

DONOR-CONCEIVED PEOPLE'S ACCESS TO GENETIC AND BIOGRAPHICAL HISTORY: AN ANALYSIS OF PROVISIONS IN DIFFERENT JURISDICTIONS PERMITTING DISCLOSURE OF DONOR IDENTITY

ERIC BLYTH* AND LUCY FRITH**

ABSTRACT

Donor conception has been practised for many years, initially as a means of bypassing male fertility problems through the use of donated semen. More recently, semen donation has provided a means by which a single woman and women in same sex relationships may build a family without engaging in penetrative heterosexual intercourse, while embryo and egg donation have provided new family-building opportunities for other groups, such as post-menopausal women. A key topic of debate, policy formulation, and regulation has been the extent to which donor-conceived people should be enabled to ascertain information about their genetic and biographical history. Currently, a minority of jurisdictions allow donor-conceived individuals to learn the identity of their donor. This article examines relevant provisions in these jurisdictions, identifying their similarities and differences, and outlines further measures that can be taken to promote the ability of donor-conceived people to learn about their genetic and biographical history.

INTRODUCTION

In most jurisdictions that permit donor conception,¹ donor anonymity is protected either explicitly by legislation or simply by virtue of

*University of Huddersfield, Queensgate, Huddersfield HD1 3DH, UK; Visiting Professor: Department of Applied Social Sciences, Hong Kong Polytechnic University.

**Lecturer in Health Care Ethics, Division of Primary Care, The University of Liverpool, The Whelan Building Brownlow Hill, Liverpool L69 3GB, UK.

We wish to thank the Alberta Law Foundation for providing financial assistance for this study. Dr Henny Bos, Dr Riitta Burrell, Dr Peter Burton, Joelle Darwiche, Joi Ellis, Angelique Heijnen, Nyaree Jacobsen, Louise Johnson, Dr Claudia Lampic, Christopher Lomax, Jacob Mbeya, Michelle Morelli, Professor Arne Sunde, Dr Petra Thorn, and Professor Olga van den Akker provided considerable information for the preparation of this paper. We are also grateful to Dr Juliet Guichon who read and provided valuable comments on an initial draft of the article.

being 'accepted practice'. In such jurisdictions, donor-conceived people have limited ability to obtain information about their genetic and biographical history. At best, they might have access to some limited non-identifying donor information. However, a number of other jurisdictions have accepted that donor-conceived people often wish to know their origins and have passed legislation prohibiting non-anonymous gamete donation. This article aims principally to analyse the legislation in 11 jurisdictions that prohibit non-anonymous gamete donation. We will consider key provisions of these statutes and draw out the similarities and differences between the different jurisdictions. We will conclude by considering what further, largely legislative, initiatives could promote the ability of donor-conceived people to learn about their genetic and biographical heritage, such as birth certificate annotation and counselling to encourage parental disclosure of the circumstances of their children's conception.

DISCLOSURE OF DONOR IDENTITY²

Since 1985, 10 jurisdictions (New Zealand, seven European nations, and two Australian states) have formally prohibited anonymous gamete donation and (where the practice of embryo donation is permitted) anonymous embryo donation. The New South Wales legislature has passed legislation, the Assisted Reproductive Technology Act 2007, which will – once implemented – also prohibit anonymous gamete donation. Beyond banning anonymity, these jurisdictions have established systems to assist donor-conceived people to discover the identity of their donor(s) (see Table 1).³

Table 1 below provides summary details of these 11 jurisdictions prohibiting the use for reproductive procedures of gametes or embryos from a donor who has not agreed to the disclosure of his or her identity to any offspring.

Two important, initial observations must be made about these 11 jurisdictions. First, most of these provisions are comparatively new. Only in Austria, Sweden, and the Australian state of Victoria have donor-conceived people reached the age at which they can request the identity of their donor – and there is currently no information from any of these jurisdictions about the experiences of donor-conceived people accessing this information. Second, none of the jurisdictions provides donor-conceived people with an unequivocal right either to identify their donor or to have any information about their genetic or biographical history – rather, they have abolished a donor's right to anonymity.⁴

AN ANALYSIS OF LEGISLATION PROHIBITING DONOR ANONYMITY

1. ROLE OF FEDERAL STATUS AND SHARED HUMAN RIGHTS CONVENTIONS

The 11 jurisdictions are a diverse group that, *prima facie*, have few characteristics that unite them in promoting the interests of donor-conceived people. Although each has ratified the United Nations Convention on the Rights of the Child (United Nations, 1989)⁵ – which has been cited as instrumental to decision making in some jurisdictions (Dr Michael Stormann, Austrian Justice Ministry, 26 November 1997 – personal communication; Ministry of Foreign Affairs, 2002) – the overall impact of the Convention on promoting the interests of donor-conceived people to date has been muted (Blyth and Farrand, 2004).

The seven European nations, which have banned anonymity, are (in order of so doing) Sweden, Austria, Switzerland, The Netherlands, Norway, the UK, and Finland. Although these nations are united in being members of the Council of Europe, and are, therefore, also co-signatories of the European Convention on Human Rights and Fundamental Freedoms (Council of Europe, 1950), neither membership of the Council nor requirements of the Convention, *ipso facto*, result in a prohibition on anonymity. No other member state has done so and the Convention has, to date, had limited impact on championing the right of donor-conceived people to information about their conception (Council of Europe, 1989). Austria cited provisions in the Convention in its decision to prohibit donor anonymity (Dr Michael Stormann, Austrian Justice Ministry, 26 November 1997 – personal communication) and the UK's similar decision seems based, at least in part, on a court case (*Rose and Another v. Secretary of State for Health and Human Fertilisation and Embryology Authority*, 2002) brought under the Human Rights Act 1998, a statute that incorporates the Convention's provisions.

Likewise, membership of a federation has not been sufficient to create uniformity in Australia. Only Victoria and Western Australia have banned anonymity and taken steps to foster disclosure, while New South Wales is in the process of doing so.

The 11 jurisdictions fall into one of two groups with respect to the implementation of legislation regulating-assisted human reproduction: (i) where legislation requiring disclosure of donor identity represents a specific reversal of previous legislation protecting donor anonymity (New South Wales, Norway, the UK, Victoria, Western Australia) or (ii) where the mandate for donor identity disclosure was preceded by no prior legislative protection of donor anonymity (Austria, Finland, The Netherlands, New Zealand,⁶ Sweden, and Switzerland).

Table 1: Jurisdictions requiring a gamete or embryo donor to agree to the disclosure of his or her identity to any offspring

Jurisdiction	Legislation	Date of implementation
Sweden	Lag om insemination (Law on Insemination) 1984 (replaced by Genetic Integrity Act 2006)	18 March 1985
Austria	Fortpflanzungsmedizingesetz. 275 Bundesgesetz.	1 July 1992
Victoria	Infertility Treatment Act 1995 (amended by the Assisted Reproductive Treatment Act 2008 – due to be implemented during 2009)	1 January 1998
Switzerland	Federal Act on Medically Assisted Procreation of 18 December 1998 – FF 1996 III, 197 (LPMA)	1 January 2001
The Netherlands	Wet donorgegevens kunstmatige bevruchting, 2002	1 June 2004
Western Australia	Human Reproductive Technology Amendment Act 2004	1 December 2004
Norway	Act on Biotechnology 2003	1 January 2005
UK	Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 (and Human Fertilisation and Embryology Act 2008 – due to be implemented during 2009)	1 April 2005
New Zealand	Human Assisted Reproductive Technology (HART) Act 2004	22 August 2005
Finland	Act on Assisted Fertility Treatments (1237/2006)	1 September 2007
New South Wales	Assisted Reproductive Technology Act 2007	Planned implementation during 2008 has not occurred

2. DONORS' ADVANCE AGREEMENT TO DISCLOSE HIS OR HER IDENTITY TO OFFSPRING

In all jurisdictions, the explicit agreement of a prospective donor to the release of her or his identity to any offspring who requests this information – together with additional information about any restrictions on the release of such information, other circumstances in which the information may be disclosed, and services that may be available when any such request is made – is secured in advance of the collection and use of gametes or embryos. In some jurisdictions, access to donor identity is limited to offspring only – although in some, a recipient may also have a right to request this information when acting in the capacity of the offspring's parent (see below for further discussion).

3. DONORS' PROTECTION FROM LEGAL AND FINANCIAL LIABILITY FOR OFFSPRING

Each jurisdiction accepts as a key principle that a donor has no legal or financial obligation towards offspring born as a result of the donation and have incorporated such a provision into their legislation.

4. LIMITS ON THE NUMBER OF OFFSPRING OR FAMILIES PER DONOR

All jurisdictions impose limits on the maximum number of children, or the number of recipients or the number of families, who may be conceived from the gametes from a single donor (subject to lower limits imposed by the donor him or herself). Nevertheless, these limits are subject to considerable variation and appear to be based on no rational formula, to minimize either the prevalence of consanguineous relationships – more of a risk in the context of anonymous donor conception – or of psychological and social complexities of ‘trying to come to grips with multiple genetically-linked siblings in a number of different families’ (Hulls, 2008: 3452) – increasingly likely where a donor and other genetic relatives are potentially identifiable (Sawyer and McDonald, 2008). It is noticeable that in jurisdictions where the removal of donor anonymity was introduced to an existing regulatory framework that protected donor anonymity, prevailing limits were not amended in any way. Of jurisdictions imposing limits on the number of *children*, Sweden sets this limit at six children, Switzerland eight children, New Zealand 10 children, while The Netherlands specifies the highest maximum at 25 children. Where the criterion is the number of *families*, Austria restricts donations to three marriages or couples in a *de facto* marriage, Finland and New South Wales⁷ to five recipients, Western Australia to five families, and the UK and Victoria⁸ to 10 families. Norway combines both criteria, with limits of up to six to seven families and 12–14 children.

5. MAINTENANCE OF A REGISTER OF DONOR PROCEDURES

All jurisdictions require providers of donor services to keep records of their procedures and to forward these to a body charged with maintaining a donor register (in some jurisdictions, the ‘donor’ register comprises part of a more detailed register of regulated-assisted human reproduction procedures). In the UK, Victoria, and Western Australia, the responsible body is the regulatory authority for assisted reproduction procedures (the Human Fertilisation and Embryology Authority in the UK, the Infertility Treatment Authority [ITA] in Victoria,⁹ and the Reproductive Technology Council in Western Australia). In New South Wales, the register will be maintained by the Director General of the Department of Health, in Norway by the Ministry of Health, in Finland by the National Authority for Medicolegal Affairs, in The Netherlands by an independent national organization, the Foundation for Donor Data, in New Zealand by the Births, Deaths, and Marriages division of the Department of Internal Affairs, and in Switzerland by the Federal Authority for Civil Affairs. In Austria, records are to be kept by the service provider for 30 years. After this period (or earlier if the service

provider ceases operations), the records are transferred to the 'Landeshauptmann' (county head). In Sweden, there is no central register and records are required to be maintained only by providers of donor treatment services.

6. THE LENGTH OF TIME FOR WHICH RECORDS MUST BE KEPT

Jurisdictions vary in the length of time they require records to be maintained. In Austria, the UK, Victoria, and Western Australia records are required to be kept in perpetuity. While Norwegian legislation is silent as regards record storage, the EU Tissue Directive (European Union, 2004) requirement for records to be kept for 30 years will likely apply. In New South Wales and New Zealand, they must be kept for 50 years; in Sweden for 70 years; and in The Netherlands and Switzerland for 80 years. In Finland, the length of time records must be kept is not known because there is an unresolved conflict between different statutes. The Act on Assisted Fertility Treatments stipulates that the records must be destroyed after 2 years from the use (or disposal) of the donated gametes or embryos. However, the Act on the Medical Use of Human Organs, Tissues and Cells (amended as required by the European Tissue Directive) stipulates that the records about the donor must be kept for 50 years after the donor's death (Dr Riitta Burrell, Terveydenhuollon oikeusturvakeskus TEO [National Authority for Medicolegal Affairs], personal communication, 13 March 2008).

7. THE AGE AT WHICH INFORMATION CAN BE ACCESSED

In most jurisdictions (Finland, New South Wales, New Zealand, Norway, Switzerland, the UK, and Victoria), eligibility to request disclosure of the donor's identity is conferred when the donor-conceived person achieves legal majority, ie 18. Exceptions are Austria (14 years), The Netherlands, and Western Australia (16 years).

In three jurisdictions, exceptions to the general rule exist. In New Zealand, a 16- or 17-year old donor-conceived person may apply to the Family Court to be treated as an 18-year old, although the court will need to be satisfied that it is in the individual's best interests to receive the information requested. In Western Australia, a donor-conceived person younger than 16 years may learn her or his donor's identity, providing that the donor consents and the young person's parent(s) consent on the young person's behalf. In Victoria, a donor-conceived person younger than 18 may currently learn her or his donor's identity, providing that the donor consents and the request is made via the young person's parent(s) and under provisions of the Assisted Reproductive Treatment Act 2008, parental or guardian consent will

not be required if the young person has received appropriate counselling and the counsellor judges the individual to be 'sufficiently mature' to understand the consequences of seeking the information. Sweden, alone, specifies no age at which the information may be requested, requiring instead that the donor-conceived person has 'achieved sufficient maturity' (United Nations Committee on the Rights of the Child, 1998). This term has been specified to mean 'the upper teens' by the National Board of Health and Welfare, though parents decide not only when their child has attained 'sufficient maturity' but also if it is in their child's best interests to be told (cited in Lalos et al, 2003).

8. OTHER PROVISIONS FOR DISCLOSING DONOR IDENTITY

Some jurisdictions provide exceptions to their general rule about when a donor-conceived person can access information about his or her donor. For example, Austria, New South Wales, New Zealand, and Switzerland permit disclosure at an age younger than majority in special circumstances, most usually where disclosure is necessary to save the life of the child or to prevent serious injury to the child's health. A court may also authorize disclosure of the donor's identity under some circumstances.¹⁰

In Switzerland, the law does not specify special circumstances; it merely states that a donor-conceived person aged under 18 years may request the donor's identity if the person, 'has an interest in this which is to be protected' (Art 27 (2)). Before providing this information, the authority must, if possible, inform the donor of the request and ascertain his¹¹ intentions regarding any personal contact. The donor-conceived person will be informed if the donor does not agree to contact, but the request must be honoured if the donor-conceived person continues to request the information. A donor-conceived person over the age of 18 does not have to invoke any such 'interest' in order to obtain details of the donor's identity.

In the UK, a donor's identity may be disclosed when a donor-conceived child is born with a congenital disability, in order to facilitate a civil action for damages against the treatment centre, the donor him or herself, or a third party that might be responsible for causing any injury to the donor which could have resulted in the child's disability [Congenital Disabilities (Civil Liability) Act 1976].

In Western Australia, the 'voluntary register' registration forms allow both donors and offspring (and parents of offspring who are minors) to agree to be notified if any offspring or the donor is diagnosed with a serious heritable medical condition or illness and (s)he or the offspring's parents request(s) this notification. This option can be selected even if

the donor or offspring do not wish to register their identifying information on the voluntary register for more 'general' contact (Nyaree Jacobsen, Western Australia Department of Health, personal communication, 22 April 2008).

In New Zealand and Victoria, a parent or guardian of a donor-conceived minor may request the identity of the donor. In New Zealand, this information must be disclosed. In Victoria, the ITA may disclose the donor's identity only after the donor has granted consent. If the donor does not consent to the release of his or her identity, non-identifying information may be provided to the child's parent(s) or guardian(s) (Infertility Treatment Act 1995 s 75).

9. RESTRICTING ACCESS TO IDENTIFYING INFORMATION

Some jurisdictions do not permit totally unrestricted access to donor information and vary considerably in how they restrict access. Restrictions currently in force relate to counselling requirements, to safety considerations and donors' wishes.

Counselling

Provisions for counselling and other support services when requests are made for donor identifying information vary. In Victoria and Western Australia, what has come to be known as 'donor-linking' counselling is mandated before information is provided to a donor-conceived person, unless the respective regulatory body decides that undergoing such counselling is not necessary. In Norway, the donor and the recipient couple must receive counselling, while counselling of a donor-conceived person is subject to parental discretion.

In New South Wales, New Zealand, Switzerland, and the UK, counselling is available but not mandatory. In The Netherlands, the Foundation for Donor Data will contact the donor to request permission to give identifying information to the donor-conceived person. If there is doubt about whether there is a correct match of offspring and donor, blood group typing or DNA investigations may be used to confirm or rule out the genetic relationship. However, Janssens et al (2006) have expressed scepticism about the government's intentions to provide necessary support and counselling.

Safety Considerations

Some jurisdictions specifically withhold information if disclosure is thought to pose a risk to the safety of any person.

In New Zealand, the clinic or the Registrar General may refuse to disclose information, if it is satisfied on reasonable grounds that the disclosure is likely to endanger 'any person' (Human Assisted Reproductive Technology Act 2004 s 50 (4)).

In Victoria, if there is a risk to the welfare and interests or the health and safety of someone affected by an application for identifying information, as a matter of practice the ITA would take this into account before continuing with the 'linking' process, although the Authority has a statutory obligation to give 'paramount' consideration to the welfare and interests of the donor-conceived person (Infertility Treatment Act 1995 s 5(1)(a)).

In Western Australia, there are no specific provisions restricting disclosure of the donor's identity on the grounds of safety. Nevertheless, during the required pre-disclosure counselling, counsellors may become aware of issues that may cause them to withhold certification that counselling has been completed. The counsellor may also communicate any concerns to the Reproductive Technology Council, thus providing at least a temporary delay in the release of the information as an opportunity for the issue to be investigated. In addition, the Director General of the Department of Health may 'impose terms, conditions or directions which it considers desirable in order to ensure that the safety, health or welfare of persons is not at risk' (Nyaree Jacobsen, Western Australia Department of Health, personal communication, 22 April 2008).

Donors' Wishes

Legislation in The Netherlands and Switzerland includes other provisions relating to donors' wishes not to provide information or to make contact. In The Netherlands:

in the event that the donor objects to the provision of information identifying him, [the Foundation for Donor Data] weighs the pros and the cons. [...] Unless there are strong counter-arguments (not further specified in the law) the wish of the donor offspring will prevail. (Janssens et al, 2006: 853).

In Switzerland, the donor-conceived person will be informed if the donor does not agree to contact, but the donor-conceived person's request must be honoured if he or she continues to request the information.

10. A DONOR-CONCEIVED PERSON'S ABILITY TO LEARN ABOUT OTHER PEOPLE SHARING THE SAME DONOR

Only two jurisdictions, New Zealand and New South Wales, specifically include provisions enabling a donor-conceived person to ascertain information about any other individual who shares the same donor. In New Zealand, a clinic or the Registrar-General may tell a donor-conceived person (or, if the person is under the age of 18, her or his guardian) whether any persons have been conceived with the gametes

or embryos provided by same donor. A request may then be made for information about the sibling or half-sibling, but this information can be released only with the consent of the sibling or half-sibling (or, if under the age of 18, her or his guardian). In New South Wales, a donor-conceived person may receive information, including identifying information, about other offspring of the donor, and if the individual concerned has agreed to the disclosure of this information.

Donor-conceived people in the UK are currently not entitled to information about people who share the same donor, but changes under the Human Fertilisation and Embryology Act 2008 grant them the right to ascertain the existence, number, sex and year of birth, and, by mutual agreement, the identity of other individuals sharing the same donor.

In the remaining eight jurisdictions, there are no specific provisions for the disclosure of such information. If there is disclosure of information (excluding identifying information), it appears to occur at the discretion of the clinic or physician. Alternatively, the existence of donor half-siblings (or full siblings in the case of embryo donation) may be discovered serendipitously if a donor-conceived person contacts his or her donor and discovers from the donor that other siblings or half-siblings have already made contact with the donor.

11. VOLUNTARY CONTACT REGISTERS

Even where there is no specific provision for disclosure of information about other children of the donor, information can be exchanged by mutual consent of the parties concerned. Some jurisdictions have fostered voluntary registers for this purpose, permitting parties to a donor procedure to register their details and to seek information about, and possibly make contact with, others to whom they are related.

Governments have tended to establish 'Voluntary contact registers' when introducing legislation banning anonymity as an alternative to retroactive application of the legislation.¹² Voluntary contact registers attempt to extend to donor-conceived people conceived under an earlier regime the possibility of obtaining some information about their origins. Examples of jurisdictions that have used voluntary registers in this way are New South Wales, New Zealand, the UK, Victoria, and Western Australia. The first state-backed voluntary register, the 'Pre-1988 Donor Treatment Procedure Information Register', but colloquially known as the 'Voluntary Register', was established in Victoria in 2001. While most jurisdictions with voluntary registers separate these from the statutory registers, New Zealand's Human Assisted Reproductive Technology Register operates both as a compulsory register for births resulting from donor conception since 22 August 2005 and as a voluntary register for previous donor-conceived births. The UK's voluntary

register, 'UK DonorLink', maintained by a UK charitable body, but with government funding, has operated since April 2004. Uniquely, UK DonorLink uses DNA profiling to confirm matching.

Other voluntary registers have been established by non-governmental bodies such as individual sperm banks and by individuals and support groups for people with personal experience of donor conception. The most successful voluntary register in terms of both registrations and 'matching' is the *Donor Sibling Registry*, an online register established in the USA in 2000 by Wendy Kramer and her son Ryan. By March 2009, the *Donor Sibling Registry* had recorded more than 23,000 registrations and had helped connect more than 6,000 half-siblings and/or donors (<http://www.donorsiblingregistry.com>).¹³

FURTHER MEANS OF PROMOTING DONOR-CONCEIVED PEOPLE'S ABILITY TO OBTAIN GENETIC AND BIOGRAPHICAL INFORMATION

Having considered the legislation produced by the jurisdictions that have prohibited donor anonymity, we now want to examine further steps that could be taken to enable donor-conceived people to obtain access to identifying information about their donor.

A first obvious step would be for jurisdictions that permit donor conception formally to prohibit the use of gametes or embryos provided by a person who is unwilling to disclose his or her identity to any offspring. A number of jurisdictions prohibit – on religious or cultural grounds – any form of donor conception (Jones et al, 2007). We are of the view that donor conception should not be practiced at all if – for cultural, religious or other reasons – it cannot be practised non-anonymously.

Registers independent of clinics and physicians should be established to hold and promote access to relevant information that is as accurate as possible. Donors should, therefore, be requested to update information on a periodic basis and to provide any relevant health-related information as and when this becomes available. Voluntary arrangements by which a donor elects whether or not to disclose their identity or where non-identifying information only is disclosed, should be prohibited since such arrangements do not adequately protect the interests of donor-conceived people. Voluntary registers should be introduced only to mitigate the adverse impact of previous anonymous systems.

However, even in the 11 jurisdictions that do allow non-anonymous donation, there are barriers to donor-conceived people gaining access to donor information. In this section, we wish to consider further measures that could be instituted that go beyond simply prohibiting non-anonymous donation.

1. ANNOTATION OF BIRTH CERTIFICATES

As we noted at the outset, with the possible exception of Eritrea, none of the jurisdictions that currently ban anonymity actually give donor-conceived people an *unequivocal right* to know about the circumstance of their conception, much less a right to know the identity of their donor. Donor-conceived people's ability to access information to which they are entitled is entirely dependent on their awareness of the nature of their conception and this is clearly compromised if parents do not tell their children about their conception in the first place. Concerns have been expressed about low levels of parental disclosure (Gottlieb et al, 2000; House of Lords and House of Commons, 2007). Although there is some indication that an increasing proportion of parents of donor-conceived children may be disclosing this information to their children and that legislative change removing donor anonymity may itself play a part in facilitating parental disclosure (Lycett et al, 2005; Blyth, 2007), it is questionable whether relying on time alone will bring about a sufficiently rapid change in parental disclosure levels. A parental decision not to tell cannot be easily circumvented and it would be difficult for jurisdictions to enforce mandatory parental disclosure. Not only would there be surveillance problems but also more to the point such intervention would appear to be an unprecedented and excessive intrusion into family affairs.

For some donor-conceived people, however, current provisions and the pace of change in parental disclosure practices are insufficient. In the United Kingdom, for example, the parliamentary review of the Human Fertilisation and Embryology Bill provided an occasion for the articulation of demands for donor-conceived people to be afforded more explicit and substantial rights to ensure that the state itself is not complicit in donor-conceived people's deception about their origins.

To this end, a number of suggestions have been advanced proposing revision of the current system for issuing birth certificates for donor-conceived people¹⁴ as a means of encouraging early parental disclosure on the basis that the child will find out about his or her conception anyway when accessing their birth certificate. Various models proposed have included: the inclusion of a code or symbol on the birth certificate of a donor-conceived person (Barker, 2007); recording both the individual's genetic and social parentage on the birth certificate of a donor-conceived person (Rushbrooke (2007, 2008; International Donor Offspring Alliance, 2007); the issue of a separate certificate to a donor-conceived person alerting them to the possibility of information held on the HFEA Register of Information (Blyth, 2007); the annotation of birth certificates of all individuals to indicate the existence of the HFEA Register of Information, the Register of Adopted Children held by the UK's three General Register Offices and the Parental Order

Register (for individuals conceived following a surrogacy arrangement and subject to a Parental Order) – also held by the three General Register Offices (Blyth, 2008); and the issue of two certificates to all people – a ‘Certificate of Birth’, identifying an individual’s legal parentage and a ‘Certificate of Genetic Heritage’, indicating where an individual’s genetic and legal parentage are different (Partnership Focus Group: on the Rights and Life Long Needs of Children created by Donor Assisted Conception, 2008). None of these proposals is without shortcomings (for a detailed critique see Blyth et al, 2009). The House of Lords and House of Commons Joint Committee on Human Rights (2008) has advised that ‘the birth registration process should be changed only if there is evidence that it is necessary and there would be no disproportionate impact on the privacy of donor conceived people’,¹⁵ while the government itself has committed to a future review (Royall, 2007).

Annotation of birth records has been discussed in other jurisdictions. In Sweden, the Children’s Ombudsman has consistently advocated notation of the means of conception of donor-conceived children on the national population register – although to date the government has not acceded to such requests (Stoll, 2008).

In Victoria, a government amendment to its own Assisted Reproductive Treatment Bill 2008, tabled only during the final hours of debate on the Bill, provides for the birth certificate of a donor-conceived child to be annotated with the text ‘donor conceived’ where a ‘birth registration statement’ specifies that the child was conceived by a donor treatment procedure. This provision will come into effect during 2009 following implementation of the Assisted Reproductive Treatment Act 2008.

2. PERMITTING DISCLOSURE WHEN THE DONOR-CONCEIVED PERSON IS READY TO RECEIVE THE INFORMATION

It is arbitrary to specify the age at which information may be accessed.¹⁶ Jurisdictions that allow donor-conceived people to obtain their donor’s identity do so from ages 14 to 18 (majority). Currently, Sweden alone uses the sufficient maturity approach, one that is endorsed by Australia’s National Health and Medical Research Council (2007) and proposed under Victoria’s Assisted Reproductive Treatment Act 2008, among others. In the UK, a sufficient maturity approach, known colloquially as ‘Gillick’ or ‘Fraser’ competence, is considered to work effectively in various areas of child welfare – although its application to donor conception has been rejected by the government.¹⁷ Moreover, a notion of sufficient maturity coincides with bioethics principles that respect an adolescent’s idiosyncratic developing maturity (Rozovsky, 2007). We believe that adopting the ‘mature minor’ proposal has considerable merit. To be sure, effective mechanisms would need to be established

to ensure that a young person's maturity can be ascertained, but this would not be an insurmountable difficulty as governments in Sweden and Victoria have concluded and as paediatricians are able to attest in their daily clinical work. A mature minor proposal goes some way to implementing states' commitments to the principles of the United Nations Convention on the Rights of the Child – in particular Article 12 (the right of a child 'who is capable of forming his or her own views' to express these freely and for these to be 'given due weight in accordance with the age and maturity of the child') and Article 13 (the child's right to freedom of expression).

3. PERMITTING OTHER PERSONS TO ACCESS INFORMATION ABOUT THEIR GENETIC RELATIVES

Donor siblings and other children of the donor should also have the right to access information about their genetic relatives; jurisdictions should facilitate the exchange of information – and contact – provided that the parties agree. Currently, only New Zealand grants a legal right to donor-conceived people to learn the identity of any persons sharing the same donor, subject to mutual consent. The UK government proposes to introduce such measures under provisions of the Human Fertilisation and Embryology Act 2008.

The descendants of donor-conceived people may also be presumed to have an interest in knowing the identity of their donor. Currently, Victoria is unique in extending to the descendants of a donor-conceived person the right to learn the identity of his or her parent's donor. It is important to grant such a right to descendants because the donor-conceived person might not exercise the right of access to information for him or herself. For example, donor-conceived people might be unaware of the circumstances of their conception or they might be aware but decide not to seek the information. A descendant's interest in knowing the identity of their grandparents is independent of whether their parent chose to exercise the right to know the identity of the donor. Given the descendant's interest in knowing, the long-term storage of records is a relevant consideration. We believe that all records about assisted human reproduction using donor gametes should be maintained in perpetuity.

4. PROVIDING COUNSELLING AND OTHER SERVICES

Jurisdictions should ensure the provision of competent advice, counselling, and other support to any individual who seeks information from a register or who is affected by an application to a register. For donors, even though they have agreed in advance to the disclosure of their identity, the transmission of identifying information must be well managed, taking account of the likely passage of time since their

donation and possible changes in their personal circumstances. These services should be provided free of charge¹⁸ and uptake should be voluntary and not mandatory. These services are probably best provided by professionals or volunteers with expertise in donor conception and identity issues and/or adoption, rather than professionals with expertise in infertility counselling only.

CONCLUSION

In this article, we have presented the main provisions of laws and regulations in 11 jurisdictions formally enabling donor-conceived people to learn the identity of their donor. Notwithstanding some variation among these legislative initiatives, we note that the legislative trend among European and British Commonwealth nations – with the notable exception of Canada’s Assisted Human Reproduction Act 2004 – is towards prohibiting anonymity. Worldwide, jurisdictions that are passing laws on the issue of assisted human reproduction tend to recognize the right of donor-conceived people to learn the identity of their donor. Despite this welcome trend, there remain additional issues that need to be considered and addressed to grant fully the *right* of donor-conceived people to access all the information about their genetic and biographical history.

NOTES

¹In this article, we have followed common convention in use of the terms ‘donor’ and ‘donation’. We recognize that generic use of these terms may be misleading since many gamete donors may receive payment. In the jurisdictions described in this article, however, commercial procurement of gametes is prohibited.

²In this article, disclosure of the identity of a gamete or embryo donor refers exclusively to disclosure to the offspring of the donor. Except where gametes or an embryo from a donor known to the recipient are used, this will mean that the donor remains anonymous to the recipient.

³Eritrea’s draft Civil Code (Article 806) provides a donor-conceived child with the ‘right’ to know the identity of her or his donor (United Nations Committee on the Rights of the Child, 2002). However, the Code has not yet been adopted (United Nations Committee on the Rights of the Child, 2008) and it has not been possible to ascertain whether donor-conceived people actually have a right to this information – as we understand the concept in respect of this article. Germany presents an ambiguous situation, but is briefly outlined here for its potential relevance to donor conception. A 1988 Constitutional Court judgment made in relation to a child conceived in an extramarital affair and was unrelated to donor conception [BVerfG, 18.1.1988 – 1 BvR 1589/87, FamRZ 1989, 147] determined the right of a child to access his or her biological origins. However, this ruling has never been applied to a case of donor conception and all records relating to donor conception have to be retained for a minimum period of 30 years only, thus significantly compromising a donor-conceived person’s ability to learn about his or her genetic origins (Hammel et al., 2006). In Australia, the Reproductive Technology Accreditation Committee of the Fertility Society of Australia (RTAC) whose remit extends throughout Australia and New Zealand, introduced guidelines effective from January 2006 requiring all accredited clinics to use gametes only from donors consenting to the disclosure of their identity to any offspring. However, the policy may not apply nationwide since not all Australian fertility clinics are yet accredited by RTAC and only Victoria and Western Australia have implemented state legislation facilitating a donor-conceived person’s access to information about their donor, while New South Wales legislation is yet to be implemented.

⁴A 'guiding principle' of Victoria's Assisted Reproductive Treatment Act 2008 is that 'children born as a result of the use of donated gametes have a **right** to information about their genetic parents' (Section 5c – emphasis added), although the Act provides no means of enforcing such a right. The Norwegian Children's Act specifies that 'anybody it may concern' has the right to find their biological origin, including the right to have putative parents/children genetically tested. No one can refuse testing. If needed, biological material can be forcefully obtained. However, these actions would presume knowledge of the person to be tested.

⁵In the case of Australia, the UN Convention has been ratified by the federal government on behalf of all states and territories.

⁶Fertility clinics in New Zealand voluntarily pioneered recruitment of identifiable donors well before the introduction of legislation. Most began recording information about donor procedures in the 1990s, about the same time that they began recruiting only donors willing to be identified (New Zealand Law Commission, 2005).

⁷Note that the calculation in New South Wales includes marital unions that result in the birth of a child, although apparently excludes any *non-marital* liaison resulting in the birth of a child.

⁸Note that the proposed calculation in Victoria under the Assisted Reproductive Treatment Act 2008 includes any family created with a donor's current or former partner, whether or not the children were conceived as a result of a treatment procedure.

⁹Under provisions of the Assisted Reproductive Treatment Act 2008, responsibility for the register of donor procedures will be transferred from the Infertility Treatment Authority to the Registrar of Births Deaths and Marriages.

¹⁰Disclosure of a donor's identity for 'medical necessity' or by court order may be mandated in jurisdictions where donor anonymity is generally protected by law (Council of Europe, 1998).

¹¹Egg donation is currently not permitted in Switzerland.

¹²In Western Australia, however, while disclosure of the donor's identity from donations made before the 2004 amendments is generally voluntary, disclosure can be made without the donor's consent where 'the CEO is satisfied that the donor was, before the donation, adequately informed that future changes in legislation might enable the information to be divulged or communicated to the child without the donor's consent' (Human Reproductive Technology Amendment Act 2004 S. 49 (2e) (ii)).

¹³For further discussion regarding 'voluntary contact registers', see Blyth and Speirs, 2004.

¹⁴The husband or male partner of a woman who conceives a child as a result of donor insemination is legally permitted to register as the child's father when registering the child's birth. A woman who conceives a child as a result of egg or embryo donation is regarded as the child's legal mother and is permitted to register as such when registering the child's birth. The child's birth certificate, therefore, provides no information regarding donor conception.

¹⁵Birth certificates in the UK are required for many purposes such as school admission, passport applications, and applications for statutory benefits and services and are accessible to any member of the public in possession of minimal information about the individual concerned.

¹⁶As part of the current review of UK legislation, a joint committee of the House of Lords and the House of Commons proposed that the age of access both to non-identifying donor information and to the donor's identity should be reduced to 16 years (House of Lords and House of Commons, 2007). Although the government conceded a reduction to age 16 for accessing non-identifying information, it proposes to maintain the current age for accessing the donor's identity at 18 years, on the grounds that the 2004 regulations require donors to consent to their identity being disclosed to any offspring reaching the age of 18, but not to a 16-year old and that earlier access to the donor's identity might adversely impact on donor recruitment (Department of Health, 2007).

¹⁷'Gillick' –or 'Fraser' – competence was established following the House of Lords ruling in *Gillick v. West Norfolk Area Health Authority* (1986). This enabled a person under 16 to give consent to medical treatment without parental knowledge or consent if (s)he is deemed to be 'of sufficient age, maturity and understanding' to understand what is proposed and thus to make an informed decision. Application of the Gillick/Fraser principle to provisions for accessing a donor's identity was advocated by the Project Group on Assisted Reproduction [PROGAR], and of which EB was chair, in response to the Department of Health Consultation on the Review of the Human Fertilisation and Embryology Act [Project Group on Assisted Reproduction (PROGAR), 2006].

¹⁸The service should be paid for by either the state on the basis that the state sanctions donor procedures or by centres providing donor procedures on the basis that this is a legitimate part of service provision – or a combination of both. In any event, since relatively few people would be making use of such services, the costs of providing them should not be prohibitive.

REFERENCES

- Barker, Baroness, *Official Report, House of Lords: cols 94–95*. available at <http://www.publications.parliament.uk/pa/ld200708/ldhansrd/text/71210-0014.htm> (last visited 10 December 2007).
- Blyth, E. *Not the Time to Change Policy on Donor Anonymity*. FertilityFriends.co.uk, available at <http://www.fertilityfriends.co.uk/content/view/489/1/> (last visited 14 December 2007).
- Blyth, E. 'Donor conception: what to do about birth certificates', *BioNews* 438, available at <http://bionews.org.uk/commentary.lasso?storyid=3676> (last visited 17 December 2007).
- Blyth, E. 'Donor conception and birth certificates – more steps in the right direction' *BioNews*, 458, available at <http://www.bionews.org.uk/commentary.lasso?storyid=3840> (last visited 19 May 2008).
- Blyth, E. and Farrand, A. (2004) 'Anonymity in donor-assisted conception and the UN Convention on the Rights of the Child', *International Journal of Children's Rights*, (12)89–104.
- Blyth, E., Frith, L., Jones, C. and Speirs, J. (2009) 'The role of birth certificates in relation to access to biographical and genetic history in donor conception', *International Journal of Children's Rights*, 172, 207–33.
- Blyth, E. and Speirs, J. (2004) 'Meeting the rights and needs of donor-conceived people: the contribution of a voluntary contact register', *Nordisk Socialt Arbeid*, (24)318–30.
- Council of Europe, *Convention for the Protection of Human Rights and Fundamental Freedoms*, (Strasbourg, France: Council of Europe, 1950), available at <http://conventions.coe.int/treaty/en/Treaties/Html/005.htm>.
- Council of Europe (1989) *Human Artificial Reproduction*, Strasbourg, France: Council of Europe.
- Department of Health (2007) *Government Response to the Report from the Joint Committee on the Human Tissue and Embryos (Draft) Bill. CM 7209*, London: Department of Health. available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/dh_079127 (last visited 8 October 2007).
- European Union (2004) 'Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells' *Official Journal of the European Union*(L102)48–58. available at <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32004L0023:EN:HTML>.
- Gillick v West Norfolk and Wisbech Area Health Authority and the Department of Health and Social Security* [1985] 3 All ER 402.
- Gottlieb, C., Lalos, O. and Lindblad, F. (2000) 'Disclosure of donor insemination to the child: the impact of Swedish legislation on couples' attitudes', *Human Reproduction*, (15)2052–6.
- Hammel, A., Bispink, G., Katzorke, T., Schreiber, G. and Thorn, P. (Arbeitsgruppe Richtlinienneuvollziehung des Arbeitskreises für Donogene Insemination e.V.), 'Richtlinien des Arbeitskreises für Donogene Insemination zur Qualitätssicherung der Behandlung mit Spendersamen in Deutschland', available at http://www.donogene-insemination.de/downloads/Richt_Druckfassung.pdf (last visited 8 February 2006).
- House of Lords and House of Commons Joint Committee on Human Rights, *Legislative Scrutiny*, London: House of Lords and House of Commons. available at <http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf> (last visited 20 March 2009).
- House of Lords and House of Commons, *Joint Committee on the Human Tissue and Embryos (Draft) Bill*. Volume I: Report (London: House of Lords and House of Commons, 2007), available at <http://www.publications.parliament.uk/pa/jt200607/jtselect/jtembryos/169/169.pdf> (last visited 20 March 2009).
- Hulls, R. (2008) *Assisted Reproductive Treatment Bill, 2nd reading*, Melbourne: Parliament of Victoria. available at <http://www.parliament.vic.gov.au/downloadhansard/pdf/Assembly/Jul-Dec%202008/Assembly%20Extract%2010%20September%202008%20from%20Book%2012.pdf> (last visited 20 March 2009).
- Infertility Treatment Authority (2006) *Time to Tell 2006*, Melbourne: Infertility Treatment Authority. available at <http://www.ita.org.au/www/257/1001127/displayarticle/1001868.html>. (last visited 20 March 2009).
- International Donor Offspring Alliance, Human Fertilisation and Embryology Bill (2008) *Birth Certificates: The Case for Reform. Briefing for Members of the House of Commons*. available at <http://web.jaguarpaw.co.uk/~tom/080408-collation.pdf>.
- Janssens, P., Simons, A., van Kooij, R., Blokzijl, E. and Dunselman, G. (2006) 'A new Dutch Law regulating provision of identifying information of donors to offspring: background, content and impact', *Human Reproduction*, (21)852–6.

- H. Jones Jr, J. Cohen, I. Cooke and R. Kempers (eds), (2007) *IFFS Surveillance 07 Fertility and Sterility*, 87(1), S1–67.
- Lalos, A., Daniels, K., Gottlieb, C. and Lalos, O. (2003) 'Recruitment and motivation of semen providers in Sweden', *Human Reproduction*, (18)212–6.
- Lycett, E., Daniels, K., Curson, R. and Golombok, S. (2005) 'School-aged children of donor insemination: a study of parents' disclosure pattern', *Human Reproduction*, (20)810–9.
- Ministry of Foreign Affairs, Human Rights (2002) *Annual Report of Norway's Efforts to Promote Human Rights*. 5.8.1. available at <http://www.regjeringen.no/nb/dep/ud/dok/rappporterplaner/rappporter/2002/hum2002.html?id=550495>.
- National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research*. available at (2007) http://www.nhmrc.gov.au/publications/synopses/_files/e78.pdf.
- New Zealand Law Commission, *New Issues in Legal Parenthood – NZLC R 88*, Auckland: New Zealand Law Commission. available at <http://www.lawcom.govt.nz/ProjectReport.aspx?ProjectID=91> (last visited 19 April 2005).
- Partnership Focus Group: on the Rights and Life Long Needs of Children created by Donor Assisted Conception (2008) , *Briefing for the Human Fertilisation and Embryology Bill*, Available from British Agencies for Adoption and Fostering. London.
- Project Group on Assisted Reproduction (PROGAR), in Department of Health Department of Health. *Responses to the consultation on the Review of the Human Fertilisation and Embryology Act*, London: Department of Health. available at http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_4132358 (last visited 29 March 2006).
- Rose and Another v. Secretary of State for Health and Human Fertilisation and Embryology Authority*, [2002] EWHC 1593 (Admin).
- Royall, Baroness *Official Report, House of Lords: Column 104*. available at <http://www.publications.parliament.uk/pa/ld200708/ldhansrd/text/71210-0016.htm> (last visited 10 Dec 2007).
- Rozovsky, L. E. (2007) *Children, Adolescents and Consent: The Canadian Law of Consent to Treatment*, Markham, Ontario: Butterworths.
- Rushbrooke, R. (2007) 'Proposals to bring donor-conceived people's rights to their genetic identity into line with those of all other UK citizens', *House of Lords and House of Commons Joint Committee on the Human Tissue and Embryos (Draft) Bill. Volume II: Evidence*, London: House of Lords and House of Commons, 432–8. available at <http://www.publications.parliament.uk/pa/jt200607/jtselect/jtembryos/169/169ii.pdf>.
- Rushbrooke, R. *Proposals to Bring Donor-conceived People's Birth Certification into Line with that of all other United Kingdom Citizens*. available at <http://www.dcbirthcertification.org> (last visited 29 April 2008).
- Sawyer, N. and McDonald, J. (2008) 'A review of mathematical models used to determine sperm donor limits for infertility treatment', *Fertility and Sterility*, (90)265–71.
- Stoll, J. (2008) *Swedish Donor Offspring and their Legal Right to Information*, Uppsala, Sweden: Uppsala Universitet.
- United Nations (1989) *Convention on the Rights of the Child*, Geneva: United Nations. available at <http://www.unhchr.ch/html/menu3/b/k2crc.htm> (last visited 20 March 2009).
- United Nations Committee on the Rights of the Child (1998) Consideration of Reports Submitted by States Parties Under Article 44 of the Convention: Sweden. State Party Report. CRC/C/65/Add.3.11 February Geneva: United Nations. available at [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/6e861614054b466e80256604003bfdae?OpenDocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/6e861614054b466e80256604003bfdae?OpenDocument) (last visited 20 March 2009).
- United Nations Committee on the Rights of the Child (2002) Consideration of Reports Submitted by States Parties Under Article 44 of the Convention: Eritrea. State Party Report. CRC/C/41/Add.12 23 December. Geneva: United Nations. available at [http://www.unhchr.ch/tbs/doc.nsf/898586b1dc7b4043c1256a450044f331/8a52da90a06e49e7c1256ce000307fc9/\\$FILE/G0246422.doc](http://www.unhchr.ch/tbs/doc.nsf/898586b1dc7b4043c1256a450044f331/8a52da90a06e49e7c1256ce000307fc9/$FILE/G0246422.doc) (last visited 20 March 2009).
- United Nations Committee on the Rights of the Child (2008) Consideration of Reports Submitted by States Parties Under Article 44 of the Convention: Eritrea. Concluding Observations. CRC/C/ERI/CO/3 23 June Geneva: United Nations. available at <http://daccessdds.un.org/doc/UNDOC/GEN/G08/426/71/PDF/G0842671.pdf?OpenElement>. (last visited 20 March 2009).