of the child alone . . . the practice should be discouraged' (p 46), evidently concluding that to be born as a result of DI was a fate worse than not being born in the first place. Unsurprisingly, the Committee

determined that it would hardly be in the interests of any child so conceived to learn about the nature of their origins. While the Feversham Committee's views that DI should not be encouraged at all found little favour with service providers, the sentiment that, if it was used, then it was best for all concerned that it be kept secret, came to characterise orthodox practice. As recently as 1987 prospective recipients of DI in the UK were being advised that 'unless you reveal [DI conception] to your child, there is no reason for him or her ever to know that he or she was conceived by donor insemination' (Royal College of Obstetricians and Gynaecologists, 1987, p 3).

The Warnock Report: the winds of change?

In the UK this approach was challenged by the Warnock Committee, which had been established by the government to undertake a wide-ranging enquiry into human assisted conception and associated research. The Committee acknowledged that secrets could 'undermine the whole network of family relationships' and that it was 'wrong to deceive children about their origins' (DHSS, 1984, p 21), at least implicitly supporting the principle that donor offspring should be told the truth about their conception. However, the Committee was also convinced that complete *anonymity* should characterise the relationship between, on the one hand, the donor and, on the other the recipient (and her partner if any) and any offspring. This was considered necessary to provide protection to the donor from parental liability for any child (without which insufficient men might be prepared to volunteer their services) and to 'minimise the invasion of the third party into the family' (DHSS, 1984, p 25). That donor anonymity might also benefit offspring was subsequently articulated by one Committee member who wondered 'whether it was really in the child's interests to confront someone who had masturbated off as a donor' (cited in Haines, 1992, p 129).

The remaining question for the Committee, therefore, was whether what,

if any, information about the donor should be provided to recipients and/or offspring. Its concern that the availability of detailed 'donor profiles' might 'introduce the donor as a person in his own right' (although the precise implications of such a 'threat' were not elaborated) or encourage demand for the creation of children with specific characteristics, was tempered with a recommendation that, at the age of 18, donor offspring should have a legal right of access to 'basic information about the donor's ethnic origins and genetic health' (DHSS, 1984, p 24).

The recommendations of the Warnock Committee provided the basis for subsequent legislation, the Human Fertilisation and Embryology Act, 1990. Under the Act donors who have donated in accordance with the Act's consent provisions are exempt from legal and financial responsibility towards any child born following use of their gametes or embryos. However, centres licensed under the Act to provide treatment are required to maintain records of donors, recipients of donated gametes and embryos and children born following such treatment. This information must be forwarded to the statutory regulatory body, the Human Fertilisation and Embryology Authority (HFEA) for inclusion on its Register of Information. The Act provides donor offspring born since the introduction of the Act who are contemplating marriage with a right to enquire whether any information held on the Register indicates that they might be genetically related to their proposed spouse. Donor offspring born since the introduction of the Act will also have a right of access at the age of 18 to certain information about their genetic origins held on the Register. The Act makes no provision for access to information about genetic origins for people born prior to its implementation. There is also a small group of individuals born within the first few months of the Act's implementation and whose birth is recorded on the Register (possibly about 900) for whom no corresponding donor information will be available because the gametes or embryos used in their conception would have been donated

prior to implementation of the Act. The nature of the information on the Register that will become available to donor offspring, to be specified in Regulations, has yet to be determined by the government. Unless the donor is already known to the recipient, the Act generally protects donor anonymity. However, the identity of the donor could be disclosed by order of a court, either in the 'interests of justice' or where a centre is subject to legal proceedings following the birth of a child with a congenital disability. There have been no known cases of the identity of the donor being released under these conditions. The Regulations cannot be used to permit *retroactive* disclosure of donor identity, although they could permit disclosure of donor identity at some future date. However, since records now exist, retroactive release of identity would be possible through separate primary legislation, as occurred in relation to adoption with the introduction of the Children Act 1975.

Information about donors held on the HFEA Register of Information is specified by *HFEA Donor Information Form (91) 4*. This includes details about the donor's height, weight, ethnic group, skin colour, eye colour, hair colour, occupation and interests. In addition, there is a small space at the foot of the form (little more than 150cm²) for the donor to provide:

... a brief description of yourself as a person. This should be something which could be passed on to any child born as a result of your help. It may also be seen by the parents.

Guidance issued by the HFEA suggests that such information could include 'further information about the donor's interests, family background, childhood, region of origin, etc', and that centres should offer recipients the opportunity to see any additional information provided by the donor prior to treatment (HFEA, 1994). The HFEA Code of Practice also advises centres to encourage donors 'to provide as much ... non-identifying biographical information about themselves as they wish, to be made

available to prospective parents and any resulting child' (HFEA 1998, p 23). For offspring already born, whatever information the government decides it is appropriate for them to receive will, self-evidently, be limited to the data actually on the Register. Blyth and Hunt (1998) note that UK licensed centres report varying responses from donors to requests for information and that this is reflected in the nature and quality of information recorded on Form (91) 4. Further, in the absence of subsequent contact with the donor to supplement or amend any information given, not only will the information that *is* provided become dated, information that *is not* provided at the point of donation will never become available. If they are to access this information, donor offspring will need to be aware both of their status and of their legal right of access to the HFEA Register and will be dependent on their parents to inform them about their status. However, as is discussed in more detail below, the reality appears to be that the majority of DI recipients do not intend to tell their children about their origins.

Sharing genetic origins information in practice

While it might be expected, therefore, that both the recommendations of the Warnock Committee and the provisions of the Human Fertilisation and Embryology Act would have set the scene for (at least limited) increased openness in donor assisted conception, the evidence of this actually occurring is ambiguous. Although some service providers have endorsed the spirit of openness (eg Johnson, 1997; Winston, cited in Wavell, 1997), others have claimed that increased openness should not be promoted because there is no evidence that either anonymity or secrecy causes harm (Shenfield and Steele, 1997). Where individuals are contemplating the use of donated gametes or embryos, centres are required to take into account:

... a child's potential need to know about their origins and whether or not the

prospective parents are prepared for the questions which may arise while the child is growing up. (HFEA, 1998, 3.18a, p 19 [my emphasis])

Prospective donors must be informed about

. . . the information which centres must collect and register with the HFEA and the extent to which that information may be disclosed to people born as a result of the donation (HFEA, 1998, 4.5.g, p 31).

Finally, both prospective donor and prospective users of donated gametes or embryos must be offered counselling, although under the provisions of the Human Fertilisation and Embryology Act they are not obliged to take it up. (However, in practice, some centres may not accept individuals as donors or recipients of donated gametes or embryos unless they *do* accept the offer of counselling.)

During counselling prospective service users or donors should be ‘invite[d] . . . to ‘consider . . . the advantages and disadvantages of openness about the procedures envisaged and how they might be explained to relatives and friends’ (HFEA, 1998, 6.20 e, p 39). In addition, donors should be ‘invite[d] . . . to consider in particular . . . their perception of the needs of any children born as a result of their donation’ (HFEA, 1998, 6.16 d, p 40). Beyond this advice and guidance, centres and their staff are left to their own devices regarding the extent to which they offer ‘counselling for openness’. Research conducted by Blyth (1995) and Cook *et al* (1995) suggests that the emphasis on the provision of ‘non-directive’ counselling means that ‘counselling for openness’ is unlikely to be provided by centres. Consequently, it should not be surprising that most individuals undergoing donor assisted conception do not intend telling the child anything about their conception (Cook *et al*, 1995; McWhinnie, 1996). Cook and colleagues’ study is frequently cited as endorsing secrecy since the majority of DI conceived children in the study had not been told about their origins and

neither they nor their parents appear to be experiencing any harm as a result. It is, therefore, worth considering some of its main findings.

The study compares family functioning and the development of the children in three types of family: those with DI conceived children, those with children conceived following *in vitro* fertilisation, and those with adopted children. Eighty per cent of mothers (no fathers were interviewed) of DI conceived children indicated they had definitely decided not to tell the child about their origins and none of the four per cent who had decided to do so at some point had told their child at the time of the study. However, 50 per cent of the same group had told at least one family member. This would suggest the precariousness of the ‘secret’ in some of the families, although the researchers found no evidence of stress associated with either secrecy maintenance or the fear of inadvertent disclosure suggested by others (eg Baran and Pannor, 1993; Snowden and Snowden, 1993). What needs to be acknowledged, however, is that the oldest children in the Cook study were aged eight years. This presents two potential dilemmas for this group of parents. The first is whether, in an unguarded moment, they themselves or someone else who *does* know about the child’s origins might inadvertently reveal the truth to the child. Second, they still have to face their child’s adolescence, and probably the most testing challenge to their secret, especially as the child becomes both more knowledgeable about genetics and inherited characteristics and more concerned about their personal identity. Cook *et al* also sought to ascertain the reasons why parents were disinclined to tell their children. The reasons given by the mothers included: fears of exposing the child to stigma; fears of exposing the father’s infertility; concerns that disclosure might damage the father–child relationship; and parents’ responses to equivocal messages about disclosure or to explicit advice to keep secret their recourse to DI. What also emerged was the impact of parents’ lack of a ‘script’ for telling and the difficulty posed by

their lack of sufficient information about the donor: 'DI parents were often conscious of the difficulty of providing an explanation in the absence of information about the donor' (Cook *et al*, 1995, p 555).

In a separate study, Blyth and Hunt (1998) examined the experiences of centres in obtaining information from donors. A number reported difficulties in obtaining further information. Among the reasons cited were: donors not being interested in, or not attaching any importance to, providing further information; donors being ambivalent about providing information about themselves; donors being unwilling to provide more than basic information about themselves; donors not knowing what information to provide about themselves; and donors fearing that ostensibly non-identifying information might, nevertheless, compromise their anonymity. Some respondents, however, indicated that it was possible to get further information from donors. Successful strategies that were identified included: explaining the rationale for requesting further information; providing encouragement; providing counselling, advice and guidance on what information could be supplied; and in one instance 'persuasion'. One significant conclusion from this study was that the quality and amount of information on the HFEA Register concerning donors could vary to a large extent depending on the centre providing the information. Meanwhile, parents who are expected to embrace the concept of disclosure in the context of institutionalised secrecy and non-disclosure are caught in a double bind. If openness is to become a reality for more donor offspring, then parents not only need to be provided with more information, but the other barriers identified by Cook *et al* also need to be addressed.

However, there is evidence of changes in attitudes and practice. Curson (1998), reporting on the views of recipients of donated gametes in a single treatment centre, indicates a significant shift in attitudes towards openness and information sharing between 1990 and

1994. Some parents of donor conceived children have indicated not only that it is possible to tell their children without disastrous effects, in particular demonstrating that it is OK for infertile fathers to 'come out' and that disclosure can strengthen rather than undermine family relationships, but that it is the *right* thing to do (eg Hewitt, 1997; Mays, 1998). Merricks (1998) makes the point succinctly (p 4):

Big secrets are unhealthy in intimate relationships . . . They are usually based in and caused by feelings of shame, and shame about the methods of family creation will inevitably colour the parent/child relationship. A method of family building about which people feel ashamed is not going to be right for them. One could argue that it is incompatible with responsible parenthood.

Just as parents of donor offspring are beginning to articulate their views and experiences, in particular through the establishment of national support groups campaigning for increased information and openness, plus global internet networks, so, too, are donor offspring. While it may be conceded that only a small minority of donor offspring, who may not be representative of the wider population of donor offspring, are actively seeking improved access to better information about their genetic origins, this should in no way devalue or invalidate either their experiences or the demands they are making. An Australian collection of personal accounts of donor offspring and parents of donor offspring (Donor Conception Support Group of Australia, 1997) makes clear the perspective of donor offspring themselves. They can be informed of the nature of their origins in sensitive and age-appropriate ways without damaging family relationships. Sometimes information about their conception is poorly managed and/or inadvertently disclosed, often resulting in conflicts about the prior concealment of this information. While the possibility of hindsight may not be ruled out entirely, offspring who have become aware of their origins in adolescence or adulthood not

infrequently comment on their awareness of unexplained physical and temperamental differences between themselves and other members of their family, or of growing up sensing something being 'different' within their family. With increasing awareness of the importance of genetics and of personal genetic biographies, donor offspring have begun to specify the information they think is important and to emphasise the need for this information to be updated and not to cease at the point of donation. In this they are supported by many geneticists. Simpson (1998), for example, makes the point (p 19) that:

In these days of rapid advances in the technology of genetics, and the practice of clinical genetics, any child born as a result of donor assisted conception who is denied knowledge of their family history could justifiably be said to be at a medical disadvantage compared to any child brought up by their biological parents.

Some offspring consider that they need to know who their donor is in order to make sense of their own identity. Such accounts are not dissimilar to those expressed by adoptees in England and Wales prior to the introduction of legislation in 1975 allowing access to their original birth records (Triseliotis *et al*, 1997). While some donor offspring have expressed less of a need to know the identity of their donor (Saffron, 1994), their views could change over time and the disinclination of *some* should not be used to justify withholding this information from those who seek it. Neither is there any basis for justifying either secrecy about the nature of their origins or withholding the identity of the donor on the grounds of the welfare of donor offspring themselves. Citing Erik Erikson, Freeman (1996) notes (pp 287 & 290):

Identity as what we know and what we feel is an organising framework for holding together our past and present and it provides some anticipated shape to future life. It is an inner personal landscape, a 'feeling of being at home in

one's own body'. . . Those who argue for secrecy [are] in effect denying children access to their own personal map.

Finally, of course, without donors there would be no donor assisted conception and no donor offspring, and both secrecy and anonymity have been cited as necessary to protect donors and to ensure that men will continue to donate. Significantly, of the three groups most directly and personally involved in donor assisted conception, the voice of donors, or semen donors at least, remains silent, so far articulated only indirectly through research studies (for a more detailed discussion of semen donors' perspectives see Daniels, 1998). There does seem reason to suppose that many current UK donors would not continue to donate if their identity were to be revealed (eg Cook and Golombok, 1995). Initial evidence following the introduction of legislation in Victoria (Australia) allowing donor offspring to access information about the donor, subject to his consent, also indicates that men who donated under a regime of anonymity may be reluctant to subsequently become known to their offspring (Anderson and Blood, 1998). At the same time there is also evidence from several countries that donors who would not be deterred by the loss of anonymity can be identified and recruited (for an overview see Daniels, 1998).

Discussion

Elsewhere (Blyth, 1998) I have argued that lack of clarity about the meaning of the welfare of the child in relation to assisted conception means, not only that even specific legal commitments to consider the welfare of the child cannot be relied upon to support the case for donor offspring's rights to learn the identity of the donor, but also that none of the major international human rights codes² offer such support. Although the UN Committee on the Rights of the Child has noted a *possible* contradiction between Danish policy on DI and the right of a child to know his or her origins (United Nations Committee on the Rights of the Child, 1995), it is unclear why

Denmark has been singled out in this way, when other countries have given donor anonymity legal protection. Indeed the French government's report on progress on implementing the Convention specifically claimed anonymity to be in the best interests of the donor conceived child, who should be treated as 'a child like any other without having to face problems of a dual relationship' (Government of the French Republic, cited in Ruxton, 1996, p 498). Further, individuals charged with the responsibility of promoting and protecting children's rights have expressed different opinions. Former Norwegian Ombudsman for Children, Målfrid Flekkøy, has questioned whether donor offspring have a right to information about their 'biological heritage' (Flekkøy and Kaufman, 1997). In contrast, Australian Federal Human Rights Commissioner, Chris Sidoti (cited by Harvey, 1997), considered donor anonymity to be a major breach of children's rights: 'This practice is denying the right of these children to know their biological fathers.' A Council of Europe committee agreed to uphold donor anonymity as a general principle, but while it considered donor offspring had no 'automatic right' to be informed about the nature of their genetic origins, it conceded that, where they did have this information, they should have a right to know the donor's identity (Council of Europe, 1989).

To date, most legislation concerning donor assisted conception safeguards anonymity and only three countries (Sweden, Austria and Victoria [Australia]) have enacted legislation that unequivocally gives donor offspring the right to learn the identity of the donor. In Germany and the Netherlands court rulings have raised doubts about the status of anonymity; other countries are either reviewing existing legislation or are actively considering introducing legislation which covers the provision of assisted conception services, eg Canada, Finland and the states of New South Wales and Western Australia. In the UK the Department of Health is drafting a position statement for ministers on the

information to be made available to donor offspring under section 31 of the Human Fertilisation and Embryology Act.

As an alternative to the current 'either/or' approach, Pennings (1997) has proposed a 'double track' model which is seen to offer greater choice than exists under systems that insist either on donor anonymity or identity disclosure. Centres would be able to recruit both anonymous and identifiable donors, thus diminishing the risk that loss of anonymity might compromise donor supply. Those seeking donor assisted conception would also have a corresponding choice of using either an anonymous or an identifiable donor. However, while such a policy would increase the choices available to donor offspring collectively, especially when compared to one institutionalising anonymity, it offers no choice to those offspring whose parents have chosen an anonymous donor.

Of the three states with legislation promoting information exchange in donor assisted conception, Victoria in Australia has not only the most recent, but also the most comprehensive provisions. Since the new Infertility Treatment Act 1995 amended previous legislation, the Infertility (Medical Procedures) Act 1984 (which established a register of information but also gave legal reinforcement to donor anonymity), the Victorian approach may offer the best model to countries such as the UK. The Infertility Treatment Act 1995 came into force on 1 January 1998. Significantly, the Act recognises that donor offspring have an existence beyond childhood, specifically stating that 'the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount' (s 5 (1) (a)) and making explicit the legitimacy of access to information about genetic origins as a welfare need and right. The Act provides that at age 18 donor offspring may have access to both non-identifying and identifying information about the donor. It specifies comprehensive details about donors that centres are required to record which may be provided as non-identifying donor information (and which could be used as a basis for specifying

information to be recorded under section 31 of the UK's Human Fertilisation and Embryology Act). The Act also provides a legal right to recipients of donated gametes to discover the donor's identity and, with the consent of recipients, to donors to know the identity of the recipients and child(ren). At age 18 donor offspring may give their own consent to the donor learning of their identity. The descendants of donor offspring also have a right to know the identity of the donor. These arrangements are similar both to practices that have been described in relation to surrogacy arrangements in the UK (Blyth, 1994, 1995a) and to 'open adoption' (Mullender, 1991).

Prior to June 1988, the implementation date of the Infertility (Medical Procedures) Act 1984, donors were also assured of anonymity and service providers were under no obligation to maintain records. Any information available about donors may, therefore, be either non-existent or incomplete, although the state's Infertility Treatment Authority will work with clinics to respond to requests for information. For births and donations taking place during the period covered by the above Act, ie up to January 1998, the new legislation provides for available non-identifying information to be released on the request of either offspring at age 18 or donor; and for identifying information to be provided to the offspring's parents, the offspring themselves or any descendant, as long as the written consent of the donor is obtained and any conditions that the donor has specified are met.

The not entirely unexpected reluctance of donors, previously assured of anonymity, to meet their now young adult offspring (Anderson and Blood, 1998) means that the sort of compromise adopted by Victorian lawmakers for the especially problematic issue of retroactive identity release will not necessarily give donor offspring what they want. A fully offspring-oriented model of information exchange would be more likely to endorse retroactive removal of donor anonymity (Lauren, 1997). An infertility counselling committee established by the UK's King's Fund Committee warned of the probable

'distress and frustration' experienced by offspring resulting from the failure to disclose all the information about their origins contained on the Register (King's Fund Committee, 1991, p 19). Merricks and Montuschi (1998), parents of teenage donor offspring, have outlined near cataclysmic scenarios in the UK if genetic origins information exchange is not satisfactorily addressed. In one they envisage donor offspring and their supporters laying siege to the offices of the HFEA to demand access to their files. In another they visualise a donor offspring gaining employment at the HFEA and releasing information on the internet. While the presentation in which these ideas were shared may have been delivered in a lighter vein than is usual at professional and academic gatherings, the issues raised by Merricks and Montuschi are serious enough, and may not be totally fanciful.

In a society that purports to recognise the rights of children, it is inarguable that donor offspring perspectives should inform understanding of their own welfare and best interests, not only during their childhood but throughout their lives. In a society that also espouses 'freedom of information', denial of access to personal records should increasingly be regarded as an anachronism. If the views of offspring are to be heeded and the spirit of 'freedom of information' implemented, the inevitable implication for the management of genetic origins information is that donor offspring should be provided with more information about their genetic history. This should unreservedly include giving those who wish to know the identity of their donor a legal right to do so.

Notes

1. While there are no statistics for donor conceived births in the UK prior to 1991, when the Human Fertilisation and Embryology Act 1990 was implemented, data published since August 1991 and up to March 1997 (the most recent date for which statistics are available) indicate that 13,460 children were born during this period as a result of treatment using donated semen, oocytes or embryos. In

1996/7, the last full year for which data are available, 2,432 children were born following treatment using donated semen, oocytes or embryos.

2. The European Convention for the Protection of Human Rights and Fundamental Freedoms (Council of Europe, 1950), the United Nations Convention on the Rights of the Child (United Nations, 1989) and the European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (Council of Europe, 1996).

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