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Introduction

According to French sociologist Simone Bateman Novaes (1998), ‘instrumental insemination’ undertaken by medical practitioners to facilitate conception in a woman has been practised in Europe since at least early in the nineteenth century. In a celebrated case reported to have taken place in 1884, Professor William Pancoast inseminated the wife of a man rendered sterile after contracting gonorrhoea, using sperm provided by his ‘best looking’ medical student. The woman had been anaesthetised and it appears that she never knew about the procedure, although her husband was told – but advised never to disclose what had transpired – as were Pancoast’s medical students who witnessed the procedure (no other instances of insemination taking place in the presence of witnesses have ever been reported). Twenty-five years later, one of these former students, Dr Adison Hard, reported Pancoast’s ministrations in a letter to a medical journal, claiming to have met the (by now) young man who had been conceived as a result (Hard, 1909).

For many years, the approach espoused by Pancoast, comprising both anonymity and secrecy, uniformly characterised donor insemination (Hurley, 2004) and also came to characterise the donation of oocytes and embryos once the feasibility of these procedures became established. During the past 30 years, however, coinciding with the rapid development of IVF and associated assisted reproductive technologies (ART) and their diverse applications, a variety of cultural, legal, ethical and religious traditions have accounted for the varied ways in which gamete and embryo donation are treated in different countries. This ranges from complete prohibition of all donor procedures in Italy (reflecting the influence of Roman Catholic opposition) – although the law supporting this ban has been challenged - and in certain Islamic nations (e.g. Egypt, Libya, Saudi Arabia, Senegal and Tunisia – although Iran, dubbed ‘the Egg Donation Capital of the Muslim World’, has developed innovative oocyte donation programmes (Hazrat-e Maryam Fertility Center, undated)), to relatively permissive arrangements that allow all forms of donor conception – often on an overtly commercial basis (e.g. India, Israel and the United States) (International Federation of Fertility Societies, 2013).

While in most jurisdictions in which donor conception is practised anonymity remains a key principle, a small number of jurisdictions have formalised systems requiring donors of gametes or embryos to agree to the release of their identity to any offspring who requests this (usually when reaching the age of majority). In recognition of the changing legal landscape and the accessibility of information via the internet, the Ethics Committee of the American Society for Reproductive Medicine (ASRM) has advised that donor programmes: ‘should make it clear to donors that they cannot give guarantees regarding immunity from future contact by offspring’ (Ethics Committee of the ASRM, p. 676). Opinion regarding the advisability of parents of donor-conceived children telling their children about their conception has also changed. For example, in 1993, the ASRM encouraged anonymous sperm donation (ASRM, 1993); by 2002 it indicated an acceptance of directed, known gamete donation if all parties agree (ASRM, 1998, 2002), and in 2013 it ‘strongly encouraged ... [parental] ... disclosure to donor-conceived persons of the use of donor gametes or embryos in their conception’ (Ethics Committee of the ASRM, 2013). In the UK, the statutory

regulator of clinical assisted conception services, the Human Fertilisation and Embryology Authority (HFEA), initially adopted a neutral stance regarding parental disclosure, requiring centres to take account of ‘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, 2001, 3.14a). However, in 2005, it changed tack, advising clinics to ‘encourage and prepare patients to be open with their children from an early age about the circumstances of their conception’ (HFEA, 2005a, 2005b). When the Human Fertilisation and Embryology (HFE) Act was revised in 2008, legislators took the opportunity to give this specific guidance statutory reinforcement, emphasising:

- (a) the importance of informing any resulting child at an early age that the child results from the gametes of a person who is not a parent of the child, and
- (b) suitable methods of informing such a child of that fact (Human Fertilisation and Embryology Act 2008 s14(3)(6C)).

This chapter examines the regulatory regimes that actively facilitate a donor-conceived individual’s ability to learn the identity of his or her donor: Austria, Finland, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the UK and the Australian states of New South Wales, Victoria and Western Australia. Details of relevant legislation in these jurisdictions, including the implementation dates, are summarised in Table 9.1. Space precludes a detailed discussion of the factors contributing to these shifts in greater openness and availability of information about the donor or the arguments for them here (see Blyth, this volume). Rather, the chapter charts the regulatory provisions of those countries and states that require ‘non-anonymous’ gamete and embryo donation, and identifies the similarities and differences between these different regulatory models, considering the following areas:

1. The organisations that maintain, and manage access to, donor conception records;
2. The length of time that records need to be kept;
3. The age at which a donor-conceived person can obtain the identity of his or her donor;
4. Provisions for earlier access to the donor’s identity for a ‘special reason’ (e.g. health, disability);
5. Ability of a parent/guardian to request the identity of a donor on behalf of a child who is a legal minor;
6. Provisions for access to information prior to the introduction of legislation mandating disclosure of donor identity;
7. Grounds for withholding identifying information when requested;
8. Limits on the number of children who may be born using the gametes of a single donor;
9. Provisions for counselling regarding disclosure of donor information to parents, donors and donor-conceived individuals;
10. Rights of donors to know about offspring born following their donation, and
11. Linking donor conception to birth registration.

In addition we discuss proposals in South Australia and Kenya (where consultations are taking place at the time of writing to establish a formalised registration system) and more limited provisions in Germany and Washington State (US) requiring donors to be identifiable to their offspring, as well as recent developments in the Republic of Ireland. The chapter concludes by outlining further provisions that may be introduced to facilitate access to genetic and biographical information following donor conception.

Table 9.1 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	Permitted donor procedures
Austria	Fortpflanzungsmedizingesetz. 275 Bundesgesetz; FMedG 1992 ⁱ	1 July 1992	Sperm donation
Finland	Act on Assisted Fertility Treatments (1237/2006)	1 September 2007	Embryo, oocyte, sperm donation
The Netherlands	Wet donorgegevens kunstmatige bevruchting 2002 ⁱⁱ	1 June 2004	Embryo, oocyte, sperm donation
New South Wales	Assisted Reproductive Technology Act 2007	1 January 2010	Embryo, oocyte, sperm donation
New Zealand	Human Assisted Reproductive Technology (HART) Act 2004	22 August 2005	Embryo, oocyte, sperm donation
Norway	Act on Biotechnology 2003	1 January 2005	Sperm donation
Sweden	Lag om insemination 1984 ⁱⁱⁱ (replaced by Genetic Integrity Act 2006)	18 March 1985	Oocyte, sperm donation
Switzerland	Federal Act on Medically Assisted Procreation of 18 December 1998 – FF 1996 III, 197 (LPMA)	1 January 2001	Sperm donation
United Kingdom	Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004; Human Fertilisation and Embryology Act 2008)	1 April 2005 1 October 2009	Embryo, oocyte, sperm donation
Victoria	Infertility Treatment Act 1995 (amended by the Assisted Reproductive Treatment Act 2008) Assisted Reproductive (Further Amendment) Act 2014	1 January 1998; 1 January 2010 July 2015	Embryo, oocyte, sperm donation
Western Australia	Human Reproductive Technology Amendment Act 2004	1 December 2004	Embryo, oocyte, sperm donation

i English translation: Reproductive Medicine Act

ii English translation: The Artificial Insemination (Donor Information) Act

iii English translation: Law on Insemination

Organisations that hold information about gamete and embryo donation

In most jurisdictions, a central register is maintained by a government department or agency. In Finland, New South Wales and Norway, this is the government health department or ministry. In the UK and Western Australia, the responsible authority is the regulatory body for ART: the HFEA and the Western Australian Reproductive Technology Council, respectively. In Switzerland, the responsible agency is the federal authority for civil affairs and in the Netherlands, it is the responsibility of a foundation created and financed by central government (Stichting donorgegevens kunstmatige bevruchting). In New Zealand and Victoria, the register is held by the Registry for Births, Deaths and Marriages (BDM). Only Austria and Sweden have no central register; there, doctors and clinics providing donor services are required to maintain relevant records.

Length of time that information on donor registers needs to be kept

Several jurisdictions stipulate specific lengths of time that information must be kept – this is 30 years in Austria and Finland (although names of donors held on the National Supervisory Authority for Welfare and Health [Valvira] donor register are kept indefinitely); 70 years in

Sweden; 80 years in the Netherlands and Switzerland. In New Zealand, information must be kept indefinitely by BDM and for 50 years by service providers, although in practice, most clinics will also keep it indefinitely. In Victoria and Western Australia, destruction of these records at any time is prohibited. Since no time limit is specified in legislation in New South Wales or the UK, it may be assumed that in both jurisdictions no records will be destroyed. Similarly in Norway, no time limit is specified; the information is kept ‘as long as it is needed’ (according to communication from the Norwegian Directorate of Health), that is, as long as a donor-conceived person can claim their right to their donor’s identity including, therefore, for a period beyond the death of the donor.

The age at which a donor-conceived person can obtain the identity of his or her donor

Several jurisdictions specify the age at which a donor-conceived person may learn their donor’s identity: 16 years in Austria, the Netherlands and Western Australia; and 18 in Finland, New South Wales, New Zealand, Norway, Switzerland and the UK. In Sweden, although no age is specified, in practice this is assumed to be around 18 years (i.e. at maturity). In Victoria, while 18 is the ‘default’ age for accessing a donor’s identity, a younger donor conceived person who is aged under 18 years can learn her/his donor’s identity with the consent of her/his parent/guardian, or with a written opinion from a counsellor that they (s)he is sufficiently mature to understand the consequences of receiving the information.

Provisions for earlier access to the donor’s identity for a ‘special reason’ (e.g. health, disability)

In specific circumstances, some jurisdictions allow access to the donor’s identity at an earlier age. In Austria, this is for medical reasons only. Similarly in the UK, the identity of a donor could be disclosed by order of a court, either in the ‘interests of justice’ (s34 of the 1990 Act, as amended) or where a clinic is subject to civil proceedings following the birth of a child with a congenital disability. In deciding whether to make such an order, the court must consider the welfare of any children who might be affected by the disclosure. In New Zealand, in ‘exceptional circumstances’ (that are not defined and have not been tested) a donor-conceived person aged 16 or 17 years can apply to the Family Court to be treated as though he or she is aged 18¹. A judge will need to be satisfied that it is in the best interests of the individual to have access to the information requested. In Switzerland, before reaching the age of 18, a donor-conceived person can request the donor’s identity if (s)he can demonstrate a ‘legitimate interest’². Before providing this information, the authority must, if possible, inform the donor of the request and ascertain his intentions regarding any personal contact.

Ability of a parent/guardian to request the identity of a donor on behalf of a child who is a legal minor

Four jurisdictions only (New South Wales, New Zealand, Victoria and Western Australia) allow the parent or guardian of a donor-conceived child who is a legal minor to access the donor’s identity, and only where certain conditions are met. In New South Wales, a parent or guardian can only request identifying information in order to save a child’s life or prevent

¹ Information received from Joi Ellis – NZ Fertility counsellor at Fertility Associates.

² English translation of Art 27(2) Federal Act on Medically Assisted Procreation of 18 December 1998.

serious damage to a child's physical or psychological health. As regards the latter, a medical practitioner or psychologist must certify that psychological damage is likely to occur. In New Zealand, a parent or guardian of a donor conceived person who is under 18 years may request, and be provided with, information about the donor from either a service provider or BDM. The parent or guardian must be advised 'of the desirability of counselling' and the donor must be advised that the information has been requested. In Victoria, a parent or guardian can apply to the Central Register and must undergo counselling before any request may be granted. The donor's identity may only be disclosed with their consent. This provision is reported to have proven very popular with parents who wish to thank the donor personally and/or parents who wish to start information exchange/contact with the donor sooner rather than later (VARTA, personal communication, 16 March 2014). In Western Australia, the parents or guardians of a donor-conceived child aged under 16 years may consent on their own behalf and on behalf of their child to sharing of identifying information. All parties must give their consent to the release of information and agree not to disclose the identity of anyone who has not given consent. Counselling must be undertaken before this information may be released.

Provisions for access to information prior to the introduction of legislation mandating disclosure of donor identity

Seven jurisdictions (Finland, New South Wales, New Zealand, the Netherlands, the United Kingdom, Victoria and Western Australia) have provisions to facilitate information exchange and contact between a donor-conceived individual and their donor – where mutually agreed – where a donor procedure took place prior to the introduction of legislation mandating disclosure of donor identity. In the Netherlands, New South Wales, New Zealand, the UK, Victoria and Western Australia, arrangements have also been introduced to facilitate information exchange and contact if desired between donor half-siblings, subject to mutual agreement.

In Finland, a donor-conceived person aged 18 years or older may ask the treating clinic to contact the donor and request her/his agreement to register her/his identity on the donor register, although the clinic has no obligation to do so. Regardless of the donor's agreement to identity disclosure, any non-identifying information that (s)he has given to the clinic can be provided to her/his offspring.

In New South Wales, the Health Central Register enables a donor-conceived individual conceived before 1 January 2010 and who has attained 18 years of age and a gamete donor who donated before 1 January 2010 voluntarily to register information about themselves and seek non-identifying and identifying information about others to whom they are related as a result of donation. A parent of a donor-conceived child who was born before 1 January 2010 can apply to the Central Register for non-identifying information, including medical history and other personal information, about their child's donor. On receipt of a request for information, the Ministry of Health will initially contact the treating hospital or clinic to ascertain whether a match can be made with the donor and/or other donor-conceived offspring. Privacy regulations preclude any active approach by the Ministry of Health to seek consent to disclose information that has not already been released. No information may be divulged by the Ministry of Health to a third party unless express permission has been given both as regards the information itself and the potential recipient.

New Zealand's Human Assisted Reproductive Technology (HART) Register also functions as a Voluntary Contact Register for people involved in a donor procedure undertaken prior to 21 August 2005. Most New Zealand clinics began recording information about donors in the 1990s, about the same time that they started restricting recruitment to donors who were willing to be identified (New Zealand Law Commission, 2005). Individuals conceived as the result of a donor procedure during this period may be able to access information from clinics, although there is no legal obligation either on clinics to release the information or on donors to agree to being identified. Generally, individuals conceived before 1990 will be entirely reliant on the voluntary register for any information that they do not already possess. The HART Register also enables donor-conceived siblings and the parent or guardian of a donor-conceived person younger than 18 years of age to share identifying information by mutual consent.

In 2010, Fiom, a national social work agency in the Netherlands with experience in counselling adopted persons and birth mothers, opened a voluntary DNA database in cooperation with the Canisius Wilhelmina Hospital in Nijmegen, for donor-conceived people born before 1 June 2004, their donors and donor half-siblings.

UK Donorlink (UKDL), a voluntary contact register, was established in the UK in April 2004 to facilitate information exchange and contact by mutual consent between an individual conceived as a result of a donor procedure undertaken in the UK before 1 August 1991, their donor and any half-siblings. UKDL used DNA profiling to establish a genetic link and provided dedicated counselling services to those using its services (Crawshaw and Marshall, 2008; Crawshaw et al., 2013). On 1 April 2013, UKDL was replaced by the Donor Conceived Register³. In addition, in April 2010, the HFEA launched the Donor Sibling Link, which helps donor-conceived people conceived after 1 August 1991 and who are aged over 18 years to find out if anyone else shares the same donor and if so, to share contact information by mutual consent. Victoria's Infertility Treatment Act 1995 established a Voluntary Register to enable donors, donor-conceived people, their parents, descendants and relatives to voluntarily record identifying details or additional information not included on the Central Register (e.g. photographs and messages). Information on the voluntary register may only be released in accordance with the wishes of the person who registered the information. A 2001 amendment to the Act extended the scope of the Voluntary Register to donor procedures taking place prior to 1 July 1988. In August 2014, the Victorian Parliament approved the Assisted Reproductive (Further Amendment) Bill 2013 which will take effect in July 2015 to extend to individuals conceived with gametes donated before 1988 the ability to obtain non-identifying information about their donor from the Central Register, and identifying information if their donor consents, that is, the rights to information held on the Central Register currently enjoyed by individuals conceived with gametes donated between 1988 and 1997. In Western Australia, the Reproductive Technology Registers assist information exchange for donors, donor-conceived adults (i.e. those aged at least 18 years of age) and parents of a donor-conceived child who is younger than 18 years, where the donor procedure took place before 2004. The Voluntary Register rules require the written consent of the individual to whom the information relates to be given for the release of any identifying information. In addition, an applicant for identifying information must also receive counselling.

³ <<http://www.donorconceivedregister.org.uk/>>

Grounds for withholding the identifying information when requested

Two jurisdictions, New Zealand and Victoria, permit some discretion as to the release of identifying information when requested to do so. In New Zealand, the clinic or BDM may refuse to disclose the information, if satisfied on reasonable grounds that the disclosure is likely to endanger any person. In Victoria, a more general concern regarding a potentially adverse effect on the welfare and interests or the health and safety of a relevant party could result in the information being withheld.

Limits on the number of children that may be born using the gametes of a single donor

With the exception of New Zealand, all jurisdictions impose an upper limit on either the number of children or the number of families that include children who may be born using the gametes of a single donor. Jurisdictions that apply a maximum limit on the number of children are Norway and Switzerland (eight) and the Netherlands (25). Jurisdictions that apply a limit on the number of families are: Austria (three); Finland and Western Australia (five); New South Wales (five women, including the donor's own partner/wife. A lesbian couple count as two women); Sweden (six), the United Kingdom (10) and Victoria (10, which includes the donor's own family). In New Zealand, clinics set their own limits, following guidelines issued by the Fertility of Australia Reproductive Technology Accreditation Committee (2010) and New Zealand standards 8181. On the basis of these, Fertility Associates, New Zealand's largest provider of ART services, imposes a maximum of 10 children in five families (Fertility Associates, personal communication, 17 December 2013).

Provisions for counselling regarding disclosure of donor information to parents, donors and donor-conceived individuals

With the exception of Austria, Norway and Sweden, all jurisdictions have established arrangements for the availability of counselling for donor-conceived individuals in conjunction with their request to discover the identity of their donor.

Rights of donors to know about offspring born following their donations

Donors have a right to know about children born following their donations as follows: in Sweden they can ascertain the number of offspring; in New South Wales and Victoria, the year of birth and gender; in New Zealand, United Kingdom and Western Australia, the number, gender and year of birth. Conversely, donors in Austria, Finland, the Netherlands, Norway, Sweden and Switzerland have no automatic rights to information about any children born as a result of their donation.

Linking donor conception to birth registration

Self-evidently, provisions enabling a donor-conceived person to ascertain information about genetic relatives they may have as a result of gamete or embryo donation are meaningless if they do not know about their conception in the first place. Clearly, the experiences of ignorance about donor conception can never be examined. However, various studies have indicated relatively low levels of parental disclosure, although some evidence of increasing levels of disclosure has been reported (see Blyth, this volume) and studies of donor-conceived individuals' experiences have highlighted adverse consequences associated with

late, accidental or inadvertent disclosure (see, for example, Turner and Coyle, 2000; Kirkman, 2003; Paul and Berger, 2007; Berger and Paul, 2008; Jadva et al., 2009; Blake et al., 2010; Cushing, 2010; Beeson et al., 2011). Annotation of birth certificates has been referred to as a possible means of encouraging parental disclosure (House of Lords and House of Commons, 2007; International Donor Offspring Alliance, 2007; Blyth et al., 2009; see also Blyth, this volume). To date, only Victoria has introduced provisions, under the Assisted Reproductive Treatment Act 2008, requiring BDM to mark the child's birth entry to note that (s)he is donor-conceived. When a birth certificate is issued to a donor-conceived person (but not to a third party, such as a parent), the certificate must include an addendum stating that further information is available from BDM about the entry. In New South Wales, following a court ruling in which the name of a sperm donor was removed from a child's birth certificate and replaced with that of the birth mother's former partner⁴, the Committee on Law and Safety of the Legislative Assembly of New South Wales (2012) advocated adoption of the model in force in Victoria. Although these recommendations were accepted by the New South Wales government (2014), to date no further legislative action has been taken.

Provisions in South Australia, Germany, Washington, Kenya and the Republic of Ireland

In South Australia, the Assisted Reproductive Technology Treatment Regulations 2010 came into force in September 2010, providing for the establishment of a register of donor procedures, the Donor Conception Register, that will enable a donor-conceived individual aged at least 16 years to learn the identity of her/his donor and for the establishment of a voluntary contact register relating to a donor procedure undertaken before the introduction of the Donor Conception Register. In February 2014, the government of South Australia launched a consultation to help determine the contents of the Donor Conception Register and arrangements for access to information contained in it. The consultation period ended on 31 March 2014; at the time of writing the outcome of this is awaited. In July 2011, Washington became the first of the US states to legislate for a donor-conceived person to learn the identity of her/his donor. A new section of the Revised Code of Washington (the state's legal code) requires any person donating gametes to a fertility clinic in Washington state that are used for family building, to disclose their identity to the clinic, and the clinic to disclose the donor's identity to any donor-conceived offspring aged at least 18 years who requests it (RCW 26.26). It is unclear what prompted the introduction of this legislation. Its potential impact is significantly constrained since it includes an opt-out clause for donors who do not wish their identity to be disclosed, by means of an affidavit of nondisclosure, so it is comparable more to the hybrid 'double-track' system advocated by Pennings (1997) than to any of the other jurisdictions described in this chapter. As far as it has been possible to ascertain, there have as yet been no efforts to establish any kind of registry or to take other steps to implement the legislation.

Save for prohibitions on both oocyte and embryo donation, Germany has not developed comprehensive regulation of gamete donation. However, various court judgments since 1988 have promoted the rights of donor-conceived individuals to access information about his or her biological origins.⁵ (*Deutsche Welle*, 2013; Thorn, 2013). In January 2015, Germany's

⁴ *AA v Registrar of Births Deaths and Marriages and BB* [2011] NSWDC 100.

⁵ Bundesverfassungsgericht [BVerfG], 18.1.1988 - 1 Beschluss vom Rundschreiben [BvR] 1589/87, Zeitschrift für das gesamte Familienrecht [FamRZ] 1989, 147.

highest civil court, the Federal Court of Justice, delivered a landmark ruling⁶ following an application by two teenage sisters who wished to learn the identity of their donor and which had been heard by lower courts in previous years. The key decisions made by the court are that, at any age, donor-conceived children have the right to obtain the name of the donor; parents of a donor-conceived child may demand the donor's identity for the purposes of informing the child. (*Deutsche Welle*, 2015) However, unlike other jurisdictions whose policies have been analysed in this chapter, Germany still lacks the infrastructure considered necessary for the effective implementation of rights to information, such as a central register of donations and births resulting from gamete donation, protection of donors from legal liability for offspring, provision of counselling and intermediary services to facilitate and support information provision – and if sought – contact.

Developments in both Washington state and Germany represent piecemeal arrangements that, whilst auguring the first steps in promoting the interests of donor-conceived people to learn about their biographical and genetic history, fall well short of the more comprehensive arrangements evident in other jurisdictions cited in this chapter.

Similarly in July 2014, it was reported that Kenyan MP Millie Odhiambo has sponsored an In Vitro Fertilisation Bill in the National Assembly, modelled on UK legislation, which would – among other provisions – establish a donor register, from which a donor-conceived person reaching the age of 18 could obtain information about their donor. Contemporary reports indicate that the Bill enjoys widespread community support, although further information about the Bill's provisions for donor-conceived individuals' access to information about their biographical and genetic history remains sparse (Standard Digital, 2014).

More recently, on 25 September 2014, the government of the Irish Republic approved proposals in the General Scheme of the Children and Family Relationships Bill 2014 which will require clinics and hospitals to provide details of donors and children to a national donor-conceived person register. According to Justice Minister Frances Fitzgerald, the new provisions, expected to become law in 2015, will enable a donor-conceived person to 'know his or her identity' (O'Loughlin, 2014).

Is the Human Fertilisation and Embryology Act fit for purpose in the twenty-first century? Further provisions to facilitate access to genetic and biographical information following donor conception

As long-standing advocates of the rights of donor-conceived people to access information about their biographical and genetic history, where donor conception is permitted, we believe that the use of donors who do not agree to the release of their identity to offspring at some future date should be prohibited. We, therefore, very much welcome the efforts of the UK government and regulatory body to ensure that the UK has for a number of years been at the forefront of the '[shift] away from exclusively anonymous donation to one with considerably more flexibility and openness' (International Federation of Fertility Societies, 2013: 75), especially given the comparative international context, and the still-contested nature of donor-conceived people's rights to information. To our knowledge, the UK was the first – and to date only – jurisdiction to enshrine in law the promotion of advice to parents of donor-conceived children to disclose the nature of their conception to their children while still young. Nevertheless, with increasing understanding of the intra- and inter-personal dynamics

⁶ BGH Judgment of 28 January 2015 XII ZR 201/13

of gamete and embryo donation and the interests of a wide range of parties personally affected by donor conception, we have identified further measures that can be taken to promote information acquisition and exchange.

Since many individuals or clinics provide donor services on a commercial basis, the security of records must be able to withstand the consequences of any individual practitioner or clinic going out of business and ceasing to provide a service. The historical review of donor records in Victoria provided by the Law Reform Committee of the Victorian Parliament highlights the perils of insufficient regard to data storage, security and access, noting that records of donor procedure undertaken by defunct service providers have ended up in the Public Records Office to which, ironically, public access is denied (Parliament of Victoria, 2012: 7.1.2.4). Our review indicates that various models appear generally capable of performing the task adequately, including bodies that regulate assisted conception services, government health departments/ministries or registries of births, deaths and marriages, or independent bodies funded by government. A necessary criterion is that the organisation responsible for maintaining and managing access to information has the necessary resources and disposition to carry out the task. In Victoria, responsibility for all donor registries transferred from the (then) Infertility Treatment Authority to the Registry for BDM in January 2010, a move that was widely considered a retrograde one because of BDM's failure to deal adequately with requests for information. This led the Law Reform Committee of the Victorian Parliament to recommend returning stewardship of the registers to the (now-renamed) Victorian Assisted Reproductive Treatment Authority (Parliament of Victoria, 2012: 6.3.2). While this recommendation was not accepted by the Victorian government, proposals to respond to these criticisms have been put forward to ensure that the service provided by BDM is better fit for purpose (Government of Victoria, 2013).

In order to ensure that records are as accurate as possible, donors should be requested to update information on a periodic basis (say every five years) and to provide any relevant health-related information as and when this becomes available, as recommended by the Ethics Committee of the American Society for Reproductive Medicine (2014). This could be achieved through confidential communications from clinics requesting any updated information. Similarly, recipients of donor gametes or embryos should be requested to provide periodic updates and information about health issues in their children that may have a genetic element, that might have implications not only for the health of the donor but also for the health of a donor's future children (Ethics Committee of the ASRM, 2014). Arrangements should be in place to ensure that service providers and/or register custodians pass on relevant information to donors, recipients of donated gametes and donor-conceived individuals. While in the jurisdictions reviewed in this chapter, the rights of *some* donor-conceived people to learn the identity of their donor has been recognised, no jurisdiction has extended this right to donor-conceived individuals where the donor did not explicitly consent to disclosure of their identity. Where donor registers were established in advance of legislation mandating disclosure of a donor's identity (currently in New South Wales, the UK, Victoria and Western Australia), this has meant that official records exist that provide information linking a donor-conceived individual to his or her donor, but to which the donor-conceived individual has no right of access. Satisfactory resolution of this problem has foundered on the competing rights of donors to privacy and of donor-conceived individuals to personal information. To date, the most extensive investigation of this dilemma has been undertaken by the Law Reform Committee of the Victorian Parliament (Parliament of Victoria, 2012) which investigated the situation of donor-conceived individuals in Victoria who were not entitled to information about their donor under the Infertility Treatment Act 1995 or the amending legislation of

2008. In the course of evidence gathering, the Committee discovered that past clinic practices assumed anonymity and that ‘donors were not given a choice as to whether they wished to be anonymous’ (Parliament of Victoria, 2012: 2.3.1.1)⁷.

Acknowledging, therefore, that objections to retrospective disclosure of donor identity that rested on claims relating to donor consent were flawed, the Committee afforded greater weight to the rights of donor-conceived individuals and recommended the retrospective disclosure of donor identity regardless of explicit consent, but that both donors and donor-conceived individuals should be able to place a veto on *contact* from each other. In the event, the government of Victoria rejected the Committee’s proposals and introduced the Assisted Reproductive (Further Amendment) Bill 2013 to extend the remit of the existing voluntary contact register. Regardless of the merits of retrospective disclosure and inequities faced by donor-conceived individuals based on the date of their conception, it seems unlikely that any government will implement retrospective disclosure of donor identity in the foreseeable future and as a necessity, donor-conceived individuals who were conceived before the implementation of legislation mandating disclosure of donor identity will have to rely on the mechanisms provided by voluntary contact registers, social media, genealogy websites (Motluk, 2005) or registries independent of government, such as the Donor Sibling Registry⁸.

In this regard we consider that governments and service providers need to run relevant educational programmes to facilitate participation in such registers by both donor-conceived people and former donors. It is important to remember that information available for a donor-conceived person on any form of donor register is meaningful only to the extent that the individual knows about the potential relevance of this information to her/him and, even if they know they are donor-conceived, that they have an interest in obtaining it. Knowledge of being donor-conceived is, therefore, central. Available evidence indicates that, historically, recipients of donor gametes have tended to heed the advice of service providers not to disclose to their donor-conceived children information about their conception, although in keeping with the relatively recent changes in policy and professional practice noted earlier in this chapter, parental practices also appear to be changing in favour of increased transparency.

As an aid, both to parental disclosure and to donor-conceived individuals’ ability to learn about their genetic and biographical history, consideration to annotating birth registration documentation, as has already occurred in Victoria and proposed in New South Wales, could be given by other jurisdictions, including the UK (see Blyth, this volume). Any such arrangements must, of course, pay due regard to individuals’ rights to privacy and confidentiality, as we have discussed further elsewhere (Blyth et al., 2009).

Recognition also needs to be given to the potential interests in information and possible contact of a range of individuals who are personally affected by donation – as acknowledged at least in part and in different ways under New Zealand, UK and Victorian legislation. In addition to donor-conceived people themselves, we would like to see the interests of parents, grand-parents, siblings, children and other descendants of donor-conceived individuals; donor

⁷ To our knowledge this is the only attempt that has been made to elicit evidence regarding donor consent to anonymity under regimes that predate donor identity disclosure. We have no reason to suppose that these practices are unique to Victoria.

⁸ The Donor Sibling Registry was founded by Wendy and Ryan Kramer in 2000. As of 6 September 2014, the DSR had 44,202 registrants and had facilitated connections between 11569 donor half-siblings and/or donors.

half-siblings; donors and their partners, children and parents afforded greater recognition. However, it is beyond the scope of the present chapter to identify the precise mechanisms by which different parties' access to information about others could be best secured whilst paying due regard to individuals' legitimate rights to privacy and non-interference.

Conclusion

This chapter aimed to give an overview of the provisions of those jurisdictions that have allowed donor-conceived people to access identifying information about their gamete donor and/or donor siblings. In the last 30 years or so there has been a trend towards the opening up of gamete donation: allowing legal options for those to find out information and encouraging those using gamete or embryo donation for family-building to tell their children that they were conceived using donor gametes or embryos. In this way it can be argued that the dominant view over how to approach gamete donation has changed – at least in the Western world – and the legislative landscape in the UK reflects this. Since publishing our first overview of legislation in this area over five years ago (Blyth and Frith, 2009), no new substantive legislation affording donor-conceived individuals the rights to learn the identity of their donor has been enacted. In this highly contentious area, the question of whether the UK's legislation is still 'fit for purpose' cannot be measured by any objective criteria but must take account of social attitudes, cultural practices, developing technologies, history and emerging evidence. However, various measures have been introduced, proposed or discussed in various jurisdictions to facilitate increased access to information about genetic and biographical history. Meanwhile, the developments in South Australia, Washington, Germany, Kenya and the Republic of Ireland highlight a perceptible, albeit gradual trend towards increased transparency and recognition of the rights to information by an increasing range of parties, particularly those conceived by donor gametes or embryos (International Federation of Fertility Societies, 2013).

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