

Swedish donor offspring and their legal right to information

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Society must adopt the attitude that donor insemination is not a right for unintentionally childless people but that the proposed child's best interests must always be in the forefront with an assessment of whether insemination may take place.

SOU 1983:42, p 87.

Acknowledgements

I first heard about Sweden's now repealed Act on Insemination in 1995, when I was a fourth year law student in Australia completing a research project on Medical Law. At that time, I was writing an essay about the Victorian Infertility Treatment Act which had just been passed and was curious to know whether any other jurisdictions in the world had enacted similar legislation, particularly in relation to a donor offspring's right to know the identity of the donor. I was therefore very excited to find that Sweden had passed a similar law to Victoria, 11 years earlier. This excitement soon turned to frustration, however, when I was unable to uncover any further information, in the English language, about the Swedish Act or how access to identifying information was regulated in Sweden. The desire to know more about this Swedish law eventually led to a visit to Uppsala, which in turn has — amongst other things — resulted in the completion of this thesis.

The process of locating the information I was after, understanding it, and then using it as the basis for this project, took somewhat longer than I could have anticipated. But perhaps it was just as well, particularly in light of the 2006 enactment of the Genetic Integrity Act; the findings of the public investigation into parenthood with assisted reproduction (SOU 2007:3) published in 2007; and recently-published studies indicating that more Swedish donor offspring appear to be finding out how they were conceived from their parents. If this project had been finalised sooner, some of the conclusions reached would have been quite different.

The time I have spent at the Faculty of Law at Uppsala University has been enjoyable and enriching and without the Faculty's support I could not have completed this project. In addition to generously financing the printing of this dissertation, the Faculty has provided me with many opportunities for intellectual and social development; many wonderful friendships; and a working environment which includes — assuming one sits at 45 degrees, precisely to the left of the window in B 315 — a glimpse of the Uppsala Castle.

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are a “dynamic duo”. Thank you for putting so much energy into your role as supervisors. I feel privileged to have been able to benefit from your wisdom and experience.

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I dedicate this work to my parents, Daphne Stoll and the late Rev Wilhelm Stoll.

Uppsala, June 2008.
Jane Stoll

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Abbreviations

ART	Assisted reproductive technology
BO	Barnombudsmannen (Children's Ombudsman)
CRC	UN Convention on the Rights of the Child
DI	Donor insemination
Dir	Direktiv (Terms of Reference)
Ds	Departementsserien (Ministry Publications Series)
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
EU	European Union
ICCPR	UN International Covenant on Civil and Political Rights
ICSI	Intracytoplasmic sperm injection
IVF	In-vitro fertilization
Prop	Proposition (legislative bill)
RF	Regeringsformen (the Instrument of Government)
SCB	Statistiska centralbyrån (Statistics Sweden)
SFS	Svensk författningssamling (Swedish Code of Statutes)
SOSFS	Socialstyrelsens författningssamling (The National Board of Health and Welfare Code of Statutes)
SOU	Statens offentliga utredningar (Swedish Government Official Reports Series)
UK	United Kingdom
UN	United Nations

1 Introduction

1.1 Introductory remarks

On 20 December 1984, when the Act on Insemination (SFS 1984:1140)¹ was passed, the Swedish Parliament became the first legislature in the world to confer on donor offspring an unconditional right to know the identity of the donor. All donor offspring born from gametes donated after 1 March 1985, when the Act came into effect, have the right to obtain identifying information about the donor when they are sufficiently mature. This was world-first legislation and without question, groundbreaking. The Act not only acknowledged that donor offspring were entitled to information about their genetic origins; it also formed the foundation for what was to become a rapidly expanding regulatory system which now governs all areas of assisted human reproduction in Sweden. An important feature of the Act on Insemination was its aim to promote and prioritise the best interests of the prospective donor offspring child. This focus on the child continued with the subsequent enactment of the In Vitro Fertilisation Act (SFS 1988:711)² and remains central today under the Genetic Integrity Act (SFS 2006:351).³

The most recent statistics from the National Board of Health and Welfare, show that 161 donor offspring were born in Sweden under the Genetic Integrity Act in 2005. Eighty-five of these children were born following donor insemination,⁴ 32 were born following in-vitro fertilisation (IVF) with donated sperm,⁵ and egg donation resulted in an additional 44 births.⁶ Between 1989 and 2005, donor insemination alone accounted for between 25 and 90 births each year.⁷ Before assisted reproductive technology (ART) was regulated, however, it was estimated that at least 230 children were born each year following donor insemination.⁸ The decline in the number of insemina-

¹ As rep by the Genetic Integrity Act. SFS is an abbreviation of Svensk författningssamling (Swedish Code of Statutes).

² As rep by the Genetic Integrity Act. Hereafter referred to as the IVF Act.

³ Ch 6, s 3 (Insemination) and Ch 7, s 5 (IVF).

⁴ See Statistik – Hälsa och sjukdomar 2008:3, Assisterad befruktning 2005, Socialstyrelsen, p 21. [Trans: Assisted reproduction: Results of treatment.] These babies were born from 79 births.

⁵ Ibid, p 10. IVF with donor sperm has been permitted since 2003.

⁶ Ibid, p 9.

⁷ Ibid, p 10.

⁸ See Barn genom insemination, Huvudbetänkande av inseminationsutredningen, SOU 1983:42, p 13. [Trans: Children conceived by artificial insemination, Main report of the In-

tion births reported is, in part, due to the availability of intracytoplasmic sperm injection (ICSI) which has decreased the need for insemination. However, the demand for insemination could be expected to increase somewhat in the future due to the fact that lesbian couples have been permitted to have donor insemination treatment since 2005. Even so, the total need for donor insemination is not completely reflected in the number of treatments reported, or the number of couples on the waiting list. According to the National Board of Health and Welfare, an unknown number of couples turn to clinics abroad, in part to have faster treatment. The 2008 report, above, states that "many" couples treated in Helsinki for insemination over recent years are Swedes who have travelled to Finland only in order to have insemination.⁹ It is also possible that some couples travel to neighbouring jurisdictions to avoid the impact of the access to information provisions of the Swedish legislation.¹⁰ Moreover, an unknown number of children are born each year following private arrangements made in Sweden. While it is not possible to know how many donor offspring are born in Sweden each year, the figures reported above reveal that Swedish ART legislation serves to protect the interests of a relatively small number of children.¹¹

Although all donor offspring born under Swedish ART legislation have a right to know the identity of the donor, it is now apparent that a considerable number of them will not be able to exercise this right because they do not know how they were conceived. When the access to information provisions first came into force almost 25 years ago, Parliament determined to leave the responsibility for disclosure about the existence of the donor with the parents of donor offspring. This decision was based on the belief that it is in the child's best interest to receive this information from their parents and on the assumption that, over time, parents would become more open with their children in relation to the child's origins. Since then, however, studies undertaken in Sweden and abroad reveal that many parents find it difficult when it comes to disclosure. As a result, some parents choose to keep the information about the donor conception secret from their children. Although two recent Swedish studies reveal that increasing numbers of parents are now making the decision to disclose, there are equally clear indications that some donor offspring will never be told how they were conceived. It follows that

semination Investigation.] Hereafter referred to as SOU 1983:42. By comparison, the total number of births reported in Sweden in 1984, according to Statistics Sweden (SCB), was 94 270. In 2005 the number was 101 647. See Statistik – Hälsa och sjukdomar 2007:9, Graviditeter, förlossningar och nyfödda barn, Medicinska födelseregistret 1973–2005, Socialstyrelsen, p 13. [Trans: Statistics – Health and Diseases, Pregnancies, deliveries and newborn infants, the Swedish Medical Birth Register 1973–2005.]

⁹ Statistik – Hälsa och sjukdomar 2008:3, p 22.

¹⁰ This, however, is not a factor that can be quantified.

¹¹ Note also that the access to identifying information provisions do not apply to donor offspring conceived following insemination treatments abroad or through private arrangements made in Sweden.

these donor offspring will not be able to exercise their right to know the identity of the donor.¹²

The effect of this situation is that a donor offspring's legal right to information about the donor is not, in reality, unconditional at all. It is, rather, contingent upon the right of the parents to decide whether or not to tell the child. In effect, the Genetic Integrity Act confers a right to identifying information on donor offspring but provides no corresponding implementation mechanism for the realisation of this right. In addition to being inconsistent with Sweden's domestic law, it is possible that this also conflicts with its obligations under international law where the interpretation of a child's right to information about his or her genetic origins has broadened significantly in recent years. In spite of this, Sweden's national access to information provisions have not, in substance, changed since they came into effect in the mid 1980s. Sweden has long been appropriately credited as a pioneer in relation to donor offspring rights; an example that several other jurisdictions have been inspired by and followed. Since many donor offspring born under Swedish ART legislation have now reached adulthood, and given the current knowledge about the disclosure patterns of parents, a review of the access to information provisions of the Act of Genetic Integrity, with a view to facilitating the right to information about the donor, is timely.

1.2 Aims and objectives

The purpose of this thesis is to examine the regulatory framework that has been established to facilitate access to identifying information about the donor for Swedish donor offspring. In doing so, the aim is to determine whether the processes already in place are consistent with Sweden's domestic and international obligations; to establish whether the existing structures that have been set up to facilitate access to information can effectively satisfy the best interests of donor offspring, particularly in light of the purposes of the legislation and Parliament's intention; to identify actual and potential problems with the law and with the existing regulatory framework; and finally, to explore, where relevant, additional ways to promote access to identifying information and parental disclosure so that the right may be exercised by as many Swedish donor offspring as possible. While the focus of this thesis is on donor offspring born under Swedish ART laws, an additional objective is to consider how the right to information could be facilitated for those donor offspring who have not been born under the legislation.

The starting point for the thesis is the legislator's view that it is in the best interests of donor offspring to know how they were conceived so that they may decide whether or not to exercise their unconditional statutory right to

¹² These studies are discussed in Chapter 4, below.

identifying information about the donor. This is based on and consistent with existing Swedish law.

While this thesis is intended primarily for Swedish readers, the problems it addresses are not unique to Sweden. To my knowledge, an in depth analysis of the Swedish law on access to information about the donor, and its supporting regulatory structure, has not been attempted before. Since Sweden was the first jurisdiction in the world to regulate donor treatment procedures and access to identifying information, this information will hopefully be of some interest to English-speaking readers in other jurisdictions that are either contemplating their own regulatory structure or seeking to resolve similar problems.

1.3 Materials and method

This thesis is, predominantly, a legal dogmatic analysis of the laws and regulatory framework supporting access to information in Sweden. Because a detailed analysis about the provisions of the relevant Swedish law has not been attempted before, in English or Swedish, the objectives of the thesis were achieved largely through the use of primary legal sources.¹³

The Swedish primary legal sources relied on essentially comprise statute law and regulations, since there is no case law available to date on the main issues addressed under the Genetic Integrity Act or on the specific issue of access to identifying information. For non-Swedish readers, it should also be pointed out that the preparatory legislative materials — assuming they have not been subsequently overridden by the Court or Parliament — are a very important source of law for the interpretation of statutes.¹⁴ Information contained in the preparatory works to ART legislation in Sweden is particularly important in relation to the right to information because it shows the extent to which the Government and Parliament identified and emphasised the special needs of donor offspring when ART legislation was first enacted. Another major source of law heavily relied upon in this thesis is the joint Regulations and Guidelines on Assisted Conception (SOSFS 2002:13)¹⁵ issued by

¹³ For an account, in English, of the nature of Swedish legal sources see H-H Vogel, 'Sources of Swedish law' in M Bogdan (ed), *Swedish law in the new millenium* (2000) 48–64. See also H Tiberg, F Sterzel and P Cronhult (eds), *Swedish law: a survey* (1994) 43–55 and 489–493.

¹⁴ Note that this is distinguishable from the situation in common law jurisdictions, where such materials are not regarded as primary sources of law. For an informative article, also in English, on the interpretation of statutes in Sweden see Å Frändberg, 'Interpretation of statutes — The use and weight of *travaux préparatoires* in Sweden', in M Andenas and N Jareborg (eds), *Anglo-Swedish studies in law* (1999) 208–219. See also M Andenas, 'Pulling the language of Parliament to pieces and making nonsense of it; Statutory interpretation and *travaux préparatoires*', in M Andenas and N Jareborg (eds), *Anglo-Swedish studies in law* (1999) 220–234. Andenas deals with the same topic but from the perspective of English law.

¹⁵ SOSFS is an abbreviation of Socialstyrelsens författningssamling (The National Board of Health and Welfare Code of Statutes).

the National Board of Health and Welfare; unique in that it is a mixed source of law combining both non-binding guidelines and binding regulations in the same instrument. Other sources of Swedish law examined include government publications, guidelines, and documents such as information sheets issued from the National Board of Health and Welfare¹⁶ in addition to doctrine.

The corresponding non Swedish-domestic legal sources, consulted in an attempt to place the issue of donor offspring and access to identifying information in an international context, include various international instruments, case law from the European Court of Human Rights (ECtHR), legislation and regulations from other jurisdictions, in addition to reports, guidelines, journal articles and doctrine.

Non legal sources are also taken into consideration in order to gain further insight into, inter alia, the needs of donor offspring and their parents and the extent and nature of parental disclosure. These sources include international sociological and medical studies and materials, journal articles, and information from various government departments, eg the Swedish Tax Agency and the National Board of Health and Welfare.

All references to Swedish primary and secondary sources used and cited in this thesis have been translated by the author, unless otherwise specified.¹⁷ Where possible, legal and other sources available up until 1 June 2008 have been taken into account.

1.4 Limitations

This thesis is an analysis of the law regulating access to information following donor treatment procedures in Sweden. To this extent, with the exception of some comparisons with the State of Victoria, Australia, it does not attempt to give an account of similar laws from other jurisdictions.¹⁸

¹⁶ An example of such a document is the Board's "Meddelandebblad", which contains up-to-date information about relevant laws and ordinances, fees, decisions of other authorities and cases etc.

¹⁷ Almost all relevant legal sources used in this thesis are written in Swedish and have not been translated into English. While there are some exceptions to this, including unofficial English translations of the Genetic Integrity Act, and the repealed IVF and Insemination acts; and short English summaries of SOU 1983:42 and SOU 1985:5, these translations have not been relied on in this thesis. Some reports issued by the National Board of Health and Welfare also contain English summaries. See, for example, the report Statistik – Hälsa och sjukdomar 2008:3.

¹⁸ For a summary of the laws governing a child's right to know the identity of the donor in other European jurisdictions see Council of Europe, Steering Committee of Bioethics (CDBI), Replies by the member States to the questionnaire on access to medically assisted procreation (MAP) and on the right to know about their origin for children born after MAP, Strasbourg, Report CDBI/INF (2005) 7 <http://www.coe.int/t/e/legal_affairs/legal_cooperation/bioethics/texts_and_documents/INF_2005_7%20e%20MAP.pdf> last checked 30

Unless otherwise mentioned, the scope of the thesis extends primarily to the right to information for donor offspring who are conceived under Swedish ART legislation; that is to say, to those offspring who have an unconditional legal right to identifying information about their genetic origins. While some consideration is given to the situation of donor offspring conceived outside of the legislation, the extent of such consideration is limited in order to avoid confusion between those donor offspring who are entitled by law to know the identity of the donor, and those offspring who have no legal right to this information under Swedish ART law.

A great deal of research has been undertaken on the information needs of adopted children, particularly since the 1970s. While an analysis or review of this work is beyond the scope of this thesis, it is acknowledged that this research has been of inestimable value in identifying the importance of the availability of information about genetic origins both for adopted people and for donor offspring. Indeed, the valuable contribution of research carried out before the law on access to information was enacted in Sweden was undoubtedly instrumental in Parliament's decision to provide donor offspring with a legal right to obtain identifying information about the donor.¹⁹

The notion "best interest of the donor offspring" is not defined in the Genetic Integrity Act. The clear view expressed in the preparatory works was that it is in the best interests of donor offspring to have a right to information about their genetic parents. The access to information provisions were based on this assumption and this thesis supports and accepts this assumption. Accordingly, while acknowledging that there may be different interpretations about what the best interests of donor offspring could include, such interpretations have little bearing where it concerns access to identifying information by donor offspring in Sweden. The Swedish Parliament has already made it clear that, in its view at least, it is in the best interests of donor offspring to have a right to know the identity of the donor.

June 2008. See also Nordic Committee on Bioethics, *Legislation on Biotechnology in the Nordic Countries – An overview*, TemaNord 2006:506. Nordic Council of Ministers, Copenhagen (2006) 14–16; and RG Lee and D Morgan, *Human Fertilisation and Embryology: Regulating the Reproductive Revolution* (2001) 265–305.

¹⁹ See for example HJ Sants, 'Genealogical bewilderment in children with substitute parents' (1964) 37 *B J Med Psychol* 133–141; J Triseliotis, *In search of origins: the experience of adopted people* (1973); and R Snowden et al, *Artificial reproduction: A social investigation* (1983). Subsequent supporting research includes JL Hoopes, 'Adoption and identity formation' in DM Brodzinsky and MD Schechter (eds), *The psychology of adoption* (1990); MD Schechter, and D Bertocci, 'The meaning of the search' in DM Brodzinsky and MD Schechter (eds), *The psychology of adoption* (1990); Snowden R, 'The family and artificial reproduction', in DR Bromham et al (eds), *Philosophical ethics in reproductive medicine* (1990); and J Triseliotis, 'Donor insemination and the child' (1993) 12 *Pol Life Sci* 195–196.

That said, it is recognised that a donor offspring's right to access identifying information about the donor co-exists alongside a number of important competing interests, including those of parents and donors. These additional interests are, of course, highly relevant even though they cannot be fully addressed or explored in this thesis. To this end, it is acknowledged that, even where a donor offspring's right to information is considered paramount — as it is under Swedish law — the relevant competing interests should, as far as possible, be accommodated when attempting to satisfy the objectives of the legislation.

1.5 Outline of chapters

The thesis is divided into six chapters. Chapter One comprises the introduction.

Chapter Two explores Sweden's possible international obligations to donor offspring under the United Nations Convention on the Rights of the Child²⁰ and the European Convention on Human Rights,²¹ particularly in relation to the right to information about genetic origins. The main focus of the chapter is on two questions: First, whether the right to know one's genetic origins under these conventions extends to donor offspring; and secondly, whether the international law right to know, assuming it exists, extends to identifying information about the donor. In attempting to answer these questions, the source and scope of the right to information under each convention is explored. Relevant cases from the ECtHR are also discussed.

Chapter Three comprises a legal dogmatic analysis of access to identifying information under Swedish law, predominantly through an examination of the IVF and Insemination chapters of the Genetic Integrity Act and the Regulations and Guidelines on Assisted Conception. Together, these govern the practice of IVF and Insemination in Sweden today. The chapter commences by giving an account of the source and the scope of the right to identifying information under Swedish law. A number of additional provisions that impact directly on access to identifying information for donor offspring are subsequently highlighted including the provisions on record keeping, consent, counselling, and known donors. Several prohibitions are also mentioned. Where relevant, legislative preparatory materials are consulted in order to further understand the history and policy behind the legislation and establish the intention of Parliament in relation to donor offspring and their right to information. To this extent, the deliberations and recommendations

²⁰ United Nations Convention on the Rights of the Child, UN Doc. A/44/736 (1989), UNGA Doc A/Res/44/25 of 5 December (1989), 28 ILM, 1448 (1989).

²¹ European Convention for the Protection of Human Rights and Fundamental Freedoms, 1950, ETS No 5.

of the Swedish Insemination Committee and the original Government Bill are particularly relevant because they laid the ground work for all future investigations in relation to access to information, essentially forming the foundation for the current law. Without an understanding of this history, it would not be possible to determine whether the current law is effective from a donor offspring perspective or whether the purpose of the law is achievable. An important question addressed at the end of this chapter is whether Swedish law has met its obligations to donor offspring under international law.

In light of the framework and background of the law, established in the earlier chapters, Chapter Four investigates the main problem existing under the Genetic Integrity Act in relation to a donor offspring's right to information; that is to say, the Genetic Integrity Act confers on donor offspring a right to identifying information about the donor but provides no corresponding implementation mechanism for the realisation of this right. After giving an account of the nature of the problem, an attempt is made to establish its extent via the results of studies undertaken on donor offspring and their families. The problem is then considered in light of Parliament's intention that the right to know the identity of the donor would become a genuine right, and Parliament's assumption that it is in the best interests of donor offspring to be able to exercise this right.

In Chapter Five, a number of alternative solutions that could facilitate the right to information are identified and explored. Both supportive and invasive solutions are considered. The aim of the supportive measures is to help or encourage parents disclose and, to this end, they include making counselling compulsory prior to donor treatment procedures, making professional counsellors responsible for the psycho-social evaluation of parents, implementing a follow up program for parents and clarifying the child's right to information in the Children and Parents Code (SFS 1949:381). Another alternative considered is giving donors a conditional right to apply for identifying information about donor offspring when the donor offspring is 18 years of age. The two most invasive measures comprise entering information about the donor on the population register and sending a letter about the existence of the donor to adult donor offspring. The possible introduction of central and voluntary registers for Sweden is also considered.

Chapter Six forms the Conclusion of the thesis.

2 The right to identifying information under international law

2.1 Introductory remarks

As highlighted in the previous chapter, all Swedish donor offspring conceived from gametes donated after 1 March 1985 have an unconditional legal right to identifying information about the donor when they are sufficiently mature. The right to information contained in the Genetic Integrity Act (SFS 2006:351), however, is only one source of the right: the domestic source. There are strong indications that Swedish donor offspring — both adults and children — also have a right to at least some information about the donor under international law because Sweden has ratified a number of international conventions which provide for the right to know ones origins. Particularly relevant to Sweden in this regard are the United Nations Convention on the Rights of the Child (CRC)²² and the European Convention on Human Rights (ECHR).²³

The aim of this chapter is to consider the possible extent of Sweden's international obligations to donor offspring under the CRC and the ECHR with respect to the right to information about genetic origins. This is an important issue, particularly for those donor offspring who have no legal right to information about the donor under the Genetic Integrity Act. It is also of significance for donor offspring who never find out how they were conceived even though many have a legal right to this information.

²² United Nations Convention on the Rights of the Child, UN Doc. A/44/736 (1989), UNGA Doc A/Res/44/25 of 5 December (1989), 28 ILM, 1448 (1989).

²³ European Convention for the Protection of Human Rights and Fundamental Freedoms, 1950, ETS No 5.

Other possible sources of the right to know one's genetic origins, not discussed here, include:
–The International Covenant on Civil and Political Rights, UNGA Res. 2200 (XXI), 21 UN GAOR, Supp (No 16) 52, UN Doc A16316 (1966).

–The European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (the Oviedo Convention), 1996. In force 1999 but not yet ratified by Sweden although it became a signatory in 1997.

–The Charter of Fundamental Rights of the European Union (the European Charter, 2000, Arts 7, 24).

Note: Although the two-last mentioned instruments are not yet binding on Sweden they are mentioned here because they appear to be interesting in relation to this topic and could be important in the future.

There are two fundamental questions in this connection: First, does the right to know ones genetic origins under the CRC and the ECHR extend to donor offspring? Secondly, does the international law right to know extend to identifying information about the donor?

In attempting to answer these questions the starting point for this chapter is that the term “parents”, as found in the CRC, includes genetic parents.²⁴ It should be emphasised, however that a child’s right to know his or her parents is qualified by the inclusion of the words “as far as possible” in Article 7, leaving it open for different interpretations by the various States Parties.

The fact that Sweden chose to confer on its donor offspring a legal right to identifying information about the donor, even before the CRC was in force, indicates its support for the view that the right to know extends not only to donor offspring but also to identifying information about the donor. The number of donor offspring who currently enjoy this right under Swedish law is nevertheless limited. If donor offspring do, in fact, also have a right to information about the donor under international law by virtue of the CRC and/or the ECHR, Sweden arguably has an obligation to make this right realisable, at least to the extent required under the conventions.

²⁴ This assumption is supported, inter alia, by the Committee on the Rights of the Child. See further Part 2.2.4.1 below. On the scope of the term “parents” see the commentary of two leading authorities on the CRC: S Detrick, *A commentary on the United Nations Convention on the Rights of the Child* (1999), pp 153–154; and R Hodgkin and P Newell, *Implementation handbook for the Convention on the Rights of the Child* (UNICEF), Fully revised edn (2002), pp 116–117. **Note:** As an indication of latter authors’ authority on the CRC, in January 2008 UNICEF Sweden published a Swedish version of the Implementation Handbook which is principally a translation of the (updated) version of the above book by Hodgkin and Newell. See UNICEF Sverige, *Handbok om Barnkonventionen* (2008).

2.2 Convention on the Rights of the Child

2.2.1 Status of the CRC under Swedish law

When the Swedish Parliament gave its consent to ratify the CRC in 1990 it considered that the obligations set out in the Convention were, on the whole, already satisfied by existing Swedish law without the need to convert it into Swedish law via transformation or incorporation.²⁵ The effect of this is that, although Sweden is bound under international law to implement the CRC, the Convention itself is not formally binding on Swedish courts and other Swedish authorities since its provisions do not constitute Swedish law.²⁶ Thus, if there were to be a conflict between the Swedish law on access to information and a convention provision, the Swedish law would take precedence.²⁷ That said, the courts and authorities are nevertheless required to interpret Swedish law against the background of the Convention's purpose and provisions. In addition, the legislator is obliged to ensure that Swedish legislation is consistent with the Convention's articles and that it is applied in accordance with the undertakings set out in the Convention.²⁸ To this end, even though the CRC does not enjoy the status of being a *part* of Swedish law through the process of incorporation or transformation, Ewerlöf et al make the observation that it has '... nevertheless a great influence over the courts' and other authorities' decision making.²⁹

Even so, the fact that Sweden chose to confirm the CRC without transforming or incorporating it into Swedish law, does have at least one disadvantage. Cameron points out that Swedish courts and administrative authorities — like Parliament — assume that Swedish law complies with the CRC.

²⁵ See prop 1989/90:107 om godkännande av FN-konventionen om barnets rättigheter, pp 3, 28. [Trans: Government Bill on the acceptance of the United Nations Convention on the Rights of the Child.]

²⁶ See G Ewerlöf et al, *Barnets bästa – Om föräldrars och samhällets ansvar*, 5th edn (2004), pp 23, 187–188. [Trans: The best interests of the child – About parents' and society's responsibility.]

²⁷ See further prop 1996/97:25 om Svensk migrationspolitik i globalt perspektiv, p 245. [Trans: Government Bill on Swedish migration policy in a global perspective.]

²⁸ Ewerlöf et al above n 26, pp 187–188. [Author's translation.] See also prop 1989/90:107, p 117; and prop 1992/93:173 om en Barnombudsman, mm, p 5. [Trans: Government Bill on a Children's Ombudsman, etc.] On converting treaties and on the Swedish law principles of presumption and treaty conform construction see I Cameron, *An introduction to the European Convention on Human Rights*, 5th edn (2006), pp 27–28.

²⁹ Ewerlöf et al *ibid*, p 188. Note also that Kilkelly, in explaining why the CRC has such great influence in spite of the fact that it is not enforceable at an international level, points out that it 'enjoys a certain moral force' by virtue of its unanimous approval in 1990 by the General Assembly and because it is the most highly ratified international instrument to date. See U Kilkelly, 'The best of both worlds for children's rights? Interpreting the European Convention on Human Rights in the light of the UN Convention on the Rights of the Child' (2001) 23 *Human Rights Quarterly* 308, p 310.

Accordingly, there is a risk that the courts and institutions will not pay sufficient attention to the CRC when they interpret and apply Swedish law.³⁰ While this risk may indeed be tangible, any suggestion of incorporating the CRC into Swedish law has to date been rejected by the Swedish Parliament.³¹ It considers that the current measures in place for the implementation and ongoing review of the CRC are sufficiently well established to meet Sweden's obligations under the Convention and that incorporating it into Swedish law would serve no useful purpose.³²

2.2.2 Implementing the CRC in Sweden

The obligation for a contracting state to implement all of the rights in the CRC is set out in Article 4 which requires, inter alia, that States Parties '... undertake all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the ... Convention ...'³³

In Sweden, the implementation of the CRC is a constantly evolving process. A major feature has been, and continues to be, the ongoing review of existing domestic legislation to ensure that it is consistent with Sweden's obligations under the Convention. The most comprehensive example of this process to date was the official investigation of the Children's Committee into the implementation of the CRC which examined the extent to which the Convention's spirit and intention were reflected in Swedish law and practice. Its main report, published in 1997, was instrumental in bringing about a number of legislative changes in line with the objectives of the CRC.³⁴ More recently, the results of an official investigation into parenthood and assisted

³⁰ Cameron (2006) above n 28, p 28. See esp footnote no. 29 on the same page of Cameron's book.

³¹ Most recently in January 2006, see Riksdagsskrivelse 2005/06:136.

³² See also SOU 1997:116, Barnets bästa i främsta rummet: FN:s konvention om barnets rättigheter förverkligas i Sverige, Barnkommitténs huvudbetänkande, p 82 in relation to emphasising the importance of continuous review. [Trans: The best interests of the child, a primary consideration: The UN Convention on the Rights of the Child implemented in Sweden.]

³³ The obligations contained in Article 4 are linked to those set out in Articles 42 and 44(6) which respectively require States Parties to make the principles and provisions of the Convention widely known to adults and children, and compel States Parties to make their reports widely available in their own countries. For a more detailed discussion of the implementation of the rights in the CRC, see Hodgkin and Newell above n 24, pp 53–83 (Article 4); 611–618 (Article 42); and 635 (Article 44(6)). See also R Stern, *The child's right to participation – Reality or rhetoric?* (2006), pp 42–56 in relation to implementation in general and about monitoring the implementation of the Convention. See further SOU 1997:116, pp 75–77.

³⁴ The report in question is SOU 1997:116. While the subsequent Government Bill did lead to a number of other significant legislative changes for the benefit of children, it did not recommend any specific measures in relation to donor offspring and access to information. See prop 1997/98:182 om strategi för att förverkliga FN:s konvention om barnets rättigheter i Sverige. [Trans: Government Bill on a strategy for the implementation of the United Nations Convention on the Rights of the Child in Sweden.]

reproduction issues were published in 2007.³⁵ This report is highly relevant to donor offspring and access to information and is expected to result in several legislative changes.³⁶

Creating the office of the Children's Ombudsman in 1993 was another significant aspect of implementation. The task of the Children's Ombudsman is to represent the interests and rights of children in light of Sweden's undertakings under the CRC.³⁷ This includes "assiduously" encouraging the implementation of the Convention and monitoring its compliance.³⁸ Since the office was created, the Ombudsman has been instrumental in promoting children's rights in Sweden and played a key role in the 1990s in having the best interest of the child principle³⁹ written into the Children and Parents Code (SFS 1949:381), the Alien's Act (SFS 1989:529) and the Social Services Act (SFS 1980:620). In 2002, amendments to the Children's Ombudsman Act (SFS 1993:335) further strengthened the mandate and authority of the Ombudsman who is now empowered to, inter alia, request information from administrative authorities, municipalities and county councils about the measures they have taken to implement the rights of children in order to ensure compliance with the Convention.⁴⁰

It should be noted that the Children's Ombudsman has on several occasions, in response to proposed legislation or amendments, commented on issues pertaining to donor offspring and access to information. In particular, the Ombudsman has repeatedly expressed concern that Swedish legislation serves to protect parents instead of guaranteeing that donor offspring children will find out the truth about their genetic origins. The Ombudsman has been unwavering in her view that a notation about how the child was conceived should be contained in the population register; a measure which, in the Ombudsman's view, would be in line with Sweden's obligations under Article 7 of the CRC.⁴¹ This has been a returning theme in the Ombudsman's responses for almost 13 years now.⁴²

³⁵ SOU 2007:3, Föräldraskap vid assisterad befruktning. [Trans: Parenthood with assisted reproduction.]

³⁶ See further Chapter 5, Parts 5.5 and 5.8.1, below.

³⁷ The Children's Ombudsman Act (SFS 1993:335), s 1. See also prop 1992/93:173, p 1. Note that SFS 1993:335 approved the appointment of the Ombudsman. It followed an inquiry that resulted in the report SOU 1991:70 Ombudsman för barn och ungdom. [Trans: An ombudsman for children and young people.]

³⁸ SFS 1993:335, s 2.

³⁹ Article 3, CRC.

⁴⁰ SFS 1993:335, s 5.

⁴¹ See for example Barnombudsmannen, 1995-10-18 Remissvar: Barnombudsmannens synpunkter angående rapporten Assisterad befruktning (dnr 9:235/95); Barnombudsmannen, 1998-01-20 Remissvar: Yttrande över betänkandet (SOU 1997:116) Barnets bästa i främsta rummet, see under "Kap 9 Politiska och medborgerliga rättigheter"; Barnombudsmannen, 2001-02-01 Remissvar: Departementspromemorian Ds 2001:51 Behandling av ofrivillig barnlöshet; Barnombudsmannen, 2004-06-29 Remissvar: Promemorian Ds 2004:19 Föräldraskap vid assisterad befruktning för homosexuella (dnr: 9.1:0550/04); Barnombudsmannen, 2007-09-03 Remissvar: Betänkandet Föräldraskap vid assisterad befruktning (SOU 2007:3)

2.2.3 Source of the right to information about genetic origins

The child's right to information about his or her genetic origins is derived from the child's right to know his or her parents.⁴³ This right can be found in Article 7(1) of the CRC:

Article 7

1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and as far as possible, the right to know and be cared for by his or her parents.

2. States Parties shall ensure the implementation of these rights in accordance with their national law and their obligations under the relevant international instruments in this field, in particular where the child would otherwise be stateless.

Article 7(1) of the CRC reflects the rights contained in Articles 24(2) and 24(3) of the International Covenant on Civil and Political Rights⁴⁴ but expands on them by adding that the child has a right to know and be cared for by his or her parents. In relation to the right to know, Article 7 of the CRC should be read together with Article 8, the right of a child to preserve his or her identity.⁴⁵

Article 8 of the CRC provides that:

Article 8

1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.

Dnr: 9.1:0538/07; **Note:** Several of these issues were also raised in Barnombudsmannen, 2001-07-02 Remissvar: Betänkandet (SOU 2001:10) Barn i homosexuella familjer.

⁴² Most recently in September 2007 in response to SOU 2007:3. See fn immediately above.

⁴³ See further C Breen, 'Poles apart? The best interests of the child and assisted reproduction in the antipodes and Europe' (2001) 9 *International Journal of Children's Rights* 157, p 163; Detrick above n 24, p 153; and Hodgkin and Newell above n 24, p 107. See also J Tobin, 'The Convention on the Rights of the Child: The rights and best interests of children conceived through assisted reproduction' (2004) Occasional Paper, Victorian Law Reform Commission, p 37. It should, however, be mentioned that there is no clear-cut interpretation about whether Article 7 gives a child the right to information about his or her genetic origins. Lucy Smith, for example, does not believe that the words 'the right to know and be cared for by his or her parents' support such an interpretation. In Smith's view, these words are directed, first and foremost, to the child's right to be raised by his or her parents. See L Smith, 'Nyere utvikling i barneretten' 2008 2(6) *Tidskrift for familierett, arverett og barnevernrettslige spørsmål* 84–94, p 93. [Trans: New developments in children's rights.] On this issue see also A Singer, *Föräldraskap i rättslig belysning* (2000), pp 402–403. [Trans: *Parenthood in legal light.*]

⁴⁴ See text in fn 46, below.

⁴⁵ See further Hodgkin and Newell above n 24, pp 107, 125. See also Detrick above n 24, p 154, Note 1; and Tobin above n 43, p 38.

2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.

Assuming donor offspring do have a right to information about the donor under Article 7, recording and preserving identifying information about gamete donors in accordance with Article 8 could be interpreted as necessary since the existence of such information is a prerequisite for donor offspring to be able to trace their genetic origins. For the purposes of this chapter, however, the discussion is confined to Article 7 of the CRC because Sweden already complies fully with its Article 8 obligations to preserve the identity of its children, including its donor offspring.⁴⁶

2.2.4 Scope of the right to information under the CRC

2.2.4.1 To whom does the right to know genetic origins extend?

The interpretation of whether the right to genetic origins under the CRC extends to donor offspring varies amongst different contracting states. Even where different states have ratified the same international instrument, there is no unified way in which the right to know has been interpreted and applied on a domestic level.⁴⁷ There is little doubt about Sweden's interpretation, however. Its view that the right extends to donor offspring is discussed further in Chapter Three.⁴⁸ There are also strong indications that the UN Committee on the Rights of the Child shares Sweden's interpretation that Article 7 applies to donor offspring.

When the CRC was drafted, a child's right to know his or her parents under Article 7 was principally concerned with the right for adopted children to

⁴⁶ It should also be mentioned that the source of the right to information about genetic origins is said to stem from the right to privacy under Article 17 of the ICCPR, which is in turn complemented by the right to birth registration under Article 24 (text of corresponding articles below). See S Besson, 'Enforcing the child's right to know her origins: contrasting approaches under the Convention on the Rights of the child and the European Convention on Human Rights' (2007) 21 *International Journal of Law, Policy and the Family* 137, p 141. See also Detrick *ibid*, p 145.

ICCPR Article 17:

1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honor and reputation.
2. Everyone has the right to the protection of the law against such interference or attacks.

ICCPR Article 24:

2. Every child shall be registered immediately after birth and shall have a name.
3. Every child has the right to acquire a nationality

⁴⁷ Moreover, the absence of unification is not confined to the differences between independent states. In Australia, for example, there is no evidence of a consensus on this issue even among the different states of the federation, where Victoria and Western Australia are the only states to date to have acknowledged the child's right to identifying information about the donor through legislation.

⁴⁸ See Part 3.7.2, below.

find out about their biological parents.⁴⁹ Now, however, it is widely accepted that beneficiaries of the right to know include donor offspring. This is evident both from the reports of States Parties to the Committee on the Rights of the Child — where States Parties have themselves raised issues concerning donor offspring, bringing this to the attention of the Committee⁵⁰ — and from statements made by the UN Committee itself.⁵¹ As to the latter, the Committee has expressed concern about the possible contradiction between Article 7 and Norway’s former policy in relation to anonymous sperm donors. Denmark has also been mentioned by the Committee in this regard.⁵² Moreover, the Committee’s critical comments about France’s policy on anonymous birth, which include references to both adoption and medically assisted procreation,⁵³ not only confirm that the definition of “parents” under Article 7 includes genetic parents; it in effect assumes that the right to know extends to donor offspring. Since the comments and recommendations of the Committee on the Rights of the Child are recognised ‘as the highest authority for interpretation of the Convention’,⁵⁴ these examples indicate that the right to, as far as possible, know one’s parents — or genetic origins — under Article 7 of the CRC extends to donor offspring and their right to information about the donor. Unlike Sweden, not all States Parties have interpreted Article 7 in this way. It is, however, clearly the view of the Committee on the Rights of the Child and to this extent difficult to disregard. Whether or not the right includes identifying information about the donor is considered below.

2.2.4.2 Does the right to know under Article 7 extend to identifying information about the donor?

While there has been a growing tendency for states to acknowledge a child’s right to identifying information about the donor, the domestic laws of most contracting states continue to remain silent on this matter, revealing that the

⁴⁹ See Detrick above n 24, pp 153–154. See also Hodgkin and Newell above n 24, p 116. See further an early article by Michael Freeman where he raises the issue of identity in relation to the CRC and ART children: M Freeman, ‘The new birth right? Identity and the child of the reproduction revolution’ (1996) 4 *International Journal of Children’s Rights* 273–297. See esp pp 283–285.

⁵⁰ See further comments in SOU 1997:116, p 212.

⁵¹ See Hodgkin and Newell above n 24, pp 116–119 regarding various States’ interpretations of the child’s right, as far as possible, to know his or her parents.

⁵² See comments made by the Committee on the Rights of the Child in its concluding observations to Norway’s and Denmark’s Initial Reports: Norway IRCO, Add.23 para 10; and Denmark IRCO, Add.33 para 11, in Hodgkin and Newell *ibid*, p 119.

⁵³ See comments made by the Committee on the Rights of the Child in its concluding observations to France’s Initial Report: France IRCO, Add.20 para 14. **Note** also that the Committee on the Rights of the Child has criticised Luxembourg for its practice of anonymous birth. See Luxembourg IRCO, Add.92 paras 11 and 29, in Hodgkin and Newell *ibid*, p 117.

⁵⁴ Hodgkin and Newell *ibid*, Intro VX.

issue is far from settled.⁵⁵ Comments made by the UN Committee on the Rights of the Child in response to anonymous births and anonymous sperm donation,⁵⁶ however, provide a strong indication that, in the Committee's view at least, the scope of Article 7 now includes the right to know the identity of the donor, irrespective of the original intention behind Article 7.

Even so, it is not unusual for States Parties to attempt to justify an interpretation of Article 7 that permits the destruction of records containing identifying information about a child's genetic parents. The qualification that a child has the right to know his or her parents "as far as possible", for example, has been a veritable breeding ground for creative interpretation by some States Parties which have used it to rationalise practices such as anonymous gamete donation, anonymous birth and secret adoptions.⁵⁷

In determining the meaning of "as far as possible", Hodgkin and Newell identify three different situations that need to be distinguished. Either:

1. A parent cannot be identified;
2. A mother refuses to identify the father; or
3. A State decides that a parent should not be identified.⁵⁸

While it is not possible to entirely prevent the first two scenarios, the third situation is different because it turns upon the will of a State Party. An example from this category is where States Parties protect the anonymity of gamete donors.⁵⁹ According to Hodgkin and Newell, this third category 'includes the most controversial aspects of the interpretation of "as far as possible", appearing to unnecessarily breach children's right to know their genetic parents.'⁶⁰ This is in line with statements made by the Committee on the Rights of the Child which consistently maintains its position that secrecy regarding a parent's identity is unacceptable.⁶¹

The assumption that it is acceptable, under certain circumstances, to withhold information from a child about his or her genetic parents is also evident from the reservations to Article 7 made by various States Parties. Such reservations have included the intention by States Parties to uphold the confi-

⁵⁵ Other States that have given donor offspring a statutory right to know the identity of the donor include Austria, New Zealand, the United Kingdom, Switzerland, the Netherlands, Norway, and the Australian States of Victoria and Western Australia.

⁵⁶ See Part 2.2.4.1, above.

⁵⁷ For the meaning of "as far as possible" and examples of the various interpretations of States parties see further Hodgkin and Newell above n 24, pp 117–119.

⁵⁸ *Ibid*, p 117.

⁵⁹ The other examples given by Hodgkin and Newell are where adoption law prevents children from finding out the identity of their parents; and where a State's law requires that paternity is falsified on the birth certificate eg where a child's father is not the mother's husband. *Ibid*, p 117.

⁶⁰ *Ibid*, p 117.

⁶¹ See esp examples in relation to Article 7 from Hodgkin and Newell *ibid*, pp 116–119.

dentiality of genetic parents in relation to ART procedures, adoption and anonymous births.⁶²

Whether the reasons for denying a child information about his or her genetic origins stem from a State Party's reservation or from its own interpretation of Article 7, however, makes no difference to the Article's scope, which appears firmly established. The UN Committee's view about a child's right to know the identity of his or her genetic parents has been unwavering. To this end it has even been unconvinced by arguments from various States Parties which, in an attempt to justify secrecy following anonymous births and so called secret adoptions, maintain that such practices are consistent with the child's best interest.⁶³ Similar arguments in relation to the secrecy of gamete donation have been no more persuasive.⁶⁴

When it comes to donor offspring then, it is doubtful that States Parties can rely on the Article 7 limitation "as far as possible", in order to justify the destruction of records containing the identity of gamete donors. On the contrary, in order for a State Party to be confident that its practices are consistent with Article 7 of the CRC, it must instead preserve, and arguably make available to donor offspring on request, information identifying the genetic parent or parents. The Committee on the Rights of the Child has unambiguously shown its hand in relation to the importance of maintaining accurate records about genetic parents in order to ensure that this information is subsequently available to the children about whom it relates. This, of course, includes securing information for donor offspring. Thus, while it is acknowledged that the limitation "as far as is possible" in Article 7 could be subject to different interpretations by individual States Parties, there is little room for an interpretation that permits the destruction of records about a child's genetic parents where this information is available, such as in the case of gamete donors.

2.2.5 Concluding remarks

Although the CRC is not a part of Swedish law, it may nevertheless be used by the Swedish courts as a source of law.⁶⁵ Moreover, due to the additional measures put in place by the Swedish Parliament, in particular the creation of the Children's Ombudsman, the CRC is certainly an influential instrument in Sweden. Whether it has, in real terms, served the interests of donor offspring in relation to access to information remains to be seen. However, there is no question that it could be relied upon as a valuable resource to promote children's interests in this respect. Even so, since the CRC has nei-

⁶² For more detail about specific reservations see Detrick above n 24, pp 153–154.

⁶³ See further Hodgkin and Newell above n 24, pp 117–118.

⁶⁴ *Ibid.*, pp 118–119.

⁶⁵ See Cameron (2006) above n 28, p 28.

ther been incorporated nor transformed into Swedish law, the fact remains that it does not have the status of law in Sweden. Irrespective of whether or not Sweden, by virtue of entering into the Convention, is bound under international law, there is no international court to oversee its implementation. As the Office of the Children's Ombudsman has stated, criticism and pressure are really the only sanctions to fall back on when a country does not live up to its obligations under the Convention.⁶⁶

2.3 European Convention on Human Rights

2.3.1 Introductory remarks

Although the CRC is the international instrument which arguably contains the clearest reference that can be linked to a donor offspring's right to information about the donor, it applies only to children and lacks an effective enforcement mechanism. The ECHR is also a source of the right to genetic origins.⁶⁷ Moreover, it guarantees rights to everyone,⁶⁸ and — since becoming part of the national legal system on 1 January 1995 when it was incorporated into Swedish law⁶⁹ — is directly binding on Swedish courts.

The ECHR is thus highly relevant for Swedish donor offspring. Unlike the CRC, Swedish law must not only comply with the ECHR; Swedish courts and administrative agencies must have regard to it when interpreting and applying national law. If not, Sweden could be found to be in breach of

⁶⁶ See the home page of the Children's Ombudsman (Swedish version) <<http://www.bo.se/Adfinity.aspx?pageid=55>> last checked 8 June 2008.

⁶⁷ See fn 23, above, for other possible sources of the right to know one's genetic origins. For the purposes of this chapter, which aims to establish that there is a right to information for donor offspring under international law, it is sufficient to confine the discussion to the CRC and the ECHR. Moreover, as to the existence of the right, Bessen above n 43, p 139 goes as far as to state that '[t]he right to know has ... been guaranteed ... by international human rights law and in particular the ECtHR's case law since 1989 based on ...' the ECHR, the CRC and the Hague Convention on the Protection of Children and cooperation in respect of Intercountry Adoption (not discussed here).

⁶⁸ Article 1 of the ECHR provides that contracting parties are required to secure the rights contained in the Convention to 'everyone within their jurisdiction'.

⁶⁹ The incorporating act being Lag (1994:1219) om den europeiska konventionen angående skydd för de mänskliga rättigheterna och de grundläggande friheterna. [Trans: Act on the European Convention on Human Rights.] It should be mentioned that when the Act was incorporated, a provision was also added to the Instrument of Government, *Regeringsformen* (RF), which provides that '[N]o act of law or other provision may be adopted which contravenes Sweden's undertakings under the European Convention for the Protection of Human Rights and Fundamental Freedoms.' (RF 2:23.) [Official English translation.] For more on the constitutional status of the ECHR see I Cameron, 'The Swedish experience of the European Convention on Human Rights since incorporation' (1999) 48 *International and Comparative Law Quarterly* 20, pp 22–25.

the Convention in the European Court of Human Rights (ECtHR). Moreover, the ECHR extends the number of potential rights holders beyond that of the CRC to all children and adults, including those who are unable to benefit from the access to information provisions of the Genetic Integrity Act.⁷⁰

To date, no cases from the ECtHR have specifically addressed the question of a donor offspring's right to know the identity of the donor. Even though the court has not ruled directly on this issue, however, it has on several occasions considered access to information about genetic origins in relation to Article 8 of the ECHR. Since the question of a donor offspring's right to identifying information about the donor continues to gather momentum world-wide,⁷¹ it is only a matter of time before this issue comes before the Court. An overview of the ECHR's potential as a tool for promoting, or perhaps even enforcing, access to information for Swedish donor offspring is thus timely.

2.3.2 Source of the right to information about genetic origins

The source of the right to information about genetic origins is the *right to respect for private life* contained in Article 8 of the ECHR. Article 8 provides as follows:

Article 8 *Right to respect for private and family life*

1. Everyone has the right to respect for his private and family life, his home and his correspondence.

⁷⁰ Kilkelly also points out that, since the ECHR is enforceable, it can compensate for the poor enforcement mechanism of the CRC, thereby further promoting children's rights. She suggests that an approach whereby the principles and provisions of the CRC are invoked to provide guidance in interpreting and applying the ECHR. Such a technique, according to Kilkelly, 'would help to fulfill the potential of both treaties to protect and promote children's rights at the international level and at the domestic level where the ECHR is part of domestic law.' Although her article focuses on the ECtHR's practice in relation to juvenile justice and physical punishment, Kilkelly also recognises the potential influence of the CRC in this connection in promoting the child's right to identity. See Kilkelly (2001) above n 29, pp 311, 325–326.

⁷¹ This is evident not only from the growing numbers of studies being undertaken worldwide on donor offspring and their parents (see further Chapter 4, below) but also from the growing number of jurisdictions which have passed legislation to give donor offspring the right to access identifying information about the donor. Such jurisdictions include Victoria, Australia (Infertility Treatment Act 1995, s 79); Western Australia (Human Reproductive Technology Act 1991, s 49(2d)); New Zealand (Human Assisted Reproductive Technology Act 2004, s 57); the United Kingdom (Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004, Reg 2(3)); and Norway (Act on the Medical use of Biotechnology (5. 12.2003/100)). These factors, in conjunction with comments made by the Committee on the Rights of the Child, above, have placed the issue of access to information for donor offspring firmly on the international agenda, irrespective of whether individual jurisdictions choose to acknowledge the right through their own domestic laws.

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

All four rights contained in paragraph one of Article 8, above, ‘can be said to fall within the concept of “privacy”’.⁷²

2.3.3 Scope of the right to information under the ECHR

2.3.3.1 Introductory remarks

Already in 1989, the ECtHR in *Gaskin v The United Kingdom*⁷³ confirmed its view that ‘respect for private life [under Article 8] requires that everyone should be able to establish details of their identity’.⁷⁴ Whether or not this decision is authority for a child’s right to know the identity of his or her genetic parents has been debated.⁷⁵ However, in light of several subsequent judgments from the Court it is now clear that the right to know one’s genetic origins — or one’s identity — falls within the concept of private life under Article 8 of the ECHR.⁷⁶ Engaging Article 8 then, does not appear to be a problem for donor offspring. But whether the right to genetic origins under Article 8 could ever be regarded as absolute is another question.

⁷² See Cameron (2006) above n 28, p 111.

⁷³ *Gaskin v The United Kingdom*, App no 10454/83, 7 July 1989.

⁷⁴ *Gaskin*, para 39.

⁷⁵ Forder, for example, assumes it is while Kilkelly and Van Buuren do not agree with this interpretation. See C Forder, ‘Constitutional principle and the establishment of the legal relationship between the child and the non-marital father: A study of Germany, the Netherlands and England’ (1993) 7 *International Journal of Law and the Family* 40, p 59; U Kilkelly, *The child and the European Convention on Human Rights* (1999), p 105; and G Van Buuren, ‘Children’s access to adoption records: State discretion or an enforceable international right?’ (1995) 58(1) *Modern Law Review* 37, p 45.

⁷⁶ See *Jaggi v Switzerland*, App, no 58757/00 para 25; *Odièvre v France*, App no 42326/98 para 29; and *Mikulic v Croatia*, App no 53176/99 paras 54 (referring to *Gaskin*) and 64.

Note, in the UK case of *Rose and Another v Secretary of State for Health (2) Human Fertilisation and Embryology Authority* [2002] EWHC 1593 (Admin), 26 July 2002, it was held that Article 8 of the ECHR was engaged with regard to both identifying information and non identifying information sought by donor offspring. This was a case for judicial review brought under the Human Rights Act 1998 (UK). Although it has no precedent value for signatories to the ECHR it is mentioned here because it gives a clear message about the way in which the UK has chosen to interpret the application of Article 8 ie the article may be engaged even where donor offspring apply for information about donors. This case should also be of interest to other contracting States. As Cameron has stated, in another context, ‘[c]onvention issues can arise under national law which have not (yet) arisen in the context of the Convention system. Thus, studying the case law of other jurisdictions dealing with the Convention can be of immediate benefit to one’s own system ...’ See Cameron (1999) above n 69, p 20.

Paragraph two of Article 8 appears to make it possible for states to limit the exercise of the right to respect for private and family life where it interferes with ‘the protection of the rights and freedoms of others.’

Of those few cases that explore the nature and scope of the right to information about genetic origins, two judgments in particular, *Odièvre v France*⁷⁷ and *Jäggi v Switzerland*,⁷⁸ indicate the extent of this limitation. They also provide a realistic idea about the potential scope of the right to identifying information. These two cases are important for donor offspring because they demonstrate a marked change in the line of reasoning by the Court, both in relation to the evaluation of the scope of the right and as regards the extent of a State’s perceived margin of appreciation. At the same time they offer insight about the extent to which donor offspring may be able to rely on Article 8 as a means to pursue identifying information about the donor.

2.3.3.2 *Odièvre v France*

In the case of *Odièvre v France*⁷⁹ the ECtHR, sitting as a Grand Chamber, confirmed that the right to private life included the right to know one’s identity in relation to an adult born following the anonymous birth procedure in France. Article 8 of the ECHR was thus engaged.⁸⁰ However, in light of the facts, the Court — by 10 votes to 7 — refused to find that the French practice of anonymous birth was in breach of the right to private life under Article 8, accepting that under French law a mother’s right to anonymity could completely override any request for identifying information made by the child. Accordingly, the applicant was not entitled to obtain information that would identify her genetic mother.⁸¹

In this case, competing interests were of little importance to the Court. Essentially, it accepted that the French legislation sought to ‘strike a balance and to ensure sufficient proportion between the competing interests.’⁸² It thus found that France had ‘not overstepped the margin of appreciation which it must be afforded in view of the complex and sensitive nature of ... access to information about one’s origins.’⁸³ The Court’s dissenting minority disagreed. In its view it was not possible to balance interests in the case in ques-

⁷⁷ *Odièvre v France*, App no 42326/98, 13 February 2003.

⁷⁸ *Jäggi v Switzerland*, App no 58757/00, 13 July 2006.

⁷⁹ *Odièvre v France*, App no 42326/98, 13 February 2003.

⁸⁰ Para 29.

⁸¹ See esp paras 40–49. For an excellent article about the law and practice of anonymous birth in France which includes the relevant background to the *Odièvre* case see N Lefaucheur, ‘The French ‘tradition’ of anonymous birth: The lines of argument’ (2004) 18 *International Journal of Law, Policy and the Family*, pp 319–342. See also Iain Cameron’s comments on the *Odièvre* case in I Cameron, ‘European Court of Human rights – July 2002–September 2003’ (2004) 10 *European Public Law* 423, pp 441–443.

⁸² *Odièvre*, para 49.

⁸³ Para 49.

tion, either in law or in practice, since ‘French law accepted that the mother’s decision constituted an absolute defence to any requests for information by the applicant, irrespective of the reasons for or legitimacy of that decision.’⁸⁴

Thus, a major problem with the *Odièvre* decision — as seen by the minority opinion — is that, in accepting as valid the supremacy of the mother’s decision under French law, the Court completely failed to consider conflicting interests.⁸⁵ According to Callus, ‘the lack of consideration of the potentially conflicting interests’ makes the judgment in *Odièvre* particularly vulnerable.⁸⁶ In light of the subsequent decision of the Court in *Jäggi v Switzerland*,⁸⁷ below, this prediction was not entirely unfounded. Interestingly, Callus also suggested that, since the case was justified on the particular facts, it could ‘prove to be inadequate to deal with other claims of a right to know one’s genetic origins’ such as those made by donor offspring seeking information about the donor.⁸⁸ But this comment was made before the Court’s apparent turn-around, evident in *Jäggi*.

2.3.3.3 Jäggi v Switzerland

Three years after the decision in *Odièvre v France*,⁸⁹ the ECtHR’s capacity as an evolving and progressive organ was demonstrated in *Jäggi v Switzerland*.⁹⁰ Here the Court grasped the opportunity to clarify its requirement to take into account competing interests in determining whether there has been a violation of Article 8 of the Convention.

First, in establishing that Article 8 was engaged, the Court confirmed that ‘the right to know one’s ascendants falls within the scope of the concept of “private life”, which encompasses important aspects of one’s personal identity, such as the identity of one’s parents’.⁹¹ Moreover, the Court could find no reason why the notion of “private life” should exclude, *inter alia*, the determination of a *biological* relationship between a child and his natural father where the child had been born out of wedlock.

The applicant in this case was an adult male who was seeking to establish the identity of his biological father, presumed to be a man who had died almost three decades earlier. In order to establish this, it was necessary to

⁸⁴ Joint dissenting opinion, para 7. The Court’s dissenting minority went on to say that ‘the mother’s refusal is definitively binding on the child, who has no legal means at its disposal to challenge the mother’s unilateral decision.’ **Note** that the Court’s decision has also been criticised by scholars for giving absolute priority to the mother without balancing the interests at stake. See further Besson above n 46, p 151.

⁸⁵ Joint dissenting opinion, para 7.

⁸⁶ T Callus, ‘Tempered hope? A qualified right to know one’s genetic origin: *Odièvre v France* (2004) 67(4) *Modern Law Review* 658, p 665.

⁸⁷ *Jäggi v Switzerland*, App no 58757/00, 13 July 2006.

⁸⁸ Callus above n 86, p 669.

⁸⁹ *Odièvre v France*, App no 42326/98, 13 February 2003.

⁹⁰ *Jäggi v Switzerland*, App no 58757/00, 13 July 2006.

⁹¹ *Jäggi*, para 25.

exhume the body so that DNA samples could be taken from the corpse, a request refused by the Swiss authorities.⁹² One of the competing interests was the deceased's legitimate family who opposed the taking of DNA samples.⁹³ The ECtHR held, inter alia, by 5 votes to 2 that Article 8 of the Convention had been violated.

This case is especially significant for donor offspring because the Court was unequivocal in pointing out that a fair balance must be struck between competing interests. In the instant case, the various interests included the applicant's right to establish his genetic parentage on the one hand and 'the right of third parties to the inviolability of the deceased's body, the right to respect for the dead, and the public interests in preserving legal certainty' on the other.⁹⁴ It should be pointed out that the Court's statement about the requirement to ensure that a fair balance has been struck between competing interests was a direct reference to comments made in the dissenting judgment in *Odièvre*.⁹⁵ In light of the facts, and of the overriding interest at stake for the applicant, the Court in *Jäggi* found that the Swiss authorities failed to ensure that he received the respect for private life to which he was entitled under the Convention by not permitting him to establish his parentage.⁹⁶ In the Court's view, the right to know one's parentage was an *integral* part of the notion of private life⁹⁷ and that persons seeking to establish their parentage have a *vital interest* protected by the Convention.⁹⁸

The majority judgment in the *Jäggi* case could indicate a change in the Court's approach towards individuals seeking their genetic origins.⁹⁹ If so, there is no reason why this should exclude donor offspring. A number of comments made by the Court are without doubt acknowledgments of the minority dissenting opinion in *Odièvre*, above. For example, the Court was unequivocal that the right to an identity 'is an integral part of the notion of private life.'¹⁰⁰ The dissenting opinion in *Odièvre* refers to this as the 'inner

⁹² For the relevant facts see *Jäggi*, paras 4–20.

⁹³ *Jäggi*, para 28.

⁹⁴ *Jäggi*, paras 38–39.

⁹⁵ There, the dissenting judges also stated, inter alia, that '[I]t is not a question of determining which interest must, in a given case, take absolute precedence over others... [The Court] must perform a "balancing of interests" test and examine whether in the present case the French system struck a reasonable balance between the competing rights and interests.' See *Odièvre*, Joint dissenting opinion, para 6.

⁹⁶ See *Jäggi*, para 44 and Reasons for decision.

⁹⁷ *Jäggi*, para 37.

⁹⁸ *Jäggi*, para 38.

⁹⁹ Besson above n 46, p 151, is optimistic that, following the *Jäggi* decision, the ECtHR will be more likely to carefully weigh up interests in favour of applicants seeking their genetic origins in the future. It will be interesting to follow subsequent cases to see if she is correct. In this connection, it should be remembered that the *Odièvre* judgment was a Grand Chamber judgment. It is therefore of a higher status than the *Jäggi* judgment where the Court was sitting as a Chamber.

¹⁰⁰ *Jäggi*, para 38.

core of the right to respect for one's private life.¹⁰¹ Moreover, the Court in *Jäggi* said that such cases call for 'particularly rigorous scrutiny ... when weighing up the competing interests'¹⁰² which is a clear mirroring of the comments made by the dissenting judges in the *Odièvre* case who provided that '... the fairest scrutiny was called for when weighing up the competing interests.'¹⁰³ In this context, the Court in *Jäggi* also confirmed its support for the notion that a State's margin of appreciation depends not only on the right or rights in question — in this case the right to privacy — but also on the very nature of the interest at stake.¹⁰⁴ This was a direct acknowledgment that the right to an identity, ie the nature of the interest, forms part of the inner core of the right to respect for private life and as such the fairest scrutiny is called for in weighing up the competing interests.¹⁰⁵

2.3.3.4 Is the right to genetic origins under Article 8 absolute?

Although it seems that the scope of the right to privacy under Article 8 of the ECHR includes a donor offspring's right to identifying information about the donor, it is clear from the wording of the article, and from the cases, that the right to private life is not absolute where it conflicts with the protection of the rights of others. Thus, a donor offspring's right to identifying information cannot be absolute but must be balanced with the conflicting right of the genetic parent to protect their own privacy by remaining anonymous. To date, all relevant judgments rendered by the ECtHR confirm this.

While there is little doubt that the *Jäggi v Switzerland*¹⁰⁶ judgment further strengthens the scope of the right to genetic origins by embracing the minority opinion of *Odièvre v France*,¹⁰⁷ it does not go so far as to suggest that the right to genetic origins should be absolute. It was shown above that the Court must still consider conflicting interests and this requirement will apply equally to all applicants in the future, irrespective of whether they are seeking information on the basis of being donor offspring, adopted or born following anonymous births. Thus, these cases provide support for the view that the right to private life under Article 8 includes the right for donor offspring to know the identity of the donor but that, in determining whether or not a donor offspring has such a right in an individual case, any competing rights must be weighed up in order to find a balance between the various interests.

In light of the decision in *Jäggi* there is certainly reason to be cautiously optimistic that the ECtHR will now be more likely to weigh interests in fa-

¹⁰¹ See *Odièvre*, Joint dissenting opinion, para 11.

¹⁰² *Jäggi*, para 38.

¹⁰³ See *Odièvre*, Joint dissenting opinion, para 11.

¹⁰⁴ *Jäggi*, para 37. See further comments from the joint dissenting opinion in *Odièvre*, para 11.

¹⁰⁵ That is, an acknowledgment of the Joint dissenting opinion in *Odièvre*, para 11.

¹⁰⁶ *Jäggi v Switzerland*, App no 58757/00, 13 July 2006.

¹⁰⁷ *Odièvre v France*, App no 42326/98, 13 February 2003.

vour of genetic offspring seeking to establish their parentage.¹⁰⁸ To subsequently infer, however, that such a balancing of interests will in turn result in a situation where all donor offspring will be entitled to identifying information about the donor under Article 8 is not only premature; it disregards the fact that States continue to enjoy a margin of appreciation in the event of conflicts between private interests, even if the extent of this margin in relation to access to information about genetic origins has been reduced somewhat by *Jäggi*.¹⁰⁹

Thus, the right to genetic origins in 2008 is by no means absolute. As long as there are legitimate interests to balance — which the Court must take account of — and national laws supporting anonymity, it is unlikely this will change. An assumption that the Court will always come down in favour of an applicant seeking information about genetic origins would be tantamount to an assumption that the Court would fail to acknowledge competing interests, something that is clearly unthinkable.

2.3.4 Importance of the Article 8 cases for donor offspring

Even though it is not possible to conclude that donor offspring have an unconditional right to information about the identity of the donor under Article 8 of the ECHR, recent case law from the ECtHR, above, is nevertheless of great importance for donor offspring. The value of the cases lies not in their promise to guarantee an absolute right to identifying information about the donor. Clearly they offer no such thing. Rather, they are valuable because they provide a strong indication that donor offspring fall within the scope of persons protected by the right to private life under the ECHR, which includes the right to information about genetic origins. In turn, this should ensure that donor offspring will be recognised as legitimate rights holders. The likely result of this is that, in a dispute, any evaluation of their right to information will be carefully balanced along with other competing interests.

2.4 Concluding remarks

There are strong arguments supporting the view that the right to know one's genetic origins under the CRC and the ECHR extends to donor offspring. The respective sources of this right are Article 7 of the CRC which provides

¹⁰⁸ That is, since the Court in *Jäggi* found that persons seeking to establish their genetic parentage have a vital interest protected by the Convention (para 38). See Part 2.3.3.3, fn 98, above.

¹⁰⁹ See in particular, comments made in *Jäggi* at para 37 of those made by the majority in para 37 of *Odièvre* where it was claimed that the 'margin of appreciation was enlarged in the instant case by the fact that no European consensus on the issue of a child's access to information about its origins existed.'

for *the right to know one's parents*; and Article 8 of the ECHR which contains *the right to respect for private life*. Between them, these articles secure for all Swedish donor offspring the right, under international law, to information about their genetic origins.

Although the scope of the right to genetic origins under international law includes identifying information about the donor, however, the right to such information is not absolute, being qualified under each convention. The CRC limits the right by providing that a child has the right to know his or her parents “as far as possible.” In turn, the ECHR right to privacy may be restricted, or limited, where it conflicts with the protection of the rights of others. Accordingly, an unconditional right to identifying information does not, in reality, exist under either convention. As regards the ECHR, case law from the ECtHR confirms this. Where the international law right to information is complemented by domestic legislation that expressly reinforces the right to identifying information, however, donor offspring should be able to find out the identity of the donor, to the extent possible. That is, subject to availability and consent. Whether Sweden has met its obligations to donor offspring under the CRC and ECHR is discussed in the following chapter.¹¹⁰

¹¹⁰ See Part 3.7, below.

3 The right to identifying information under Swedish law

3.1 Introductory remarks

The regulation of ART in Sweden has undergone several changes since 1 March 1985 when the Act on Insemination (SFS 1984:1140)¹¹¹ came into force. Originally, the provisions governing access to identifying information applied only to sperm donation since egg donation was unlawful prior to 1 January 2003. From that date, however, the IVF Act (SFS 1988:711)¹¹² was amended to, inter alia, permit egg or sperm donation in combination with IVF under certain limited circumstances. In effect, this means that all Swedish donor offspring born from gametes donated after 1 March 1985 have a prospective right to obtain identifying information about the donor in accordance with the legislation. That is, assuming they were conceived either in a publicly-funded Swedish hospital or an institution authorised to perform ART procedures by the National Board of Health and Welfare.¹¹³

On 1 July 2006 both of the above acts were repealed and re-enacted, essentially unchanged, as individual chapters of the new Genetic Integrity Act (SFS 2006:351)¹¹⁴ which now governs all activities related to assisted human reproduction and associated research in Sweden, including access to information following donor treatment procedures.¹¹⁵ In substance, however, nothing has changed where it concerns access to information for donor offspring. Chapter Six of the Genetic Integrity Act now regulates the practice of insemination in Sweden, replacing the former Act on Insemination. In turn, the practice of IVF is now governed by Chapter Seven of the Genetic Integrity Act, replacing the repealed IVF Act. The insemination and IVF chapters

¹¹¹ The Act on Insemination was proclaimed on 20 December 1984. Subsequent references to the Act on Insemination are references to the repealed act.

¹¹² **Note:** Although the IVF Act was proclaimed on 14 June 1988, coming into effect on 1 January 1989, the Swedish Parliament at that time chose not to allow the use of donor gametes in conjunction with IVF procedures. The IVF Act was repealed by the Genetic Integrity Act on 1 June 2006. Subsequent references to the IVF Act are references to the repealed act.

¹¹³ See Genetic Integrity Act Ch 6, s 2 (Insemination); Ch 7, s 4(1) (IVF).

¹¹⁴ Hereafter referred to as the Genetic Integrity Act or the 2006 Act.

¹¹⁵ The Genetic Integrity Act also repealed, and subsequently consolidated, the following acts: Act Concerning the use of Certain Genetic Technology in Medical Screening (SFS 1991:114); and Act Concerning Measures for Purposes of Research or Treatment Involving Fertilised Human Ova (SFS 1991:115).

of the 2006 Act have mirror provisions with respect to the right of donor offspring to obtain identifying information about the donor, although the section numbers of the corresponding chapters are different.

The National Board of Health and Welfare's Regulations and Guidelines on Assisted Conception (SOSFS 2002:13), came into force on 1 January 2003 in conjunction with the above-mentioned amendments to the IVF Act. These regulations and guidelines are, in fact, a consolidation of two separate instruments: the former Regulations and Guidelines on Insemination¹¹⁶ and the Regulations and Guidelines on IVF.¹¹⁷ Although the IVF and insemination acts were repealed in 2006, the 2002 Regulations and Guidelines continue to apply to all activity under both the insemination and IVF chapters of the Genetic Integrity Act.¹¹⁸ It should be mentioned that the Regulations and Guidelines on Assisted Conception have been issued together and are contained in the same document. Accordingly, they are dealt with together in this chapter. The combined regulations and guidelines contain 13 chapters. In turn, each chapter contains numbered provisions, commencing with the relevant binding regulations. Where the National Board of Health and Welfare has found it appropriate to issue guidelines in relation to a given regulation, the guidelines are presented immediately underneath the regulation or regulations in question. The respective definitions of the regulations and guidelines are clarified by the National Board of Health and Welfare in the instrument itself, leaving no doubt as to their status. The regulations are defined as binding rules. By contrast, the guidelines contain recommendations about how a law may, or should, be applied and do not rule out other ways to attain the objectives of the legislation.¹¹⁹

This chapter gives an account of the source and the scope of the right to identifying information under Swedish law, beginning with the relevant provisions of the Genetic Integrity Act and the Regulations and Guidelines on Assisted Conception. It subsequently highlights several additional provisions that are directly relevant to access to identifying information for donor offspring including those about record keeping, consent and counselling, and known donors. A number of prohibitions are also mentioned. The chapter concludes by considering whether Swedish law has met its obligations to donor offspring under international law.

¹¹⁶ SOSFS 1987:6, as rep by SOSFS 2002:13.

¹¹⁷ SOSFS 1989:35, as rep by SOSFS 2002:13.

¹¹⁸ When the Genetic Integrity Act came into force, repealing the insemination and IVF acts, relevant amendments to the regulations and guidelines were incorporated by SOSFS 2006:10 (M). These amendments, however, made no substantive changes to SOSFS 2002:13. The purpose of the amendments was, rather, to match up the existing regulations with the new provision numbers of the Genetic Integrity Act. Subsequent references to the Regulations and Guidelines on Assisted Conception are references to SOSFS 2002:13 as amended by SOSFS 2006:10(M).

¹¹⁹ See SOSFS 2002:13, p 2.

3.2 Source of the right

3.2.1 Genetic Integrity Act

The right to identifying information about the donor can be found in Chapters 6 and 7 of the Genetic Integrity Act. The relevant mirror provisions provide that:

A person conceived ... [as a result of a donor treatment procedure] ... has, if he or she has reached sufficient maturity, the right to access the information about the donor which is recorded in the hospital's special medical record.

If anyone has reason to suspect that he or she was conceived through ... [a donor treatment procedure] ... the Social Welfare Board is obliged to, on request, help them find out if there is any information recorded in a special medical record.¹²⁰

3.2.2 Regulations and Guidelines on Assisted Conception

Chapter 10 of the Regulations and Guidelines on Assisted Conception is entitled "The child's right to his or her genetic origin".¹²¹ Neither the regulations nor the guidelines, however, add anything to the provisions of the Act, above, about the actual process of access to information for donor offspring.

What the non binding guidelines do emphasise is that a prerequisite for donor offspring to be able to seek out their genetic origin is that the parents have told them how they were conceived. The guidelines further recommend that parents should, in light of the prospective child's situation and the importance of openness, be offered discussions with a psychologist or social worker both before and after a donor treatment procedure.¹²²

¹²⁰ Ch 6, s 5 (Insemination); Ch 7, s 7 (IVF). [Author's translation.]

¹²¹ It is interesting to note that the heading of Chapter 10 of the regulations and guidelines remains as "The child's right to his or her genetic origin" whereas the corresponding headings in the legislation have been amended to "Right to information". [Author's translations.] See SFS 2006:351, Ch 6, s 5 (Insemination) and Ch 7, s 7 (IVF). The current wording of the headings came about following alternative proposals made by the Council on Legislation and the Ministry of Health and Social Affairs prior to the 2002 amendments to the IVF legislation (SFS 2002:252). The Council on Legislation recommended that the heading proposed by the Ministry of Health and Social Affairs in Section 7 of the IVF Act be changed from "The child's right to information" to "Right to information" since the right applied also to adults. This suggestion was subsequently taken up in the Bill (see prop 2001/02:89, p 86) and adopted although no corresponding change was made to the regulations and guidelines.

¹²² Ch 10 (Guidelines).

3.3 Scope of the right under the Genetic Integrity Act

3.3.1 Right conferred on donor offspring

While the *process* of access to identifying information under Swedish law appears to lack certainty due to the absence of direction in the regulations and guidelines, the law is absolutely clear when it comes to the *scope* of the right to identifying information: The unconditional legal right applies only to donor offspring conceived under the Genetic Integrity Act — or the repealed IVF and insemination acts — from gametes donated after 1 March 1985.¹²³ Moreover, in order to exercise their right to information under the Genetic Integrity Act, donor offspring must have reached “sufficient maturity”.¹²⁴

It follows that donor offspring born through private arrangements or following treatment procedures carried out abroad have no right to information about the donor under the Genetic Integrity Act.¹²⁵ Likewise, parents and donors have no right to identifying information about each other and donors have no right to know the identity of the donor offspring.¹²⁶

The question of whether the parents of donor offspring should be entitled to find out the identity of the donor before the donor offspring child is 18 years old was raised by the original Insemination Committee in 1983. It could not, however, find any convincing reasons to ever permit the release of identifying information to the parents.¹²⁷ Accordingly, it recommended that only donor offspring should have a right to this information.¹²⁸

¹²³ **Note** that although the right to identifying information about the donor is not retrospective, the Government Bill on artificial insemination emphasised that, in consideration of the child’s right to know the identity of the donor, any remaining sperm donated before the access to information provisions came into force should not be used. See further prop 1984/85:2 om artificiella inseminationer, pp 17–18, 31. [Trans: Government Bill on artificial insemination.]

¹²⁴ SFS 2006:351, Ch 6, s 5 (Insemination); Ch 7, s 7 (IVF).

¹²⁵ The term “private arrangements” is used in this context to refer to “do it yourself” inseminations arranged or carried out between private persons ie as opposed to donor treatment procedures performed in hospitals or by medical practitioners that have been authorised to perform such procedures by the National Board of Health and Welfare.

¹²⁶ Cf Victoria, Australia, where it is currently possible for parents and donors to obtain identifying information about each other subject to the consent of the party about whom the information relates. See Infertility Treatment Act 1995 (Vic), ss 74–78.

¹²⁷ SOU 1983:42, p 123. The Committee did not explain its reason for this. Interestingly, however, the subsequent Government Bill provides that such information should not be given to the parents ‘out of consideration for the donor.’ [Author’s translation.] See prop 1984/85:2, p 16.

¹²⁸ This was in turn reinforced in the Government Bill and supported by the Swedish Parliament. See prop 1984/85:2, p 27. For comments made by the Council on Legislation see p 40.

3.3.2 Donor offspring must be “sufficiently mature”

Until recently, the Swedish legislation has been unique in that it expressly enables mature minors to find out the identity of the donor.¹²⁹ The Genetic Integrity Act provides that all donor offspring who have reached “sufficient maturity”¹³⁰ have a right to such information.

This issue was discussed at considerable length by the original Insemination Committee before the Act on Insemination was proclaimed.¹³¹ In its deliberations it found that even children who were younger than 18 years of age could experience a great need to find out the identity of their biological parent, particularly during the teenage years. Although the Committee believed that, in general, teenage children were not sufficiently emotionally mature to use this information in a responsible way it nevertheless considered it appropriate that the social authorities help them work through the feelings they were experiencing — feelings which were associated with the knowledge that they had been conceived through insemination.¹³² Moreover, it considered that in exceptional cases it may be justified to give the child the possibility to find out the identity of the donor, especially where the child was almost 18 years of age. To this end the Committee proposed that mature minors should have the right to obtain identifying information about the donor provided that the donor first consented to the release of the information.¹³³

The Swedish Parliament, however, had a different view, determining instead that all donor offspring should have an unconditional right to identifying information about the donor if they have reached “sufficient maturity”. For adult donor offspring, sufficient maturity is presumed. Donor offspring who are under 18 years of age, however, must first be evaluated by the Social Welfare Board in order to establish whether or not they are sufficiently mature to know the identity of the donor.¹³⁴ When the Act on Insemination was passed it was anticipated that the requirements for sufficient maturity would generally be fulfilled when the child was in the upper teens.¹³⁵

¹²⁹ Cf, eg, legislation in Victoria, Australia and regulations in the UK which require that donor offspring must be 18 years of age before they may exercise their right to apply for identifying information about the donor. See respectively Infertility Treatment Act 1995 (Vic), s 79; and, in relation to the UK, The Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 (2004 No. 1511) r 2(3). But **note** that in recent years, some other jurisdictions have legislated to enable donor offspring to find out the identity of the donor before the offspring is 18. Western Australia and New Zealand are two examples.

¹³⁰ Ch 6, s 5 (Insemination); Ch 7, s 7 (IVF).

¹³¹ See esp SOU 1983:42, pp 122–123, 168.

¹³² SOU 1983:42, pp 122–123.

¹³³ See SOU 1983:42, pp 123, 164 (s 10).

¹³⁴ See prop 1984/85:2, pp 16, 27. See also the Council on Legislation’s comments at p 40.

¹³⁵ Prop 1984/85:2, p 16.

3.4 Best interests of the prospective child — always the starting point for donor treatment procedures

The requirement to consider the best interests of the prospective child is arguably the cornerstone of the insemination and IVF chapters of the Genetic Integrity Act. Mirror provisions contained in these chapters provide, *inter alia*, that donor insemination or IVF ‘... may be performed only if it can be presumed that the prospective child will grow up under good conditions.’¹³⁶

It is self evident, from the wording alone, that this sentence was inserted into the respective provisions in order to ensure that the best interests of the future donor offspring would be prioritised over the needs and interests of prospective parents and donors. Its origin lies in the Insemination Committee's mandate, already in 1983, to protect, foremost, the interests of children born following donor insemination. The Committee's obligation to ensure that the starting point for insemination treatment was that the child would ‘grow up under good conditions’¹³⁷ clearly meant that a donor treatment procedure could only be undertaken if it was in the best interests of the future donor offspring. With regard to the issue of access to identifying information, the Committee drew heavily on the experiences of adopted children, and was convinced that it was in the best interests of donor offspring to be told the truth about their genetic origins.¹³⁸ The connected presumption that openness is presumed to be a pre-condition for the child to grow up under good conditions and therefore in the best interests of the child is further reinforced in the Government Bill.¹³⁹

This focus on the best interests of the child has continued to be a common theme in virtually all subsequent preparatory works connected to donor offspring and access to information. Moreover, the wording of the respective sections of the Genetic Integrity Act,¹⁴⁰ above, is almost identical to the wording contained in the original directive given to the Insemination Committee. This demonstrates a history exceeding 20 years where the requirement to consider the best interests of the prospective child prior to donor treatment procedures has been well established under Swedish law. When one takes into account that the United Nations Convention on the Rights of the Child was not yet in force in the 1980s, Sweden's success in firmly entrenching the best interest of the child principle in its insemination and IVF laws should be regarded as particularly significant.

¹³⁶ Ch 6, s 3 (Insemination); Ch 7, s 5 (IVF). [Author's translation.]

¹³⁷ SOU 1983:42, p 25.

¹³⁸ See esp SOU 1983:42, pp 110–121.

¹³⁹ See prop 1984/85:2, pp 24–25.

¹⁴⁰ See Ch 6, s 3(1) (Insemination); Ch 7, s 5(1) (IVF).

3.5 Right to information — supporting provisions

3.5.1 Introductory remarks

Several other provisions contained in the Genetic Integrity Act and the Regulations and Guidelines on Assisted Conception are directly connected to a donor offspring's right to information about the donor and to this extent should be mentioned here. The record keeping provisions are outlined first since, without these, the unconditional right to identifying information could not be guaranteed to all donor offspring. Secondly, and equally important, are the consent and counselling provisions for parents and donors. One of the main purposes of these provisions is to ensure that parents and donors fully understand the implications of the prospective child's right to identifying information about the donor before the donor treatment procedure takes place. Accordingly, they play a crucial role in the access to information process even though their focus is, by necessity, on the prospective parents rather than on the unborn donor offspring. Finally, the provisions relevant to the known donor process are mentioned in addition to a number of prohibitions.

All of these provisions support the process of access to information for donor offspring and reflect the intention of the Swedish Parliament that, in the carrying out of donor treatment procedures, the best interests of the prospective child must not only be taken into account but must also, as far as possible, be satisfied.¹⁴¹ Moreover, they reinforce the obvious policy of the Swedish Parliament — at least on paper — that donor offspring not only have a right to information about the donor but that it is also in their best interests to have the opportunity to find out about their genetic origins.

3.5.2 Record keeping requirements

A donor offspring's unconditional right to information about the donor would be worthless without an effective system for the preservation of records. Before the Act on Insemination came into force in 1985, record keeping associated with donor treatment procedures was arbitrary and the possibility for donor offspring to discover that they were born through insemination or find out the identity of the donor was very small. All documents concerning insemination treatment were either destroyed or inaccessible to anyone other than the responsible doctor, largely in an attempt to keep the information secret from the child.¹⁴² This situation, whereby society accepted the fact that paternity was founded on a lifelong deception, was contrary to

¹⁴¹ See prop 1984/85:2, p 8 in relation to the requirement to, as far as possible, satisfy the best interests of the child. In general, however, the policy of the Swedish Parliament in this regard is obvious from the provisions of the legislation alone.

¹⁴² See esp SOU 1983:42, pp 51, 54, 56–57.

the Swedish legal development, which continued throughout the 1900s, in relation to the importance of establishing paternity and the child's right to know about his or her origin.¹⁴³ The record keeping provisions of the Swedish insemination and IVF laws were thus principally designed to preserve information about the donor for future donor offspring. To this end they fulfill a vital support function necessary for the access to information process.

The Genetic Integrity Act stipulates that information about the donor shall be recorded in a special medical record which shall be preserved for at least 70 years.¹⁴⁴ The Regulations and Guidelines on Assisted Conception expand on the legislation.

Chapter 11, section 2 of the regulations provides that:

The notes in the medical record about the donor shall be made with consideration to the child's legally prescribed right to find out about his or her origins and right to have the information about the donor which is in this medical record. The donor's medical record shall be labelled with a code.¹⁴⁵

Section 3 of the regulations further stipulates that:

A medical record shall be kept for the woman who undergoes assisted fertilisation.

The woman's medical record shall be maintained in such a way that it is clear which attempt at fertilisation has led to the pregnancy. The donor's code shall be entered into the woman's medical record with every fertilisation occasion.¹⁴⁶

¹⁴³ See further SOU 1983:42, pp 56–57. For an extensive account on the legal aspects of parenthood in Sweden, see Anna Singer's book *Föräldraskap i rättslig belysning* (2000), above n 43. Singer devotes four chapters of her book — over 200 pages — to issues connected to parenthood and adoption, parenthood and assisted conception, and the child's right to know about their genetic origins; with a view to promoting the best interests of the child; On the establishment of paternity in Sweden see A Agell, Å Malmström, and T Sigeman, *Civilrätt*, 20th edn (2007), pp 387–390. [Trans: *Civil law*.]; On the particular issue of the establishment of parenthood in the context of assisted reproduction see Å Saldeen, *Barn- och föräldrarätt*, 5th edn (2005), pp 78–87. [Trans: *Children and parents law*.] The third chapter of Saldeen's book, above, concerns the establishment and annulment of parenthood while the subject of the fourth chapter is "Children through assisted reproduction".

¹⁴⁴ Ch 6, s 4 (Insemination); Ch 7, s 6 (IVF).

¹⁴⁵ Ch 11, s 2 (Regulations). [Author's translation.]

¹⁴⁶ Ch 11, s 3 (Regulations). [Author's translation.]

Details about the nature of information which should be noted in the donor's medical record, and about the preservation of information about the donor, may be found in Chapter 11 of the guidelines. It provides as follows:

In the special medical record about the donor there should be information which can be of value for the child who wants to search his or her genetic origin. The notes should give information about the donor's appearance such as eye- skin- and hair colour, weight and height, work, interests as well as relatives and family circumstances. A photo of the donor can be attached.

To guarantee that the medical record about the donor, and the information about the donor code in the woman's journal, is saved for at least 70 years ... these records should be kept in such a way that elimination [of the donor code and information about the donor] cannot occur before then.¹⁴⁷

In light of the purpose behind the record keeping provisions, Swedish law appears to have effectively fulfilled its obligations to donor offspring by ensuring that identifying information about donors is carefully preserved. Thus, all donor offspring who know that they have a right to information under the legislation will be able to find out the identity of the donor. It is simply a matter of turning to the hospital where the information is stored, or to the relevant office of the Social Welfare Board for assistance.

In addition, record keeping in Sweden appears to be relatively straightforward and easy for health professionals to comply with. The fact that there is no central register no doubt contributes to this by reducing the amount of administration that would otherwise be associated with collating and sending information to a central institution for storage.¹⁴⁸ Work-wise, this is a definite advantage for those collecting the information. In the long term, however, the present system of record keeping could prove to be more labour intensive for the Social Welfare Board when it comes to administering applications for identifying information since the information sought will have to be located and retrieved from the donor's medical record at the hospital where the treatment procedure took place. While this in no way affects whether or not donor offspring can find out the identity of the donor, it is an inefficient and inconvenient way to administer access to identifying information. On this basis alone the establishment of a central register containing information about all Swedish donors and donor offspring should be considered.¹⁴⁹

¹⁴⁷ Ch 11 (Guidelines). [Author's translation.]

¹⁴⁸ Cf the significantly more demanding requirements placed on Victorian licensed centres in relation to recording and sending information to the Victorian Infertility Treatment Authority. See Infertility Treatment Act 1995 (Vic), ss 66–70, and the Victorian Infertility Treatment Regulations (1997) Vic, rr 13–17.

¹⁴⁹ The issue of a central register for Sweden is further discussed in Chapter 5, below.

3.5.3 Consent and counselling

3.5.3.1 Introductory remarks

The counselling and consent provisions for prospective parents and donors contained in the Genetic Integrity Act and the Regulations and Guidelines on Assisted Conception also contribute to the access to identifying information process. The objective of these provisions is, broadly, to thoroughly equip both parents and donors about the implications of donation, particularly in relation to the special needs and rights of any prospective child so that the child may grow up under good conditions. Before the regulations and guidelines were drafted, it was assumed that a major feature of such preparation would and should include an emphasis on the importance of openness on behalf of the parents. Such openness was, needless to say, seen to be in the best interests of the child. The assumption was — and continues to be — that information about the donor is best received when it comes from the parents.¹⁵⁰ Moreover, well prepared parents who have had the opportunity to work through the many issues associated with creating a donor family are more likely to disclose, which means that more children will be able to exercise their unconditional right to identifying information about the donor. In light of the legal obligation to satisfy the best interests of donor offspring, an evaluation of the counselling and consent provisions in order to see whether they promote disclosure — thus enabling donor offspring to exercise their right to information — is timely.

3.5.3.2 Consent requirements — prospective parents

Since oral consent from a patient prior to medical and surgical treatment is generally regarded as sufficient consent in Sweden, and donor treatment procedures do not fall under one of the exceptions to this rule,¹⁵¹ the Genetic Integrity Act does not require written consent from a woman prior to insemination or IVF treatment.¹⁵² The Act does, however, require written consent from the spouse of the woman undergoing insemination or IVF before the procedure may take place.¹⁵³ The main reason for obtaining written consent from the spouse is to avoid problems with the establishment of paternity or, where it concerns lesbian couples, “parenthood”. A written consent ensures that an unmistakable declaration of will has been made on behalf of the

¹⁵⁰ See, eg, SOU 1983:42, p 116; prop 1984/85:2, p 15; prop 2001/02:89, pp 46–48; and SOU 2007:3, pp 92 (and see further pp 127–128).

¹⁵¹ Two examples of situations where written consent is required are prior to organ donation (ie of a live patient) and prior to sterilisation procedures. See E Rynning, *Samtycke till medicinsk vård och behandling: en rättsvetenskaplig studie* (1994), p 177. [Trans: *Consent to medical care and treatment: a legal scientific study.*]

¹⁵² This is also in line with the recommendations made by the Insemination Committee in 1983. See SOU 1983:42, p 104.

¹⁵³ See Ch 6, s 1 (Insemination); Ch 7, s 3 (IVF). The term “spouse” refers to the husband or the cohabiting partner of the woman undergoing treatment.

prospective parent who is not genetically connected to the child.¹⁵⁴ Needless to say, securing such consent is in the best interests of future donor offspring because it ensures that the consenter will be the legal parent of the child.

Further information on the recommended management of spousal consents may be found in Chapter Six of the Regulations and Guidelines on Assisted Conception. Here, the guidelines provide that the doctor should inform the couple about the implications of the consent. In addition, prior to each conception attempt, the doctor should ensure that the consent is still valid and make a note of this in the woman's medical record. Written consent by the spouse should be given on the prescribed form which is to be countersigned by the doctor.¹⁵⁵ The guidelines further stipulate that the spouse of the woman undergoing the treatment procedure should be informed that consent applies from the date it is given. It can be revoked either orally or in writing and such revocation applies from the time the doctor receives notification about it.¹⁵⁶

Two factors evident from the pre-treatment consent requirements, however, could be seen as inconsistent with Parliament's intention that prospective parents are fully aware of the implications of donation, particularly in relation to the importance of disclosure. First, the procedural and information requirements for consents prior to donor treatment procedures in Sweden are set out as recommendations in the non-binding guidelines. As such there is no guarantee that the same information will be provided for all prospective parents prior to their consent being obtained. Secondly, the consent process lies in the hands of the responsible doctor who retains sole responsibility for ensuring that parents understand not only the medical but also the psycho-social implications of donation.¹⁵⁷

¹⁵⁴ See also SOU 1983:42, p 105. Rynning refers to this requirement that spouses must give written consent as "something special", since the consent is not required to be given by the person who is having the treatment. Rather, the consent is important — above all — for the establishment of paternity. See Rynning, above n 151, p 178.

¹⁵⁵ Standard Consent Form SoSB 37231 for Consent to insemination with donated sperm (also as Attachment 1, SOSFS 2002:13 as amended by SOSFS 2006:10 (M)); Standard Consent Form SoSB 37251 for Consent to IVF using either donated ova or sperm, or the spouse's own sperm (also as Attachment 2, SOSFS 2002:13 as amended by SOSFS 2006:10 (M)).

¹⁵⁶ See Ch 6 (Guidelines).

¹⁵⁷ This is in stark contrast with the requirements in Victoria, Australia, for example where the corresponding information and procedural requirements for consenting prior to donor treatment procedures are prescribed by the legislation. **Note** also that in Victoria it is not possible for a woman to consent to a donor treatment procedure before the woman and her spouse have received counselling from a licensed counsellor approved under the Act. The Regulations further prescribe the matters that must be covered during such counselling sessions. See Infertility Treatment Act 1995 (Vic), ss 10–11, and Infertility Treatment Regulations 1997 (Vic), r 6.

3.5.3.3 Consent requirements — donor

In addition to spousal consent prior to donor treatment procedures, the Genetic Integrity Act requires written consent from egg and sperm donors before their gametes may be used in IVF procedures.¹⁵⁸ Surprisingly, no corresponding written consent by the donor is required for “straightforward” donor insemination.¹⁵⁹ This has been the case since the Act on Insemination came into effect in 1985. At that time, however, it was not possible under the legislation to use donated sperm for IVF purposes. Why the issue of consent with insemination was not reviewed when the new consent requirements came in for IVF procedures came into effect in 2003, is unclear.

The Regulations and Guidelines on Assisted Conception also contain a standard consent form which egg and sperm donors are required to sign prior to donating their gametes for the purpose of IVF.¹⁶⁰ The guidelines recommend that the doctor countersign the consent of the donor and advise the donor that he or she may revoke the consent orally or in writing before a treatment procedure has taken place.¹⁶¹ Importantly, these guidelines and the standard consent form apply only to donor consents where IVF procedures are undertaken.

It is difficult to understand why Swedish egg and sperm donors are required, under the law, to provide written consent before their gametes may be used in IVF procedures, while sperm donors donating for “straightforward” insemination are not. Considering the implications of donation, particularly the fact that the donor offspring may attempt to locate the donor later in life, it should be assumed that all donors must be treated equally when it comes to written consent; the potential consequences are the same for all donors, irrespective of whether a procedure involves IVF or not.

3.5.3.4 Counselling and psycho-social evaluation — prospective parents

Mirror provisions contained in the Insemination and IVF Chapters of the Genetic Integrity Act provide that it is the responsible doctor who must evaluate whether or not it is suitable — in light of a given couple’s medical, psychological and social circumstances — for a donor treatment procedure to take place.¹⁶² The same provisions also stipulate that a donor treatment procedure ‘may be performed only if it can be presumed that the prospective child will grow up under good conditions’,¹⁶³ above, making it absolutely clear whose interests the Act seeks to protect.

¹⁵⁸ See Ch 7, s 2 (IVF). Revocation of consent prior to fertilisation is also possible under this section of the Act.

¹⁵⁹ See Ch 6 (Insemination).

¹⁶⁰ Standard consent form SoSB 37270. See also Attachment 3, SOSFS 2002:13 as amended by SOSFS 2006:10 (M).

¹⁶¹ See Ch 7 (Guidelines).

¹⁶² See Ch 6, s 3 (Insemination); Ch 7, s 5 (IVF).

¹⁶³ See Ch 6, s 3 (Insemination); Ch 7, s 5 (IVF).

However, the Act does not contain any specific provisions regarding counselling for prospective parents prior to donor treatment procedures even though counselling is implied through the requirement that the doctor must ensure that a psycho-social investigation of the couple is undertaken prior to the commencement of treatment.¹⁶⁴ That there is no express requirement for pre-treatment counselling in the Act is surprising given the emphasis on the importance of counselling in the preparatory works and the apparent support of such a requirement in the Government Bill prior to the enactment of the Act on Insemination.¹⁶⁵

The regulations on assisted conception are no more enlightening about the counselling process. Instead, it is the guidelines on assisted conception that provide the framework for both counselling and the psycho-social evaluation.¹⁶⁶

According to the guidelines on assisted conception, the investigation and assessment of a couple's psychological and social suitability should always be carried out jointly by the doctor and a social worker or psychologist. The purpose of the investigation is to enable the doctor to acquire an opinion about the couple's suitability as parents, and the investigation should be based upon discussions with the couple, both together and individually.¹⁶⁷ Importantly, the guidelines provide that the doctor should, as far as possible, be certain about six matters under the investigation. Specifically, the doctor should be satisfied that the prospective parents:

- long for and sincerely desire a child,
- have, between them, a relationship that is stable and permanent,
- have the capacity to take care of and raise a child,
- emotionally, practically, socially and legally are prepared to accept the prospective child as their own,
- are conscious of and will be able to handle the inequality which may arise through [the fact that] only one parent will be the genetic parent of the child, and
- will tell the child about the child's origin.¹⁶⁸

The items described above indicate that the counselling process probably does, in practice, take place assuming the guidelines are followed. Without such a process, it would be almost impossible for the doctor to form a view about whether or not a particular couple would make suitable parents to the prospective child. This is, of course, crucial because such an evaluation is a precondition under the Genetic Integrity Act for the commencement of

¹⁶⁴ See Ch 6, s 3 (Insemination); Ch 7, s 5 (IVF).

¹⁶⁵ See esp SOU 1983:42, pp 88, 96–97, 102, 162; and prop 1984/85:2, pp 24–25.

¹⁶⁶ See Ch 4 (Guidelines).

¹⁶⁷ See Ch 4 (Guidelines).

¹⁶⁸ See Ch 4 (Guidelines). [Author's translation.]

treatment.¹⁶⁹ The guidelines, above, carefully set out the considerations which should be taken into account. They also describe the form of the investigation¹⁷⁰ and clearly point to the need to have an assessment of the prospective parents, jointly undertaken by the doctor and the counsellor.¹⁷¹

Even so, since the guidelines are not legally binding, it is not mandatory to follow them to the letter. Two recently-published Swedish studies, discussed below, provide strong indications that the guidelines are not always followed, particularly in relation to the psycho-social investigation where the doctor should be satisfied that the prospective parents ‘will tell the child about the child’s origin.’¹⁷² Why such an important matter as the psycho-social evaluation has been left to the guidelines instead of being expressly catered for by the legislation, or at least by the regulations, is puzzling since it can have such an impact on the best interests of any future child.

Moreover, given Swedish ART law’s unquestionable focus on the best interest of the child, one could question the utility of leaving it up to the responsible doctor to decide whether, in light of the prospective parents’ psychological and social situation, insemination or IVF should be permitted.¹⁷³

3.5.3.5 Counselling and psycho-social evaluation — donors

The Genetic Integrity Act is also silent with respect to the counselling of donors prior to the donation of gametes. The regulations which govern the choice of donors provide that before a doctor makes a decision about whether to accept an egg or sperm donor, the doctor shall be clear about, inter alia, the donor’s relevant social relationships and the donor’s motive for donating their gametes.¹⁷⁴ Although the meeting of these requirements would seem to necessitate some form of extended discussion, or “counselling”, between the doctor and the donor about the implications of donation, the regulations provide no further direction about how this should be achieved.

The guidelines on assisted conception also include recommendations that indicate some form of counselling for donors is at least expected.¹⁷⁵ However, it appears as though, in contrast to the Swedish guidelines for the “counselling” of prospective parents,¹⁷⁶ the doctor is assumed to bear the sole responsibility for the counselling of donors. These recommendations clearly

¹⁶⁹ See Genetic Integrity Act, Ch 6, s 3 (Insemination); Ch 7, s 5 (IVF).

¹⁷⁰ See Ch 4 (Guidelines): “The medical investigation” and “The psychological and social investigation.”

¹⁷¹ Ch 4 (Guidelines): “The psychological and social investigation.”

¹⁷² See Ch 4 (Guidelines), above. For a discussion of the studies in question see Part 5.3.3, below.

¹⁷³ This issue is discussed further in Chapter 5, below.

¹⁷⁴ Ch 5, s 2 (Regulations).

¹⁷⁵ See Ch 5 (Guidelines).

¹⁷⁶ That is, where the doctor carries out the psycho-social investigation in conjunction with a social worker or psychologist: see Ch 4 (Guidelines) under the heading “The psychological and social investigation”.

spell out the important issues which should be discussed between the doctor and the donor prior to donation.

The guidelines provide that '[o]nly the man or woman who has a mature and discerning attitude towards egg or sperm donation should be considered as [a] donor ...' and that the '[d]octor should inform a prospective donor about the legal, psychological and social consequences that a donation can give rise to.'¹⁷⁷ The guidelines further provide that the doctor should also find out about the prospective donor's attitude towards the following:

- the child who has been begotten with the help of donated eggs or, alternatively, donated sperm has [a] right to find out who the donor is,
- the child may come to contact [the donor] in the future,
- information in the journal about [the donor's] appearance, such as eye colour, skin colour or hair colour, weight and height, work, interests as well as relatives and family circumstances can be a source of joy for a child who searches his or her genetic origin, and
- it may be necessary that [the donor] is contacted later in life in order for a blood test to be taken, or for some other investigation.¹⁷⁸

Moreover, '[t]he doctor should take into account the proposed donor's position in relation to these questions when choosing a suitable donor.'¹⁷⁹

The guidelines carefully outline the issues that donors need to consider prior to donation. The wording of the provisions certainly gives the impression that every effort has been made to ensure that donors are fully aware of the personal consequences associated with donating, in addition to the impact such donation is likely to have on donor offspring. However, the same problem regarding the non-binding nature of the guidelines in relation to parent counselling, identified above, is also evident when it comes to the provisions for the counselling of donors. That is, these important recommendations, which set out to steer the practice of pre-treatment donor counselling, emanate from the guidelines.

Neither the Swedish legislation nor the regulations on assisted conception expressly provide for the counselling of donors. Moreover, the responsibility for the process of donor counselling, according to the guidelines, is left up to the doctor. Thus, unless the doctor ensures that the donor is well informed and counselled appropriately, it may not occur.¹⁸⁰ In light of the significance of donation and the potential consequences of a donor possibly meeting a genetic child in future years, it is difficult to accept that the Swedish Parliament intended that the medical profession should bear sole responsibility for

¹⁷⁷ Ch 5 (Guidelines). [Author's translation.]

¹⁷⁸ Ch 5 (Guidelines). [Author's translation.]

¹⁷⁹ Ch 5 (Guidelines). [Author's translation.]

¹⁸⁰ This can also be clearly distinguished from the Victorian law which has unequivocally spelt out its counselling requirements for donors through its act and regulations, leaving no doubt that they are binding. See Infertility Treatment Act 1995 (Vic), ss 16–17, and Infertility Treatment Regulations 1997 (Vic), r 7.

the counselling and approval of potential donors and that this process should be undertaken via non-binding guidelines.

3.5.3.6 Concluding remarks

The Swedish provisions governing counselling and consent for prospective parents and donors have no doubt increased the likelihood that both parties will have the opportunity to receive counselling prior to consenting to donor treatment procedures. This situation is certainly an improvement on the previously unregulated nature of counselling which existed before the Act on Insemination came into force in 1985. Yet even after more than two decades, there is still no strict legal requirement that counselling must be undertaken.¹⁸¹ Where counselling is routinely offered, both prospective parents and donors will presumably be better informed about their obligations to the prospective donor offspring. Counselling is also an excellent starting point to prepare parents for the challenges associated with raising a donor offspring child. This is clearly important since, as already pointed out above, one of the doctor's obligations under the Act is to be satisfied, prior to performing a donor treatment procedure, that any future donor offspring child will grow up under good conditions.

Even so, where it concerns counselling and consent under Swedish ART law much of the important detail regarding the obligation of parents to inform donor offspring of their legal right to information — something intended to be covered by pre-treatment counselling — exists in the guidelines. From a donor offspring perspective this situation is far from satisfactory. It may well be the case that, on most occasions, the guidelines are followed by practitioners prior to treatment procedures and the importance of the prospective child's right to information about the donor is reinforced with the prospective parents as intended. Where this occurs, the best interests of the prospective donor offspring are satisfied, as far as possible, as intended in accordance with the law. However, because there is no legal requirement for doctors or allied health professionals to adhere to the guidelines in the same way as they must follow the legislation or the regulations, there is a risk that, on occasions, formal counselling may be omitted. Accordingly, some of the information recommended in the guidelines may not be covered with the parents in the lead-up to a donor treatment procedure. This could lead to a situation which is not consistent with the requirement to, as far as possible, satisfy the best interests of any future child in relation to a donor treatment procedure because Swedish law assumes that it is in the best interests of donor offspring to know about the existence of the donor. If prospective parents are not sufficiently counselled, they may be less inclined to

¹⁸¹ Genetic Integrity Act, Ch 6, s 3 (Insemination); Ch 7, s 5 (IVF). Cf Victoria's consent requirements for prospective parents, mentioned above in fn 157.

be open with their child which would in turn defeat the purpose of the access to information provisions.

3.5.4 Known donors — pre donor treatment procedure

The possibility for a couple to select their own donor is not expressly provided for in the Swedish legislation. Rather, as was seen above, the provisions of the Genetic Integrity Act charge the doctor with the responsibility of selecting a “suitable donor”.¹⁸² The intention is that the donor is selected by the doctor without any input at all from the parents.¹⁸³ However, it is still possible under Swedish law for couples to request a known donor. The source of this alternative is the original preparatory works to the Act on Insemination.¹⁸⁴ While the Swedish Insemination Committee did not support the notion of parents making demands in respect of the selection of a suitable donor, it could not find any reason to recommend a total prohibition on the use of identified or known donors, selected by the parents, in individual cases. Thus, the Committee recommended that it be left up to the doctor to decide whether the chosen donor would be suitable, leaving the door open for the use of known, or identified, donors in Sweden.

This recommendation was not rejected by Parliament in 1984 when the original legislation on insemination was passed. Nor has it been contradicted on any subsequent occasion. The Committee’s view that, in exceptional cases, a donor known to the prospective parents may be used is reflected in the guidelines on assisted reproduction.¹⁸⁵

The guidelines provide that where an identified donor is used, the doctor should, *inter alia*, advise the couple about the psychological and social consequences that such a donation can give rise to. The doctor should also attempt to assess whether the prospective parents and the donor will be able to handle the situation.¹⁸⁶ Moreover, before a donor treatment procedure using a known donor takes place, both the couple and the donor should be offered the opportunity to meet with a psychologist or social worker.¹⁸⁷

There is no doubt that the best interests of future donor offspring were taken into account when the guidelines about donors identified prior to treatment procedures were contemplated and issued. This is obvious from the wording of the guidelines which carefully follow the recommendations of the Swedish Insemination Committee. An important factor, however, which is perhaps not totally consistent with Parliament’s requirement that the best interests of future donor offspring be satisfied, is that the identified

¹⁸² Ch 6, s 4 (Insemination); Ch 7, s 6 (IVF).

¹⁸³ SOU 1983:42, pp 162–163 s 8.

¹⁸⁴ See SOU 1983:42, pp 102, 162–163 s 8.

¹⁸⁵ Ch 5 (Guidelines).

¹⁸⁶ This was also recommended by the Insemination Committee. See SOU 1983:42, p 163.

¹⁸⁷ Ch 5 (Guidelines).

donor procedure — including any counselling requirements for prospective parents — is regulated only by the guidelines.

3.5.5 Prohibitions supporting access to information

The Genetic Integrity Act contains two prohibitions particularly relevant to the best interests of donor offspring and their right to identifying information about the donor: the prohibition against the importation of sperm and the prohibition against using the gametes of dead donors. In addition, the regulations on assisted conception prohibit the mixing of gametes in a treatment procedure.

The importation of frozen sperm into Sweden without permission from the National Board of Health and Welfare is prohibited by the insemination chapter of the Genetic Integrity Act.¹⁸⁸ The origin of this prohibition was the Insemination Committee's recommendation that the unauthorised importation of sperm from other countries be prohibited.¹⁸⁹ The reason for this recommendation was to prevent foreign sperm banks from selling sperm by mail order to women in Sweden for the purpose of self insemination.¹⁹⁰ In particular, the Committee felt that this activity would not be consistent with the best interests of the child.¹⁹¹ In addition to promoting the best interests of donor offspring, this prohibition supports the access to information process by attempting to ensure that all Swedish donors are traceable for donor offspring who may wish to exercise their right to identifying information.

The Genetic Integrity Act also prohibits the use of gametes from a dead person in a donor treatment procedure.¹⁹² This is reinforced in the regulations.¹⁹³ According to the guidelines, this requirement may be met through personal contact with the donor or by checking the population register before each donor treatment procedure.¹⁹⁴ An important motivation behind the prohibition is that it could potentially have negative consequences for the child if the child were to discover that the donor was already dead at the time of the child's conception.¹⁹⁵ In addition to being in the best interests of the child, such a prohibition promotes access to identifying information by leaving open the possibility for contact between the donor offspring and the donor in the future. It is interesting to note that although the legislation pro-

¹⁸⁸ Ch 6, s 7.

¹⁸⁹ See SOU 1983:42, p 164 s11.

¹⁹⁰ SOU 1983:42, p 164. This was supported and confirmed in the subsequent Government Bill. See prop 1984/85:2, p 29.

¹⁹¹ SOU 1983:42, p 164.

¹⁹² Ch 6, s 4 (Insemination); Ch 7, s 6 (IVF).

¹⁹³ Ch 5, s 7 (Regulations).

¹⁹⁴ Ch 5 (Guidelines).

¹⁹⁵ See prop 2001/02:89, 6.4.2 p 44. See also 10.2 p 61 (in relation to s 6); and 10.3 p 65 (in relation to s 3).

vides that the gametes of a dead *donor*¹⁹⁶ or a *donor* who has died¹⁹⁷ may not be used in a donor treatment procedure, the regulations use the term *person* in the same context.¹⁹⁸ The reason for this difference in terminology is not entirely clear, particularly since the regulations point specifically to those sections of the Act which apply to gamete donors.¹⁹⁹

Finally, the former practice of mixing gametes from different donors in the same donor treatment procedure is also prohibited by the regulations on assisted conception which provide that IVF or insemination may not be carried out on a woman using the gametes of more than one donor in each treatment cycle.²⁰⁰ The source of this prohibition also stems from the deliberations of the Insemination Committee which reported that the practice was at that time known to occur in the USA and in Norway even though there was no indication that it was a problem in Sweden. Nevertheless, since the priority of the Committee was to ensure that the identity of the donor could be established because it was in the best interests of the child, it proposed that the practice of mixing sperm from different donors in order to achieve a pregnancy should not be permitted.²⁰¹ It would have been reasonable, however, to have expressly provided for such an important prohibition in the legislation.

3.6 Concluding observations regarding the right to information

3.6.1 The supporting provisions

Overall, it appears as though the additional supporting provisions associated with access to information strive, as far as possible, to satisfy the best inter-

¹⁹⁶ Genetic Integrity Act, Ch 6, s 4 (Insemination).

¹⁹⁷ Ch 7, s 6 (IVF).

¹⁹⁸ Ch 5, s 7 (Regulations).

¹⁹⁹ It is possible, however, that the use of the term “person” is intended to indicate or reinforce an assumption that the rule applies also to IVF where no donor is involved. Since the use of posthumous gametes clearly has an impact on the best interests of the future child — regardless of whether that child is born from the gametes of a donor or from the gametes of someone who is the child’s legal, social and genetic parent — this would seem to be a reasonable explanation. When one delves into the history of the Act on Insemination this line of reasoning is in part supported by the original Insemination Committee’s recommendation that the spouse of the woman undergoing treatment must be alive at the time of the insemination. See SOU 1983:42, p 160 s 3. The stated reason for this requirement was to protect the prospective donor offspring. The Committee’s opinion was that a child should not be begotten if the prospective child’s legal and social father had died. The same reason applied also for AIH (ie where the sperm of the woman’s husband is used) (SOU 1983:42, p 160).

²⁰⁰ Ch 5, s 6 (Regulations).

²⁰¹ SOU 1983:42, p 144.

ests of donor offspring.²⁰² The provisions are further reinforced by the Genetic Integrity Act's general requirement that donor treatment procedures may *not* be undertaken unless it can be assumed that the child will grow up under good conditions.²⁰³

The record keeping requirements, in particular, clearly reflect the legislature's intention to satisfy the best interests of donor offspring. In some other respects, however, the Act struggles to meet its obligation to ensure that, in the carrying out of donor treatment procedures, the best interests of the prospective child are not only taken into account but where possible satisfied.²⁰⁴ The Act's failure to clarify important issues regarding the counselling and consent of prospective parents and donors prior to treatment procedures, addressed in Parts 3.5.3.4 – 3.5.3.5, above, exemplifies this. Of particular significance for donor offspring is the Genetic Integrity Act's uncertainty surrounding both the responsibility for and requirement of pre-treatment counselling for prospective parents. As was seen above, the Act contains no express reference about the necessity for such counselling, leaving it to the non-binding guidelines to provide the framework for this important process.

It has been shown that the aim of Swedish law is to ensure that all prospective parents are thoroughly counselled about the child's right to information about the donor and about the implications of having a donor offspring child. If Swedish law is to truly safeguard the best interests of future donor offspring in this way it should unambiguously provide that pre-treatment counselling is compulsory for all parents. Moreover, the current position regarding the allocation of responsibility in relation to such counselling should be reviewed so that it is more consistent with the best interests of the prospective child. This could be satisfied if Parliament were to amend the Genetic Integrity Act to provide that the psycho-social investigation of prospective parents must be carried out by an appropriately trained professional counsellor.²⁰⁵

3.6.2 Absence of provisions about the access to information process and donor offspring counselling

In Part 3.2.2, above, it was shown that the Genetic Integrity Act is silent in relation to the *process* of access to information for donor offspring. Moreover, neither the regulations nor the guidelines are any more enlightening on this issue. While this in no way impacts on the right to information itself, it is surprising that the Swedish law on access to information, with its emphasis on the best interests of donor offspring, does not expressly address this

²⁰² See prop 1984/85:2, p 8; and fn 141 in Part 3.5.1, above, re this requirement.

²⁰³ Ch 6, s 3 (Insemination); Ch 7, s 5 (IVF).

²⁰⁴ Prop 1984/85:2, p 8.

²⁰⁵ This issue is further explored in Chapter 5, below.

issue. Moreover, considering the fact that Chapter 10 of the Regulations and Guidelines on Assisted Conception is entitled “The child’s right to his or her genetic origin”, one would expect this chapter to contain further information about how to deal with applications by donor offspring for information, or about the right of donor offspring to counselling. This omission is particularly unexpected since the same guidelines emphasise the counselling needs of parents.²⁰⁶

The preparatory legislative materials contain some information about the anticipated process of access to information. In the absence of any other directives via the legislation or regulations, these could provide guidance for those responsible for the release of information to donor offspring.²⁰⁷ However, even if non legally-trained personnel were aware of the existence of this information it would be unreasonable to expect them to interpret sources of law when such guidance should be provided by the relevant authorities.²⁰⁸

The absence of regulations and guidelines for health and social service personnel in relation to the process of access to information was also recently observed in the 2007 report of the investigation into parenthood with assisted reproduction.²⁰⁹ Although the investigation found that there had been no known applications made by donor offspring for identifying information at the time, it was emphasised that both hospitals and the social authorities must be better prepared to assist children who apply for information about the donor. To this end the investigator recommended that the National Board of Health and Welfare should formulate guidelines for this purpose.²¹⁰

Yet the repealed Regulations and Guidelines on Insemination, drafted by the National Board of Health and Welfare, contained a relatively comprehensive set of guidelines issued for this purpose already in 1987.²¹¹ Clearly then, the importance of donor offspring counselling and the process of ac-

²⁰⁶ Victoria’s legislation, by comparison, requires that donor offspring applying for identifying information must have received counselling by a counsellor licensed under the Act prior to the release of information. Where donor offspring apply for non identifying information counselling must be offered. See Infertility Treatment Act 1995 (Vic), ss 79–80.

²⁰⁷ See for example SOU 1983:42, pp 122, 163 (s 9); and prop 1984/85:2, pp 16, 27.

²⁰⁸ Even in relation to the release of information to donor offspring there are slight discrepancies evident between the Insemination Committee’s recommendations to the Government and the subsequent Government Bill. The report of the Insemination Committee, for example, recommended that all donor offspring should turn to the local office of the Social Welfare Board if they wish to find out information about the donor, irrespective of their age. The Government Bill on Artificial Insemination, on the other hand, provided that adult donor offspring may, if they prefer, turn directly to the hospital where the donor treatment procedure took place rather than go through the Social Welfare Board. At the same time, however, the Bill provided that this option was not open for mature minors who must first turn to the Social Welfare Board. See respectively SOU 1983:42, p 122; and prop 1984/85:2, p 27. While these differences may be regarded as slight, it is easy to see how, in the absence of clear guidelines, they increase the risk for confusion and inconsistency.

²⁰⁹ SOU 2007:3, p 102.

²¹⁰ SOU 2007:3, p 102–103.

²¹¹ SOSFS 1987:6 as rep by SOSFS 2002:13.

cess to information was not at all overlooked by the National Board of Health and Welfare at that time. On the contrary, the subject of the child's need and right to know about his or her origin — including the importance of the availability of counselling — was provided for in some detail, albeit via the guidelines.²¹² These guidelines were carefully considered and gave valuable direction to those responsible for the provision of access to information and counselling services for donor offspring. They also accurately and thoroughly reflected the Insemination Committee's recommendations; recommendations that were subsequently endorsed by the Swedish Parliament.²¹³

Why the replacement Regulations and Guidelines on Assisted Conception were re-drafted and re-issued in 2002 without including this component of the repealed guidelines, is an important question. One possible explanation for the omission is that similar information is now contained in a special Message Sheet²¹⁴ that was issued in April 2004 by the National Board of Health and Welfare.²¹⁵ The Message Sheet deals exclusively with the child's right to find out about his or her origins following donor treatment procedures and was sent out to, inter alia, the Social Welfare Board offices, school health services and clinics performing ART treatment. There is no question that the information contained in the message sheet could be valuable for those who work with donor offspring. However, a message sheet cannot be regarded as a substitute for regulations or guidelines. Moreover, the information contained in this sheet is four years old and still refers to the right of donor offspring under the repealed acts. Since each local office of the Social Welfare Board is responsible for assisting donor offspring with access to information about the donor,²¹⁶ clear guidelines setting out a procedure that could be consistently applied would not only facilitate this process; it would also promote the interests of donor offspring.

²¹² See SOSF 1987:6 (rep) "The child's need and right", Part 5, pp 17–20; and "The child's right to know about their origin", Part 7.1.2 (ie of SOSF 1987:6), pp 23–24. Although no regulations were prescribed, the guidelines in respect of these two areas were extensive. Together they comprise approximately 2000 words, none of which are in the current instrument.

²¹³ See SOU 1983:42, pp 122–123, 163–164 s 9. It is also important to note that the Government Bill expressly reinforced the importance of making counselling accessible for both donor offspring adults and children. See prop 1984/85:2, pp 16, 27.

²¹⁴ See Socialstyrelsen, Meddelandeblad – Barnets rätt att få kännedom om sitt ursprung efter en assisterad befruktning med donerade ägg eller spermier, April 2004 (6 pages). [Trans: Message Sheet – The child's right to know about his or her origins following assisted conception using donated eggs or sperm.]

²¹⁵ This was recently indicated by Elin Siljehag of the National Board of Health and Welfare (Health and Medical Services) who said that the information contained in the 2004 Message Sheet, above, had replaced the details that had formerly existed in the repealed guidelines, ie details in relation to access to information and the child's need and right to know about his or her origins. This information was obtained during a telephone conversation between Jane Stoll and Elin Siljehag on 3 June 2008.

²¹⁶ See SFS 2006:351, Ch 6, s 5 (Insemination); Ch 7, s 7 (IVF).

Since the importance of counselling prior to the release of information about the donor is so relevant to the best interests of donor offspring, this requirement should also be expressly provided for in the Genetic Integrity Act. A reference clarifying the Social Welfare Board's obligation to *offer* counselling to donor offspring would suffice.²¹⁷ Additional detail regarding the process or nature of such counselling could be left to the National Board of Health and Welfare to determine through its Regulations and Guidelines on Assisted Conception.

If the Genetic Integrity Act were to be amended as suggested above, it would provide a clear and undisputed declaration of Parliament's will that donor offspring have a right to be offered counselling prior to the release of information. In conjunction with any subsequent changes made to the regulations and guidelines, this would help promote the interests of donor offspring by ensuring that they received counselling appropriate to their special needs.

3.7 Swedish law and its international law obligations to donor offspring

3.7.1 Introductory remarks

In this chapter it has been shown that according to Swedish domestic law, the right to genetic origins includes the right of donor offspring to know the identity of the donor. An important question remaining, however, is whether Sweden has met its international obligations to donor offspring under the CRC and the ECHR — obligations which were accounted for in Chapter Two above and which apply equally to all contracting states.

Where it concerns the CRC, Sweden's perceived obligations to donor offspring in relation to the scope of the right to genetic origins are well documented. This is significant because Sweden's interpretation in this connection reveals an internal policy that is very much focused on the best interests of donor offspring. This issue is therefore addressed in some detail below before considering whether Sweden has met its obligations to donor offspring under each convention.

²¹⁷ **Note** that a requirement to “offer” counselling would also be consistent with the opinion of the Swedish Insemination Committee. Although the Committee emphasised the importance of counselling for donor offspring, it also believed that the release of information should not be refused on the basis that counselling had not occurred. This view has not subsequently been contradicted or challenged. Accordingly, it seems clear that while counselling in Sweden should at least be offered to donor offspring, it should not be made obligatory. See SOU 1983:42, p 164.

3.7.2 Meeting obligations to donor offspring under the CRC

3.7.2.1 Donor offspring as rights holders

From a Swedish perspective there has been a long standing assumption that the right to know ones genetic origins under the CRC extends to donor offspring. This was seen as self evident already in the Government Bill on the acceptance of the CRC,²¹⁸ where the Convention articles were discussed in relation to, *inter alia*, their application to relevant Swedish law. Here, the issue of donor offspring and their right to information about the donor was expressly raised in connection with the right to, as far as possible, know one's parents under Article 7. What is clear from the wording of the Bill is a presumption that Sweden had already fulfilled its obligations in this respect through Section 4 of the Act on Insemination²¹⁹ before it even ratified the Convention. The Bill even goes so far as to justify why the child's right to information about the donor under Swedish law was qualified by the requirement of sufficient maturity, stating that this limitation was made in the child's own interest and was therefore — on a reasonable interpretation — consistent with Article 7 of the Convention.²²⁰ The Bill makes no specific reference to donor offspring in its analysis of Article 8.

The sufficient maturity qualification and its connection to the best interests of the child, above, was clearly regarded as important for Sweden since it returned to this issue in its initial report to the Committee on the Rights of the Child²²¹ and in its second periodic report.²²² In the initial report, commenting on Sweden's implementation of Article 7, it is provided that:

Under the Insemination Act, a child conceived through artificial insemination is entitled to obtain particulars concerning the donor, provided the child is sufficiently mature. The decision to be made on this point, however, is governed by the child's interests.²²³

Implicit in this statement is an assumption that extending the right to information to donor offspring is consistent with Article 7. What the statement also implies is that the right is functional. The Committee on the Rights of

²¹⁸ Prop 1989/90:107.

²¹⁹ Prop 1989/90:107, p 36. The corresponding provisions of the Genetic Integrity Act are Ch 6, s 5 (Insemination); Ch 7, s 7 (IVF).

²²⁰ Prop 1989/90:107, p 36.

²²¹ See CRC/C/3/Add.1, 23 September 1992, p 19 para 61(b).

²²² See CRC/C/65/Add.3, 11 February 1998, p 46 para 263. In the subsequent two periodic reports — CRC/C/125/Add.1, 12 July 2004; and Sweden's fourth periodic report to the UN Committee on the Rights of the Child 2002–2007 — Sweden does not raise the issue of donor offspring and access to information at all. An explanation for this could be that since it has already been canvassed in previous reports without being remarked upon or noted by the UN Committee, the assumption of both the Swedish Government and the UN Committee on the Rights of the Child is that the process is working effectively in Sweden.

²²³ CRC/C/3/Add.1 p 19 para 61(b). **Note** that this report was published in 1992, before all ART activity in Sweden was governed by the Genetic Integrity Act.

the Child must have assumed this since it has not raised the issue as a potential area of concern in any of its concluding observations about Sweden's initial or periodic reports.²²⁴ The assumptions certainly appear as self evident to Hodgkin and Newell who, in their commentary on Article 7 — and based on Sweden's initial report — conclude that Swedish legislation '... contains some of the strongest provisions [in the world] for enabling children to know their parentage.'²²⁵ In this regard it should be mentioned that the authors commend Sweden not only for its laws that facilitate access to information for donor offspring but also for its laws that establish parenthood. Whether Sweden lives up to this accolade in relation to donor offspring remains to be seen, but there is no question that the wording contained in the access to information provisions of the Genetic Integrity Act has genetic truth as its goal.²²⁶

The assumption that the right to know ones genetic origins under Article 7 includes genetic parents and extends to a donor offspring's right to know the identity of the donor was further reinforced by the Swedish Children's Committee in its 1997 report on the implementation of the CRC in Sweden, mentioned above. In the Committee's view, the child's right to know his or her origin has, above all, its significance where it concerns adopted children and children born through assisted conception.²²⁷ While the Committee noted that questions regarding the permissibility of assisted conception were not regulated by the CRC, it stressed that the principle about considering the best interests of the child 'should, however, obviously characterise the activity of assisted conception.'²²⁸ These comments made by the Children's Committee show that, in Sweden's view at least, donor offspring children were clearly included in the group of children to whom the right was intended.

In the same investigation, the Children's Committee also reviewed the legal and practical implications of the Act on Insemination²²⁹ in relation to a donor offspring's right to information about the donor;²³⁰ and highlighted society's duty to guard the interests of donor offspring with respect to proposals for new law permitting egg or sperm donation with IVF,²³¹ providing

²²⁴ See Concluding observations of the Committee on the Rights of the Child: Sweden, 18/02/93, CRC/C/15/Add.2; Concluding observations of the Committee on the Rights of the Child: Sweden, 10/05/99, CRC/C/15/Add.101; Concluding observations of the Committee on the Rights of the Child: Sweden, 30 March 2005, CRC/C/15/Add.248.

²²⁵ Hodgkin and Newell above n 24, p 119.

²²⁶ See Ch 6, s 5 (Insemination, Right to information) and Ch 7, s 7 (IVF, Right to information).

²²⁷ SOU 1997:116, p 25.

²²⁸ SOU 1997:116, pp 25, 224. [Author's translation.] It was also noted that, at that time, the right for donor offspring children to find out about their genetic origins was at that time over 10 years old. See p 25.

²²⁹ At that time all donor treatment procedures were still regulated by this act.

²³⁰ SOU 1997:116, pp 214–215.

²³¹ SOU 1997:116, pp 216–217.

further support for the notion that Swedish donor offspring fall within the scope of Article 7 of the CRC.

More recently, the 2007 report of the investigation into parenthood with assisted reproduction, mentioned above, has specifically addressed the issue of a donor offspring child's right to find out about his or her genetic origins, expressly linking it to Articles 7 and 8 of the CRC.²³² While the investigator points out that the international interpretation of Article 7 is not unequivocal, references contained throughout the report clearly confirm that Sweden's interpretation of the right to information about genetic origins under the CRC extends to donor offspring.²³³ Already in the terms of reference for the investigation, the investigator was commissioned to, *inter alia*, evaluate whether any measures were required to improve the possibilities for donor offspring to find out about their genetic origins.²³⁴ The investigation was also directed to make its considerations in light of the acknowledged rights contained in the CRC.²³⁵ Since the source of the terms of reference is the Swedish Government, the assumption must be that, in accordance with Swedish policy, Article 7 of the CRC applies also to donor offspring and their right to information about the donor.²³⁶

3.7.2.2 Donor offspring and identifying information “as far as possible”

In Sweden the interpretation of a child's right to know the identity of the donor varies depending on when the child was born and on the circumstances under which he or she was conceived. As has been shown above, all donor offspring conceived under Swedish ART legislation from gametes donated after 1 March 1985, have an unconditional right to obtain identifying information about the donor when they are sufficiently mature.²³⁷ This clearly reflects the current view that the right to know one's parents under Article 7 of the CRC extends to identifying information about the donor.

Donor offspring conceived from gametes donated prior to this date, however, have no such right to identifying information about the donor under the Genetic Integrity Act. Nor do they have a right to non identifying information under the Act. To date, there has been no indication that Sweden has considered that it may also have obligations under Article 7 to this group of

²³² SOU 2007:3, pp 63–64.

²³³ See in particular SOU 2007:3: Ch 2, pp 47–66; Ch 4, pp 75–89; and Ch 5, pp 91–92.

²³⁴ Dir 2005:115, 3 November 2005. See para 3 under heading “Uppdraget”. (A copy of the terms of reference may also be found in SOU 2007:3, Bilaga 1, pp 125–128).

²³⁵ Dir 2005:115, “Uppdraget” para 5. Of interest is that the words of the Swedish Government, contained in the terms of reference, virtually mirror those of the Swedish Children's Committee 10 years earlier which was of the view that, in light of (then) new research and debate about the right of donor offspring to know about the donor, the possibility of strengthening the child's right to find out about his or her origin needed to be investigated — from the perspective of the best interests of the child. See SOU 1997:116, p 225. See also p 25.

²³⁶ Such an application of Article 7, however, presupposes that information about the donor is both available and accessible.

²³⁷ Ch 6, s 5 (Insemination, Right to information) and Ch 7, s 7 (IVF, Right to information).

donor offspring, even though a significant number of them must have been children when the CRC came into force. Donor offspring born following so called private donations or from ART procedures abroad have no right to information about the donor under the Genetic Integrity Act either, irrespective of when they were conceived. Although the needs of this particular group of children have recently been highlighted in the report of the investigation into parenthood with assisted reproduction,²³⁸ at the time of writing, Sweden's interpretation that Article 7 of the CRC extends to identifying information about the donor appears to apply only to those children born under the Genetic Integrity Act.²³⁹ This, however, is not necessarily inconsistent with Sweden's obligations under the CRC. Article 7 provides that a child has the right to "as far as possible" know his or her parents. In the situations described above, information about the donor is often impossible to obtain.

Whether Article 7 requires that Sweden should, where possible, do more to facilitate access to identifying and/or non identifying information for those donor offspring children who have no right to information under the Genetic Integrity Act, is an open question.²⁴⁰ What is clear is that since the mid 1980s, before the CRC was even in force, Sweden has been unequivocal in its view that all donor offspring born under Swedish ART legislation have a right to identifying information about the donor. Moreover, since the Convention was ratified, Sweden has regarded it as self evident that this view is consistent with the child's right to know his or her parents under Article 7. Accordingly, from a Swedish perspective, there is no doubt that Article 7 extends to identifying information about the donor.

On the face of it, Sweden appears to have fulfilled its obligations to donor offspring under Article 7. The fact that all donor offspring born under the Genetic Integrity Act have an unconditional legal right to identifying information about the donor²⁴¹ and that information about the donor must be recorded and preserved for at least 70 years in a special medical record²⁴² is evidence of this. In reality, however, because a Swedish child's right to identifying information about the donor applies only to those children born under the legislation, it does not, and cannot, guarantee that all donor offspring will

²³⁸ See esp SOU 2007:3, pp 78–83.

²³⁹ Clearly, this includes those donor offspring children born under the repealed Act on Insemination and the repealed IVF Act.

²⁴⁰ In light of the CRC's definition of a child as being under 18 years of age (Article 1), one question that could arise in the context of access to identifying information is whether it must be possible for children themselves to enforce the right to genetic origins as children because the CRC protects and promotes the rights of children, ie as opposed to adults who have survived childhood. This question is beyond the scope of this study, however.

²⁴¹ See Ch 6, s 5 (Insemination) and Ch 7, s 7 (IVF).

²⁴² See Ch 6, s 4 (Insemination) and Ch 7, s 6 (IVF).

have the opportunity to discover the identity of the donor.²⁴³ It follows that, for some Swedish donor offspring children, the right to find out about their genetic origins under Article 7 is tenuous, limited by the reality of the words “as far as possible.”

In relation to Sweden’s perceived obligations to donor offspring, however, it could be mentioned that, although the CRC itself does not specify which of the convention articles include civil and political rights, and which rights are economic, social or cultural,²⁴⁴ Sweden has clearly interpreted the right to information about genetic origins as falling under the civil and political group of rights.²⁴⁵ The distinction between the civil and political rights on the one hand and the economic, social and cultural rights on the other, could be of some significance where it concerns Sweden’s own interpretation of its obligations to donor offspring under the CRC, since Article 4 of the Convention places a more immediate obligation on States Parties with regard to the civil and political rights. That is to say, a contracting State undertakes ‘... all appropriate legislative, administrative and other measures for the implementation of the ...’ right. By contrast, the economic, social and cultural rights are limited to measures that are ‘... to the maximum extent’ of a State Party’s available resources. To assume that Sweden would be expected to take all appropriate measures to implement a donor offspring’s right to information *only* in relation to children conceived under the Genetic Integrity Act²⁴⁶ would be an implausible interpretation of Article 7.

Thus, although Sweden has certainly satisfied its Article 7 obligations to donor offspring at least as well as, if not better than, all other States Parties, it could still — in line with its own interpretation of the nature of the right to information about genetic origins — do more for those donor offspring who have not been born under its domestic legislation.

3.7.3 Meeting obligations to donor offspring under the ECHR

In the previous chapter it was shown that there is no absolute right to information about genetic origins under Article 8 of the ECHR.²⁴⁷ In effect, this means that a donor offspring’s right to identifying information under the

²⁴³ But see Singer above n 43, pp 411–413 in relation to establishing genetic origins in situations other than adoption or following legally-regulated donor treatment procedures.

²⁴⁴ See further Hodgkin and Newell, above n 24, pp 53, 63. Hodgkin and Newell also point out, however, that in the guidelines for both initial and periodic reports, Article 7 is located in the group of articles under the heading “Civil rights and freedoms.” See pp 63, 108.

²⁴⁵ See SOU 1997:116, pp 25, 212–218. On page 25 of the report the Committee states that the civil and political rights contained in the CRC ‘include the right to a name and a nationality and the right to know about one’s parents.’ [Author’s translation.] Moreover, Chapter 9 of the report, which discusses a child’s right to know about his or her genetic origins, is entitled Civil and political rights.

²⁴⁶ And its predecessors.

²⁴⁷ On the scope of Article 8 of the ECHR and the significance of Article 8 cases for donor offspring see Parts 2.3.3–2.3.4, above.

Convention must be balanced, *inter alia*, with the conflicting right of a genetic parent to remain anonymous.²⁴⁸

The scope of a donor offspring's right to identifying information under the Genetic Integrity Act, by contrast, is significantly broader. In light of both past and present ART legislation, it seems clear that Sweden has more than met its international obligations under Article 8 of the ECHR with respect to the right to identifying information for donor offspring. All Swedish donor offspring born from gametes donated after 1 March 1985 already have an unconditional right to identifying information about the donor. Moreover, the Swedish Government is currently considering alternatives that could increase both the availability of information for donor offspring born outside the legislation and the incidence of disclosure by parents. One of these initiatives is likely to include amendments to the Children and Parents Code outlining, *inter alia*, parental responsibility for disclosure.²⁴⁹

As regards donor offspring who have no right to information under the Genetic Integrity Act, it is difficult to anticipate a situation where an application for information would be unreasonably denied if the information were available, irrespective of whether identifying or non identifying information was sought. That said, it is possible that Sweden could be found to be in breach of Article 8, if it permitted information about donors to be unreasonably withheld from donor offspring without carefully balancing the legitimate interests in question. This conclusion is the only reasonable one to draw from the cases, above, which make it clear that people seeking to establish their genetic origins have a vital interest protected by the ECHR.²⁵⁰

3.8 Concluding remarks

There is no question that the IVF and insemination chapters of the Genetic Integrity Act²⁵¹ have convincingly improved the situation of all donor offspring who wish to find out more about their genetic origins. Provided Swedish donor offspring have been told about their conception they may exercise their unconditional right to obtain identifying information about the donor as soon as they are regarded as sufficiently mature.

A significant feature of the Swedish legislation, and directly connected to the right to identifying information about the donor, is its commitment to, as far as possible, satisfy the best interests of the child born from a donor treatment procedure. As stated above, Swedish law provides that donor treatment procedures may *not* be undertaken unless it can be assumed that the child

²⁴⁸ See esp Part 2.3.3.4, above.

²⁴⁹ See SOU 2007:3, esp Part 5, pp 91–103. These issues are addressed in Chapter 5, below.

²⁵⁰ See *Jäggi v Switzerland* no 58757/00, para 38 (case discussed in Part 2.3.3.3, above).

²⁵¹ And, of course, its predecessors: the Act on Insemination and the IVF Act.

will grow up under good conditions.²⁵² Since 1985, this requirement has been supported through, *inter alia*, more effective record keeping, strict consent requirements for prospective parents and donors prior to donor treatment procedures, more consistent standards of practice for donor treatment procedures and — albeit via the guidelines — an element of pre-treatment counselling. These factors constitute an immense improvement from the pre-regulation era where records were often destroyed and little attention was given to the psycho-social needs of prospective parents, donors and donor offspring.

As to fulfilling its international obligations to donor offspring, Sweden's performance must be regarded as impressive. Swedish law goes even further than arguably required under either the CRC or the ECHR by conferring on all donor offspring born under the Genetic Integrity Act an unconditional legal right to identifying information about the donor. Compared with most other contracting nations Sweden's interpretation of the right to information is thus broad. On the other hand, this unconditional right serves to benefit a relatively small group of donor offspring. Even in Sweden, where the right to information is already assumed, international law reinforces the importance of the existing right to information about genetic origins. It also provides strong arguments for augmenting the right, as far as is possible, in order to ensure that even donor offspring who do not come under the legislation, and donor offspring who have not been told how they were conceived, may be included as rights holders.

In spite of these advances, however, there is a risk that the Genetic Integrity Act is unable to ensure that the best interests of donor offspring are, as far as possible, satisfied. Three factors in particular contribute to this: First, the Act is silent on some issues which are of critical importance to donor offspring, such as the process of access to information and the need for counselling prior to the release of identifying information about the donor; secondly, the Act is not clear about whom, if anyone, bears the ultimate responsibility for the counselling of prospective parents or donors prior to donor treatment procedures; and thirdly, no one has an obligation under the Act to ensure that donor offspring find out about their right to know the identity of the donor. Before the right to information can become fully functional, Swedish donor offspring must know how they were conceived.

²⁵² Genetic Integrity Act, Ch 6, s 3 (Insemination); Ch 7, s 5 (IVF).

4 A right with no implementation mechanism

4.1 Introductory remarks

In the two preceding chapters it was shown that a donor offspring's unconditional right to identifying information about the donor is firmly entrenched in Swedish domestic law and that the same right — albeit not unconditional — also exists under international law. In addition, Sweden has demonstrated its commitment to donor offspring by establishing and implementing a regulatory framework for donor treatment procedures and access to information. In doing so, it has clearly attempted — and in many respects succeeded — to ensure that the best interests of donor offspring have not only been taken into account but are, where possible, satisfied.²⁵³ Moreover, in showing that it is serious about promoting the best interests of its own donor offspring, Sweden has played a decisive role in inspiring other jurisdictions to follow suit. To this extent, the significant inroads achieved for donor offspring both nationally and internationally must be acknowledged.

Contrary to all expectations, however, it is now obvious that many donor offspring, including those born since the Act on Insemination came into force in 1985, will never find out how they were conceived from their parents. The purpose of this chapter is to investigate this problem, primarily in order to find out whether a donor offspring's right to identifying information about the donor is an effective legal right. Without information about the existence of the donor, donor offspring cannot exercise their right to information; yet it is not possible to compel parents to disclose. If no institution or individual has an obligation under the Genetic Integrity Act to ensure that donor offspring find out how they were conceived, it follows that most of these offspring will not be able to exercise their right to know the identity of the donor. Thus, the tremendous advances made by setting up a regulatory regime, principally in order to satisfy the best interests of donor offspring, appear to be in vain for a significant portion of them.

After outlining the nature of the problem, an attempt is made to establish its extent via the results of studies undertaken on donor offspring and their families. The problem is subsequently considered in light of Parliament's intention that the right to information would become a genuine right and its assumption that such a right is in the best interests of donor offspring.

²⁵³ See, eg, prop 1984/85:2, p 8 re satisfying, as far as possible, the best interests of the child.

4.2 Many donor offspring never find out how they were conceived

4.2.1 Overview of the problem

If the right to identifying information is to be guaranteed to donor offspring, they must not only be aware that they are donor offspring; they must also know that they have a statutory right to information about the donor. Thus, one could say that disclosure involves two steps:

1. The child must have been told how he or she was conceived.
2. The child must have been told that he or she has a right to identifying information about the donor.

If the first step is not fulfilled, the child has very little chance of exercising his or her right to information. At the moment, the responsibility for both steps of disclosure has been left entirely in the hands of the parents of donor offspring, not all of whom disclose or intend to disclose.

The two steps connected to disclosure, above, are self evident and have been described in various ways. Lucy Frith, for example, has interpreted the right to genetic origins as comprising two different rights; a moral right and a legal right. Step one, above, corresponds with what she calls a moral right. Step two — the right to know the identity of the donor — is in Frith's view the legal right.²⁵⁴ This way of dissecting the right to genetic origins could be particularly valuable for those determining ART policy. In Frith's own words, she aims:

to show that analysing the role of rights in this way can serve to exemplify the contradictions that currently exist in the way that policies of non-anonymous gamete donation have been organised.²⁵⁵

One of the objectives of this chapter is to ascertain whether the first step — the moral component of the right — is being fulfilled, since the effective implementation of the legal the right is contingent upon the satisfaction of the first step.²⁵⁶ This is particularly important in jurisdictions where donor offspring have a legal right to information about the donor because the evidence that many donor offspring never find out how they were conceived is now overwhelming. And this problem is in no way unique to Sweden. Stud-

²⁵⁴ L Frith, 'Beneath the rhetoric: the role of rights in the practice of non-anonymous gamete donation' (2001) 15 (5/6) *Bioethics* 473–484.

²⁵⁵ *Ibid*, p 476. **Note** that Frith has written an interesting article on ethical and legal aspects of gamete donation where she also summarises international trends. See L Frith, 'Gamete donation and anonymity: the ethical and legal debate' (2001) 16 *Human Reproduction* 818–824.

²⁵⁶ Alternative ways to promote both the moral right and legal right are subsequently explored in Chapter 5, below.

ies undertaken in other jurisdictions about the attitude of parents to donor anonymity, both before and after the Act on Insemination came into force, consistently have one factor in common: there are always some parents — sometimes a majority — who do not tell their donor offspring child how the child was conceived. To date, the results available from Swedish studies reinforce this pattern. Generally, whether or not donor anonymity has been abolished by law appears to make little difference to parents' decisions to be open with their donor offspring children.²⁵⁷

By taking into account the study results, below, it is possible to obtain some idea of the extent, or likely extent, of parental disclosure. This information is important, not in order to evaluate *compliance* with the law — since there is no positive obligation to tell donor offspring they have a right — but, rather, to form a view about the *effectiveness* of the law in order to determine whether it is fulfilling its function, as intended.

Before turning to the individual studies, however, a number of matters should be clarified. First, the methods used in the studies reported vary considerably. Some studies, for example, are undertaken by anonymous questionnaire, others by personal interview or telephone interview; some are performed before the child is born, others after; some studies are the result of a follow up from a previous study or studies while others are the result of single “one-off” investigations. Another important feature of the studies presented is that the number of participants varies considerably from study to study. Finally, many of the donor offspring children in question were very young when their parents were interviewed. Accordingly, actual disclosure was not always possible to establish even where parents had stated that they intended to disclose in the future. This highlights the need for follow up studies that include, where possible, the same parent population in order to see whether an intention to disclose corresponds with actual disclosure.

It is acknowledged that all of the factors mentioned above can have an impact on the interpretation of the results of the studies and to this end firm conclusions cannot necessarily be drawn in relation to the intentions of the entire donor offspring parent population where it concerns disclosure. Even so, the available studies supply valuable information about the current and potential patterns of parental disclosure both in Sweden and abroad which could serve as a useful planning tool for policy makers.

²⁵⁷ Some exceptions to the general pattern of disclosure are outlined below in Part 4.3. These include, but are not limited to, the situation where parents have been able to choose whether or not to select an anonymous or identifiable donor themselves. See for example A Brewaeys et al, ‘Anonymous or identity-registered sperm donors? A study of Dutch recipients’ choices’ (2005) 20 *Human Reproduction* 820–824. Some aspects of this study are highlighted below in Part 4.3.3. In this study there was an intended rate of disclosure of 93% by the group of parents who had chosen identifiable donors (see p 822). This study, however, was undertaken when the double-track system of sperm donation was in place, ie before it became compulsory following the 2004 reform to use only identity-registered gamete donors in the Netherlands.

4.2.2 Swedish studies on parental disclosure

4.2.2.1 Stockholm-Umeå study published in 2000

In 2000, a multidisciplinary study which examined the impact of the Act on Insemination²⁵⁸ on the attitudes of couples in respect of disclosure issues was published by the Swedish National Board of Health and Welfare.²⁵⁹ The results of the study, subsequently accounted for in an English article by Gottlieb et al, revealed that 89 per cent of a cohort of parents had not informed their children about the child's donor insemination (DI) conception.²⁶⁰ The stated aims of the investigation were as follows:

- To clarify whether children have been advised about their origin and, if so, how they have received the information.
- To investigate the significance of the legislation and its possible effect where it concerns the child's right to find out about the donor particularly with regard to the CRC.
- To develop a knowledge base to support the possible amendment of the legislation regulating assisted conception.²⁶¹

It should be mentioned that the investigation was confined to couples who had used donor sperm since egg donation was unlawful in Sweden when the study was undertaken. The study sample comprised 148 of the 194 couples from two major DI centres in Sweden who had conceived a donor insemination child between 1985 and 1997. The centres in question — the Department of Obstetrics and Gynaecology at Umeå University Hospital and the Reproductive Medical Centre at Karolinska Hospital, Stockholm — were chosen because the patients using donor insemination services in these units represented a broad cross-section of Swedish rural and urban areas.²⁶² All

²⁵⁸ That is, the now repealed Act on Insemination. A follow up study published in 2007 is reported below.

²⁵⁹ The study was undertaken by the National Board of Health and Welfare in co-operation with researchers within the areas of gynaecology and child psychology/psychiatry. See the Introduction of SoS-rapport 2000:6 'Får barnen veta? Barn som fötts efter givarinsemination', Socialstyrelsen. [Trans: 'Can the children find out? Children born following donor insemination'].

²⁶⁰ C Gottlieb et al, 'Disclosure of donor insemination to the child: The impact of Swedish legislation on couples' attitudes' (2000) 15 *Human Reproduction* 2052, p 2052. **Note** that the authors were all participants of the original study.

²⁶¹ SoS-rapport 2000:6, p 14. [Author's translation.] These aims are directly translated here because they differ slightly from those reported in the English report of the study, possibly due to the fact that the study was reported in a medical journal rather than a legal journal. The English version provides that one aim of the study was to establish whether parents who had been treated with DI after the Act came into effect had told their children about their donor conception. It also states that another aim was to discover when and how the children had been informed and whether the parents were satisfied with their decisions. It omits the aims in relation to the CRC and possible legislative amendment. See Gottlieb et al, *ibid*, p 2053.

²⁶² The reported response rate of 80% excluded nine couples who were unable to be located. **Note** also that 62 of the couples who responded to the questionnaire had more than one child from DI. While they were instructed to respond to the questions in respect of the first child

couples were invited to participate in the study by completing an anonymous questionnaire that contained both structured and open questions. Couples were asked to answer the questions together.²⁶³ The children in question were between one and 15 years of age. Half of them were aged four or younger.²⁶⁴

Eleven per cent of couples²⁶⁵ had told their child about the DI. Of the 17 children from these families, 15 had been told before they were eight years old with the average age for disclosure in this group being 5.5. The parents who had told their child about the DI were satisfied with their decision to disclose.²⁶⁶

An additional 41 per cent of parents reported that they intended to tell their child about the DI in the future, indicating that 52 per cent of the total number of parents questioned had either disclosed or planned to do so.²⁶⁷ The fact that those couples planning to disclose had not yet done so is not surprising because the average age of their children at the time of the questionnaire was approximately 3.5 years.²⁶⁸ In light of the parent responses, it is reasonable to assume that at least a number of these children will find out about the DI as they grow older. Gottlieb et al point out, however, that '[t]he possibility that a child will not actually be told about the DI probably increases with the increasing age of the child.'²⁶⁹ With this in mind, conclusions about parents' intentions to disclose are difficult to draw. Moreover, a parent's intention to disclose in the future is quite a different matter from actually carrying that intention out.²⁷⁰

born after the law came into effect some of the respondents misunderstood and responded in respect of their first DI child, ie a child conceived or born before the law came into effect. Gottlieb et al, *ibid.*, p 2053. As to the number of couples who were involved in the study, ie 148, see SoS-rapport 2000:6, p 16.

²⁶³ Gottlieb et al, *ibid.*, p 2053.

²⁶⁴ SoS-rapport 2000:6, p 17. No overall average age of the children from the entire group was reported.

²⁶⁵ At the time of the study, 94% of the couples were still living together. **Note** also that the authors of the study refer to the opinions of "parents" or "families" in their report when discussing the intention of the couples/parents of the DI child. For consistency, these parents will be referred to as "couples" although it is acknowledged that in some cases, there may be only one parent or a parent may have re-partnered. See Gottlieb et al, above n 260, pp 2052–2053.

²⁶⁶ *Ibid.*, p 2054. According to Gottlieb et al, the 80% response rate to this study is considered high. They believe, however, that the incidence of disclosure is probably higher amongst those who completed the questionnaire.

²⁶⁷ *Ibid.*, pp 2052, 2054.

²⁶⁸ That is, those children of the 61 couples who intended to tell their children later. *Ibid.*, p 2053.

²⁶⁹ *Ibid.*, p 2054.

²⁷⁰ **Note** that this view is also consistent with the findings of Brewaeys et al (1997) who, after questioning 38 Dutch couples about their opinions regarding donor anonymity, found that only one DI couple and two IVF couples had already told their child about the way in which the child was conceived. Their conclusion was that '[c]onsidering that the study children were between 4 and 8 years old, there seems to be a trend among parents to postpone the decision to tell until a later developmental stage. As intending to tell does not mean that they will actually do so, it remains to be seen in the further follow-up of these families how many of

Twenty-eight couples reported that they would not tell their child about the DI and 16 couples had not yet decided. The average age of the children from the respondents who were undecided was approximately seven years.²⁷¹

An interesting observation made in the study was that the reported incidence of disclosure by parents had increased from six per cent with respect to children born before 1985, to 18 per cent in relation to children born between 1987 and 1990.²⁷² The increase shown by these figures is promising. However, it is still a long way from the outcome apparently expected by Parliament ie that all donor offspring should be told that they have a legal right to information about the donor.

4.2.2.2 Follow up to the Stockholm-Umeå study published in 2007

The results of a follow up to the Stockholm-Umeå study, above, were published in 2007.²⁷³ In this study, undertaken in 2004, nineteen families participated. These families comprised 36 individuals from the original cohort of 148 couples from the 2000 study. Results were obtained via a telephone interview which took approximately 45 minutes. Both male and female participants were interviewed separately.²⁷⁴

The average age of the children at the time of the study was seven.²⁷⁵ More than half of the parents interviewed, ie 11 men and 11 women (61 per cent) had told their children about the DI treatment. Where there was more than one child, all the parents in this group had disclosed to all of the chil-

these parents will ever get to the decisive point of informing their child.' See A Brewaeys et al, 'Donor insemination: Dutch parents' opinions about confidentiality and donor anonymity and the emotional adjustment of their children' (1997) 12 *Human Reproduction* 1591, p 1595.

²⁷¹ See Gottlieb et al, above n 260, pp 2052–2053. See also SoS-rapport 2000:6, p 25 and **note** that these particular figures were not obtained from the entire sample of 148 parents. They were, rather, obtained from 105 of the 132 parents who had not yet disclosed and who had responded to an open question about disclosure. Accordingly, there may be more parents in this group who do not intend to disclose in the future and more who remain undecided.

²⁷² That is to say, a reported rate of 6% of 12–15 year olds born before 1985, ie before the Swedish law came into effect, had been informed about the DI. In the group from 1987–1990, by comparison, the children were 8–11 years old and 18% had been informed about the DI. See Gottlieb et al, *ibid*, p 2054.

²⁷³ For an account of the study in English see A Lalos et al, 'Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking' (2007) 22 *Human Reproduction* 1759–1768. A report of the study in Swedish, written by Ann Lalos, can be found in SOU 2007:3. See A Lalos, 'Lagstadgad rätt till sitt ursprung men hur resonerar föräldrarna och vad får barn födda efter givarinsemination veta?' Bilaga 3 in SOU 2007:3, pp 135–159.

²⁷⁴ Regarding the study composition of 36 individuals: After the first study 27 of the 148 couples agreed to be contacted in the future in relation to participating in a follow up interview. Of those 27 couples, it was possible to contact 26 couples. Each of the 26 men and women were contacted individually and 19 families agreed to participate. This resulted in a 73% response rate of those contacted. See Lalos et al, *ibid*, p 1760.

²⁷⁵ The age range was 1–15, *ibid*, p 1761.

dren.²⁷⁶ Although the age for disclosure varied, the most common age for the first child in a family to be told was at five years of age. If the child had siblings the average age for disclosure in relation to the younger child was 3.5 years.²⁷⁷

Five women and three men had not told their children about the DI at the time of the study but intended to tell them in the future. From this group of parents, one of the women had already told two out of three of her children.²⁷⁸ Three women and three men had not told any of their children and did not intend to tell them.²⁷⁹

As mentioned above, for full disclosure, two steps must be fulfilled, ie the child must be told how they were conceived, and the child must be advised that they have a right to know the identity of the donor. Without this information it is difficult for donor offspring to exercise their legal right to information. A question that was not raised in the 2000 study, but was addressed in the study published in 2007, was how parents reacted to the second step. That is to say, whether those donor offspring who had been told how they were conceived had also been told that they had a right to know the identity of the donor.

Lalos reports ‘that to tell the child that he or she also has a right to (at maturity) find out the identity of the sperm donor did not prove to be equally self-evident [to the parents] as to tell the child about the insemination treatment.’²⁸⁰ Of the 36 participants in the follow up study, 14 had told the child about the DI treatment and about the child’s right to information. Fifteen parents²⁸¹ had not yet told all of their children about the right to information but intend to tell them.²⁸² Seven parents had not told any of their children that the child had a right to information about the donor. Nor did they plan to tell them in the future.²⁸³

In relation to the rate of disclosure and intention to disclose, the results from this study are positive. Compared with the actual disclosure rate of only

²⁷⁶ Ibid, pp 1761–1762. The figures given in fact represented 13 families, not 11. One of the discrepancies was due to the fact that in the individual interviews it was discovered that one woman was unaware that her husband had already told their child about the DI. An additional example affecting the figures came about because the father in another family had told all three children but the wife had not told the youngest child. For a full explanation of the reasons behind the different figures see further pp 1761–1762.

²⁷⁷ Ibid, p 1762.

²⁷⁸ Ibid.

²⁷⁹ Ibid.

²⁸⁰ SOU 2007:3, p 145. [Author’s translation.]

²⁸¹ Eight of whom had told their child/ren about the DI conception.

²⁸² In SOU 2007:3, on p 145, Lalos refers to the fact that ‘all except one woman intended to, however, in the future, tell her child/ren about this possibility.’ [Author’s translation.] In the English report of the study it was also mentioned that one mother had only told two of her three children at the time of the report. See Lalos et al, above n 273, p 1762. It is not clear whether these issues are one and the same. However, the tables in each report are identical.

²⁸³ Lalos et al, *ibid*; SOU 2007:3, p 146.

11 per cent reported in the first study in 2000, this follow up study, which also appears to be the most recent Swedish study, reveals an actual disclosure rate of 61 per cent. When the intended disclosure rate is taken into account the potential number of parents who either have or could disclose from this group is in fact 83 per cent.²⁸⁴

These figures appear to indicate an increased tendency by parents to be open with their children. However, there are some difficulties in comparing the results of the two studies, particularly because the number of parents participating in the second study was significantly smaller than the number of couples involved in the first study. The 19 families from the second study represent less than 13 per cent of the original cohort of couples from the first study. In relation to this, however, Lalos et al emphasise that the second study was a qualitative study, the focus of which was to attempt to understand ‘the meaning that people attach to their decisions ...’²⁸⁵ and to this extent ‘the design gives important indications of information that have [sic] not previously been known regarding Swedish DI parents.’²⁸⁶ Another issue that could raise questions about the results of the study is the fact that it was carried out via telephone interview. However, Lalos et al believe that such interviews can in fact promote more openness from some participants. Moreover, because over one third of participants had not yet disclosed, Lalos et al could find no grounds to assume that the design of the study attracted only those who were likely to disclose and that participants who dropped out of the study had not told their children. As they point out, even some participants who were not in favour of disclosure at all joined the study.²⁸⁷

Accordingly, while Lalos et al do acknowledge that the sample of participants cannot be regarded as representative of donor offspring parents in general, they believe that the findings from the follow up study indicate, *inter alia*, that a considerable proportion of parents do ‘recognize the importance of sharing DI information with their children.’²⁸⁸

4.2.2.3 Linköping study

Finally, a third Swedish study, not connected to the Stockholm-Umeå studies, above, was reported in 2006 by Leeb-Lundberg et al.²⁸⁹ All 20 couples who had become parents of donor offspring following donor insemination at

²⁸⁴ That is, of the 36 parents interviewed, 22 individuals had already disclosed and 8 plan to disclose.

²⁸⁵ Lalos et al, above n 273, p 1765.

²⁸⁶ *Ibid.*

²⁸⁷ *Ibid.*

²⁸⁸ *Ibid.* They also believe that the findings provide additional insight into the reasons why parents may oppose disclosure despite knowing that the child has a right to this information, p 1766.

²⁸⁹ S Leeb-Lundberg et al, ‘Helping parents to tell their children about the use of donor insemination (DI) and determining their opinions about open-identity sperm donors’ (2006) 85 *Acta obstetrician et Gynecologica* 78–81.

the University Hospital in Linköping between 1997 and 2003 were invited to participate in the study. Sixteen couples agreed to take part. The children in question were between one and seven years of age, with an average age of 2.9.²⁹⁰

In the Linköping study, three of the 16 couples had already disclosed to their child. While this amounts to an actual disclosure rate of just under 19 per cent, which is low when compared with the follow up Stockholm-Umeå study published in 2007, above, the children in the Linköping study were younger.

A promising finding for donor offspring where it concerns this study is the high combined actual and intended disclosure rate which is 75 per cent. Nine couples of the remaining 13 who had not yet disclosed reported that they intend to tell their child but believed that the child was too young at the time of the report. These particular children were between one and four years of age at the time.²⁹¹

The fact that only three couples had told their children about the DI in the Linköping study is not surprising considering the age of the children.²⁹² Leeb-Lundberg et al believe that the reported 75 per cent of parents who have already disclosed or intend to do so in the future is a high percentage, both from an international and national perspective;²⁹³ something which is supported by the findings of the other studies discussed in this chapter, below.²⁹⁴ The authors' acknowledge that one of the weaknesses of this study is the low number of subjects and state that, accordingly, no general conclusions may be drawn. On the other hand, they believe that the personal interviews, whereby men and women were interviewed separately, provided a greater depth of information in relation to the responses of parents than a questionnaire could have done.²⁹⁵

4.2.2.4 Concluding observations regarding Swedish studies

Although the first Stockholm-Umeå study published in 2000 revealed a very low rate of actual disclosure, the contrasting rate of disclosure reported in the follow up study several years later seems to be remarkably high. This appears to indicate that more parents will be likely to disclose in the future. In relation to the intended rate of disclosure, both the follow up study and the

²⁹⁰ Ibid, p 79. Note that the "16 couples" comprised 31 individual respondents.

²⁹¹ Ibid.

²⁹² Ibid, p 80.

²⁹³ Ibid.

²⁹⁴ While the most recent Swedish study reported by Lalos et al, above n 273, reveals an even higher combined actual and intended disclosure rate, the Lalos study was reported after the Linköping study. In any event, both studies reveal a significantly higher combined actual and intended disclosure rate than the first Stockholm-Umeå study from 2000 which was 52% (See Part 4.2.2.1, above).

²⁹⁵ Leeb-Lundberg et al, above n 289, p 80.

Linköping study show very positive results for donor offspring, assuming that the intentions of parents will in fact be carried out.

Even though there are reasons to be cautiously optimistic, however, the Swedish studies nevertheless continue to show that a number of donor offspring will never have a chance to find out about their origins. Each study to date has reported that some parents have no intention of telling their child about how the child was conceived at any time in the future. Since these children cannot exercise their right to information without this knowledge, the study results point to an inherent weakness in the Genetic Integrity Act itself and the structures established to administer access to information.

4.2.3 Studies from other jurisdictions support Swedish results

4.2.3.1 Early Victorian study shows most parents do not disclose

Information about the apparent or anticipated rate of disclosure by Victorian parents could be of particular interest for Sweden since the two jurisdictions began to regulate ART at the same time. At the time of writing, however, no studies have been reported about the disclosure patterns of those Victorian parents whose children were conceived from gametes donated after 1 January 1998 — the date on which the access to identifying information provisions of the Infertility Treatment Act came into effect. Accordingly, the true extent of the impact of the legislation on the disclosure patterns of Victorian parents is unknown.

An unpublished study from the year 2000, however, provides some insight into the disclosure patterns of Victorian parents whose children were conceived before donor offspring had a right to identifying information about the donor. The study, undertaken by the Royal Women's Hospital in Melbourne, examined, *inter alia*, the impact of the original Victorian Central Register on parents' decision to tell their child how the child was conceived.²⁹⁶ The group in question comprised 134 couples of a cohort of parents who had a donor conceived child born between 1975 and 1996.²⁹⁷ The age of the children at the time of the study was between 3–24 years.²⁹⁸ The study revealed that at the time of commencing treatment 54 per cent of couples had made the decision to tell their children about the donor conception.²⁹⁹ This figure increased to 55 per cent following the birth of the child.

²⁹⁶ J Blood, 'Impact of the Victorian Central Register on donor conceived families and their parents [sic] decision to tell their children', unpublished paper, Melbourne, 2000.

²⁹⁷ *Ibid*, p 3.

²⁹⁸ *Ibid*, p 10.

²⁹⁹ *Ibid*, p 8.

However, at the time of the study only 37 per cent of the couples had actually disclosed.³⁰⁰

It is important to emphasise that all parents involved in this particular study participated in donor treatment procedures either before or under the former Infertility (Medical Procedures) Act 1984 (Vic).³⁰¹ That is to say, at a time when the life-long anonymity of donors was presumed. Even after the first central register had been established under the legislation, the Act was unequivocal in relation to protecting the identity of people entered on the register. To this extent, it provided that no person could have access to any information which identified another person ‘unless that other person, or a person acting on behalf of that other person’ consented in writing to the release of such information.³⁰²

Accordingly, the results of this study cannot be interpreted in the same way as the Swedish results because the Swedish studies, above, were undertaken after anonymity had been abolished, on parents who commenced their treatment knowing that any donor offspring child subsequently born would have a right to identifying information about the donor. The results can nevertheless be compared with the results of similar studies published in other jurisdictions where the anonymity of donors prevails and to this extent they are valuable.

4.2.3.2 Additional international studies show most parents do not disclose

Most studies on parental disclosure patterns undertaken in other jurisdictions support the Swedish and Victorian findings, above, that there will always be some parents who will not tell their children about the donor conception. Several of these studies are highlighted below.³⁰³ While the percentages of non-disclosure vary, one factor common in most studies is that a significant

³⁰⁰ Ibid, p 9. **Note** that this study did not address the question of whether parents had told others of the donor conception.

³⁰¹ The Infertility (Medical Procedures) Act and its regulations were repealed by the Infertility Treatment Act and its regulations. All subsequent references to the former act and regulations are references to the repealed instruments.

³⁰² Infertility (Medical Procedures) Act section 22(3); Infertility (Medical Procedures) Regulations 1988 (Vic) Schedule 8 (r 13), item 2(c)–(d). See also s 23(1) of the Act which further defined the prohibition against disclosure and included a penalty. Re consent by a person ‘acting on behalf of’, not surprisingly, the legislature did not define what this term meant which left the meaning somewhat vague. Presumably, however, it intended the term to encompass parents and guardians of donor offspring, and not a wider group.

³⁰³ One exception found to this pattern is reported below in Part 4.3.2 but note that at the time of the study in question, 60% of parents had not yet disclosed. An interesting paper that compiles and summarises the results of a number of studies from jurisdictions around the world in relation to parental disclosure was published by the Infertility Treatment Authority in January 2006. See Infertility Treatment Authority, ‘Parents disclosing donor conception to their children: What does the literature tell us?’ January 2006, Victoria.

number of parents have not told their donor offspring child how the child was conceived. Nor do they intend to.

In a comparative study undertaken by Brewaeys et al, published in 1997, the opinions of 38 Dutch donor insemination families were compared with two control groups: one group comprising 30 IVF families where no donor gametes were used for conception; and the other, 30 families with naturally-conceived children.³⁰⁴ One aim of the study was to investigate attitudes about donor anonymity amongst the parents of donor offspring.³⁰⁵ Seventy-four per cent of the donor insemination parents had decided not to inform their child about the conception while 21 per cent planned to tell the child. By comparison, none of the IVF couples in the study intended to keep the fact of the IVF secret from their children. Only two sets of parents in each group were undecided about this issue and one couple in the insemination group had already told their child about its conception.³⁰⁶

A Finnish questionnaire study from 1998 shows a similar result. Söderström-Anttila et al compared the health and development of 59 children born from egg donation between October 1991 and December 1996 with 126 children born following IVF where no donated gametes were used.³⁰⁷ One of the three aims of the study was to investigate the parents' attitudes regarding secrecy.³⁰⁸ The study revealed that only 38 per cent of the egg donation parents intended to tell their child about the child's conception. By comparison, 60 per cent of the IVF parents intended to inform their child about the way in which the child was conceived.³⁰⁹

Another Finnish questionnaire study published three years later by Söderström-Anttila et al investigated the outcome and attitudes of donors and recipients with respect to embryo donation over a six year period ending in February 2000. Five of the 11 couples who already had an embryo dona-

³⁰⁴ See Brewaeys et al (1997), above n 270. At p 1592 the authors report that the data for this particular study was collected as part of The European study of assisted reproduction families. See further S Golombok et al, 'The European study of assisted reproduction families: Family functioning and child development' (1996) 11 *Human Reproduction* 2324–2331.

³⁰⁵ The other aims were to: 'examine the emotional/behavioural development of DI children and ... to investigate whether or not secrecy was associated with differences in the emotional adjustment of DI children.' The children were aged between 4 and 8 years old at the time of the study. See Brewaeys et al (1997), *ibid*, p 1592.

³⁰⁶ Brewaeys et al (1997), *ibid*, p 1593.

³⁰⁷ V Söderström-Anttila et al, 'Health and development of children born after oocyte donation compared with that of those born after in-vitro fertilization, and parents' attitudes regarding secrecy' (1998) 13 *Human Reproduction* 2009–2015. One of the three aims of the study was to investigate the parents' attitudes regarding secrecy (see p 2010).

³⁰⁸ *Ibid*, p 2010.

³⁰⁹ *Ibid*, p 2009. The authors pointed out that studies regarding parents' attitudes on secrecy issues show a greater tendency towards openness in donor oocyte recipients than donor sperm recipients, eg in most studies 26–70% of oocyte recipients intend to tell their child about the nature of his or her conception while only 10–30% of DI parents intend to tell their child that he or she was conceived from donor sperm. See further pp 2009, 2014.

tion child, had decided to tell their child about the nature of its conception. One had decided not to do so and five couples had left the decision open.³¹⁰

In a New Zealand study published in 1999, Rumball and Adair examined, inter alia, the attitudes of 181 parents who had been through a donor insemination program at Fertility Associates in Auckland.³¹¹ The parents, between them, had 142 children ranging from infancy to eight years of age. Thirty per cent of the participants had told their children about the donor conception.³¹² Seventy per cent of the parents had not told their children about this. However, 54 per cent of parents in the study intended to tell their children about it at some stage in the future although they had not done so yet.³¹³ Taking into account the fact that an additional 30 per cent of the parents had already told their children at the time of the study³¹⁴ it appears that there is considerable potential for disclosure amongst this particular group, even if all of those who intend to disclose may not do so. Twelve per cent of parents in the study did not intend to tell their children about their donor conception.³¹⁵

More recent studies reinforce the disclosure patterns reported above, ie that considerable numbers of parents, sometimes more than 50 per cent of a given cohort, do not favour disclosure and do not intend to tell their child about the donor conception.³¹⁶ These results appear to be completely inde-

³¹⁰ V Söderström-Anttila et al, 'Embryo donation: Outcome and attitudes among embryo donors and recipients' (2001) 16 *Human Reproduction* 1120, p 1124.

³¹¹ A Rumball and V Adair, 'Telling the story: Parents' scripts for donor offspring' (1999) 14 *Human Reproduction* 1392, p 1396. **Note** that the term 'parents' is used here as opposed to couples. Some parents had more than one child. The results of this study are very interesting and would be particularly useful to those involved in the counselling of donor recipients because it so thoroughly records the experiences of parents who have actually walked through the process of disclosure.

³¹² That is, 54 parents comprising 21 couples and 12 females. Of those parents who had more than one child, some had told all of their children while others had told only their eldest child. *Ibid*, pp 1395–1396.

³¹³ *Ibid*, p 1396. **Note** that it was necessary to adjust the reported percentage for this response to 54%, above, in order to maintain consistency with the methods of calculation in the other studies mentioned above, ie in this part of the thesis. The authors' calculation was reported as 77% but this figure represented 98 of the 127 parents who had not yet told their children, rather than 98 of the total parent cohort of 181.

³¹⁴ *Ibid*, p 1395.

³¹⁵ *Ibid*, p 1396. **Note** that it was also necessary to adjust the reported percentage for this response to 12%, above, in order to maintain consistency with the methods of calculation in other studies. The authors' calculation was reported as 17% but this figure represented 22 of the 127 parents who had not yet told their children, rather than 22 of the total parent cohort of 181.

³¹⁶ See for example E Lycett et al, 'Offspring created as a result of donor insemination: a study of family relationships, child adjustment, and disclosure' (2004) 82(1) *Fertility and Sterility* 172–179. Sixty-one per cent of the participants in this UK study favoured nondisclosure (28 out of 46 participating families) even though the policy of the clinic in question, ie the King's College Hospital Assisted Conception Unit, was to encourage prospective parents to disclose. See further p 173. This study was also reported in E Lycett et al, 'School-aged children of donor insemination: a study of parents' disclosure patterns' (2005) 20 *Human Reproduction* 810–819. In relation to embryo donation families, a study reported in 2007

pendent of the methods used to obtain the information. The only reasonable conclusion to draw from this is that there will always be some donor offspring who will not find out how they were conceived.

4.3 Studies contradicting assumptions about disclosure

4.3.1 Introductory remarks

Although most available studies appear to indicate that many parents of donor offspring are reluctant to disclose, some studies do deviate from this pattern. Three studies — one each from the United Kingdom, the Netherlands and Western Australia — exemplify a particularly high intended and/or actual disclosure rate amongst participating parents. These results contradict the patterns found in the studies reported above and to this extent should be highlighted.³¹⁷

It is important to point out, however, that conclusions about the intentions of donor offspring parents in general cannot be drawn on the basis of these studies alone, particularly where it concerns the UK and Dutch studies. The UK sample was selected from an organisation established as a self help donor network to support disclosure; in the Dutch study, parents could decide for themselves whether to choose an identifiable donor or an anonymous donor. These factors alone could contribute to the higher than expected rate of disclosure or intended disclosure reported in these studies compared with that found in other studies. Even so, the results serve as a reminder that some groups of donor offspring parents do in fact have a greater tendency to disclose than to be secretive, even if this phenomenon does not reflect the overall pattern reported above.

found that 43% of mothers questioned had decided they would never tell their child about the donation and 24% were undecided. See F MacCallum and S Golombok, 'Embryo donation families: mothers' decisions regarding disclosure of donor conception' (2007) 22 *Human Reproduction* 2888, p 2888.

³¹⁷ There is also a recent New Zealand study published in 2007 by Hargreaves and Daniels which found that most parents had told their children about the child's DI origins. In addition, it showed that most parents had also shared information about the DI with their family and close friends. This study explored, inter alia, parents' decisions to tell their donor offspring children about their origins. See K Hargreaves and K Daniels, 'Parents dilemmas in sharing donor insemination conception stories with their children' (2007) 21 *Children & Society* 420–431. This study was special in that the research, which included the carrying out of 52 interviews, was not only directed at the parents of donor offspring. Others interviewed were extended family members including grandparents, aunts and uncles. Professionals working with DI were also interviewed. While children were not formally interviewed for the study, a number of informal interviews also took place with five children aged between 8–12 years (pp 421–422). From the figures given at pp 421–422, it appears that 26 couples/individual parents of donor offspring were involved but no figures or percentages were given in relation to disclosure rates. Accordingly, it is not accounted for, above.

4.3.2 The United Kingdom

The first study, reported in 2000, comprised 83 individuals who had been recruited from a donor insemination support group in the UK.³¹⁸ Hunter et al reveal 40 per cent of the couples had already told their child about the DI and the remaining 60 per cent also intended to disclose but were ‘waiting for the right time, or when the child was older.’³¹⁹ The average age of the children who had been told about the DI was 3.5 years, with the range being between 3 months and 15 years. By comparison, the average age of those children who had not yet been told was 1 year and five months and the age range in this group was 11 weeks to four years. The main reasons given for disclosure were that family secrets were damaging and that the child should know about his or her origins.³²⁰ While this study was one of the first studies to explore the disclosure experiences of parents of donor offspring, Hunter et al emphasise that ‘[t]he participants, being drawn from members of the DI network, were inevitably unrepresentative of DI parents in general, being chosen specifically because of their support of disclosure.’³²¹

4.3.3 The Netherlands

The second study, published in 2005, examined the choices of 105 Dutch lesbian and heterosexual recipient parents who had the option of choosing an identity-registered sperm donor or an anonymous donor.³²² When this study was undertaken in 2003, the parents in question had participated in the former double track system of donor insemination that was available in the Netherlands prior to June 2004. Two aspects of this study are particularly interesting where it concerns access to identifying information: First, the results show that a surprisingly high number of parents — ninety-eight per cent of lesbian couples and 63 per cent of heterosexual couples — selected an identity-registered donor.³²³ Secondly, the study showed a clear difference between the intentions of parents to disclose, depending on the type of donor selected.³²⁴ Amongst the parents who had selected an identity-registered donor, 93 per cent had decided to tell their child about the donor conception

³¹⁸ See M Hunter et al, ‘Donor insemination: Telling children about their origins’ (2000) 5(4) *Child Psychology & Psychiatry Review* 157–163. The support group in question, the DI Network, was established in 1993 and at the time of the study, the group had approximately 280 members. The study population comprised 44 women and 39 men. This included 39 couples. See further p 158.

³¹⁹ Ibid, p 159.

³²⁰ Ibid, p 161.

³²¹ Ibid.

³²² See Brewaeys et al (2005), above n 257, p 820. Of the 105 couples in this study, 61% (64) were heterosexual and 39% (41) were lesbians (see further p 821).

³²³ This represented all but one of the lesbian couples in the study. Ibid, p 822.

³²⁴ Ibid, p 820.

while 7 per cent had not yet decided.³²⁵ By contrast, only 17 per cent of couples who had selected an anonymous donor intended to disclose this information to their child; 48 per cent from this group did not intend to disclose at all and 35 per cent remained uncertain.³²⁶

The extremely high percentage of parents who selected an identifiable donor must be regarded as positive for proponents of openness. However, the result cannot be directly compared with the results of other studies from “single track” systems where parents do not have the option to select an identifiable or anonymous donor. Since Dutch couples now have no option but to choose an identity-release donor,³²⁷ it will be interesting to see how this will impact on the overall disclosure patterns of parents.

Where it concerns couples who may prefer an anonymous donor, Brewaeys et al point out that ‘[a] compulsory choice for an identifiable donor does not change individual motives and might even lead to more secrecy and family isolation.’³²⁸ They thus conclude that the concerns and fears of DI parents must be taken seriously because the ‘child’s well-being is strongly influenced by the quality of the family relationships’.³²⁹ This is a very important point and provides strong support for the establishment of well-structured professional counselling for all prospective parents of donor offspring parents, something that will be addressed in Chapter Five, below.

³²⁵ Ibid, pp 822–823. At p 823, Brewaeys et al also point out that the decision to disclose by couples in this group was made irrespective of their sexual orientation.

³²⁶ Ibid, p 822. Note that these figures are expressed in a slightly different way in the article’s introduction at p 820 where it is instead stated that 83% of the anonymous donor group of parents did not intend to tell their child about the donor (ie 35% + 48%).

³²⁷ The Netherlands abolished donor anonymity in June 2004 giving donor offspring born from gametes donated after that date the right to identifying information about the donor when they are 16 years old. See further P Janssens et al, ‘A new Dutch law regulating provision of identifying information of donors to offspring: Background, content and impact’ (2006) 21 *Human Reproduction* 842–856.

³²⁸ See Brewaeys et al (2005), above n 257, p 824 and **note** that in relation to this comment Brewaeys et al refer to Pennings. See further G Pennings, ‘The “double track” policy for donor anonymity’ (1997) 12 *Human Reproduction* 2839–2844. Brewaeys et al provide no page reference in Pennings’ article but presumably they are referring to his comments made at pp 2842–2843 under the heading “Co-ordination with the position of the parents on secrecy”. It should be pointed out here that Pennings provides some very persuasive arguments in support of the double-track system which was then in place in the Netherlands. He also presents some thoughtful and convincing arguments in favour of enabling the parties to donor treatment procedures to choose for themselves whether to have identifiable or non-identifiable donors instead of imposing a particular method by law. While it is beyond the scope of this book to explore these arguments they are nevertheless interesting in that they question the need to impose a system that requires donors to be identifiable, even though the Netherlands has since introduced such a system itself.

³²⁹ Brewaeys et al (2005) *ibid*, p 824.

4.3.4 Western Australia

Finally, the purpose of the Western Australian study was to examine, inter alia, the intentions of prospective parents in relation to disclosure and to find out how they felt about the release of identifying information.³³⁰ This study was carried out by anonymous questionnaire in response to amendments made to the Human Reproductive Technology Act 1991 (WA) which now permits mature donor offspring born from gametes donated after December 2004 to obtain identifying information about the donor.³³¹

The sample questioned was drawn from 53 women from one fertility clinic who underwent a donor treatment procedure using donor sperm between July 2004 and December 2005. Both recipients and their partners were invited to participate and this group comprised heterosexual and lesbian partners, and single women. Ten of the women already had children and almost half of the recipients were single women.³³² Thirty-three recipients and 12 partners completed the questionnaire.³³³

Godman et al report that 82 per cent of the recipients and 92 per cent of their partners intended to advise their donor offspring child about how the child had been conceived. A somewhat lower number of participants, however — 69 per cent of recipients and 67 per cent of partners — considered that the child should be given identifying information about the donor.³³⁴ These figures are still impressive by international standards but they do reveal that not all prospective parents who intend to disclose are in favour of their child knowing the identity of the donor. Moreover, while these figures, like the other two studies mentioned above, show a high rate of intended disclosure, Godman et al do mention that responses in relation to disclosure varied depending on the status of the relationship. To this extent, the intended disclosure rate of the single women (87.5 per cent) and lesbian women (88.9 per cent) was considerably higher than the intended disclosure rate of women in heterosexual relationships (62.5 per cent).³³⁵ In relation to the results, Godman et al state that:

³³⁰ See KM Godman et al, 'Potential sperm donors', recipients' and their partners' opinions towards the release of identifying information in Western Australia' (2006) 21 *Human Reproduction* 3022, pp 3022–3023. **Note** that the study also explored the opinions of 45 potential sperm donors.

³³¹ *Ibid*, p 3022. The relevant provision of the Human Reproductive Technology Act 1991 (WA) is s 49(2d).

³³² See Godman et al, *ibid*, p 3024.

³³³ *Ibid*, p 3022. In the case of Western Australia, some of the recipients interviewed were already undergoing treatment before the new law abolishing anonymity had come into effect. See p 3023.

³³⁴ *Ibid*, pp 3022, 3024. **Note** that in the table on p 3025 the number of recipients who believe that a child should be told about the donor is described as 84.4%, ie more than the 82% reported in the text of the report.

³³⁵ *Ibid*, p 3024.

[t]he high intended disclosure rates seen in this study suggest that the change to an open-identity programme will create a culture in which parents feel able to tell their child about the nature of their conception.³³⁶

While it seems premature to draw such a conclusion from 45 volunteers, in part since almost half of the recipients comprised single women, and 27 per cent of those interviewed were in lesbian relationships,³³⁷ this study provides valuable insight into the opinions of prospective recipients and their partners in Western Australia. Importantly, Godman et al also emphasise an issue already raised above: that the intention to disclose does not necessarily equate with actual disclosure and — closely connected — that disclosure rates may decrease after the child is born. Moreover, they acknowledge that ‘the absence of a male partner increases the likelihood of disclosure’ and, in relation to this, refer to the high levels of lesbian and single recipients who participated in their study.³³⁸

When one compares the results of this study with those of the more recent Swedish studies discussed in Part 4.2.2, which show that the tendency of Swedish heterosexual couples to disclose many years after anonymity was abolished is still somewhat lower than expected, it is interesting to observe that the intended disclosure rate of 62.5 per cent amongst the Western Australian heterosexual women is in fact less than the figure reported in the two most recently published Swedish studies.³³⁹ Even so, the overall intended disclosure rates for these Western Australian couples appears to be extraordinarily high and it will be interesting to follow the results of subsequent studies to see what eventuates.

4.4 Most parents do tell others about donor conception

4.4.1 Sweden

Another feature commonly found in many studies on parents of donor offspring is that most parents tell others about the donor conception, irrespective of whether or not they plan to tell their child about it. If parents share this information with others, but do not share it with their donor offspring child, the child could hear about it from another source. Such a situation is

³³⁶ Ibid, p 3024.

³³⁷ The breakdown was 48.5% single women, 27.3% lesbian women, and 24.2% heterosexual individuals. Ibid, p 3024.

³³⁸ Ibid, p 3025.

³³⁹ That is, the follow up to the Stockholm-Umeå study reported a combined actual and intended disclosure rate of 83% (Part 4.2.2.2, above) and the Linköping study reported a corresponding rate of 75% (Part 4.2.2.3, above).

inconsistent with the Swedish Parliament's view that it is best for the child to find out this information from his or her own parents.³⁴⁰

As regards the Stockholm-Umeå study from 2000, fifty-nine per cent of the couples, ie 87 of 148, had told another person about the DI, usually a close family member. The study also reveals that half of this group had in fact told many other people about the insemination.³⁴¹ Importantly, all couples who had told their child about the DI had told others and 53 per cent of the couples who had not told their child about it had told others.³⁴² The results also show that the number of parents who chose to tell other people about the insemination had increased steadily over time. While 31 per cent of the parents of 12–15 year olds had told other people about the insemination, 68 per cent of the parents from the 1–3 year old age group had done so.³⁴³ Whether the increased tendency to tell others is due to changing attitudes over time or because of the existence of the legislation is impossible to say. It could, however, be a positive indication that increasing numbers of Swedish parents will tell their children about the donor assisted conception in the future.³⁴⁴ On the other hand, it could also mean that more children might hear about the donor treatment procedure from a family friend or relative before they are told by their parents.

In the follow up Stockholm-Umeå study, above, 89 per cent of participants had told one or more people outside the family about the DI treatment. In relation to this, '[o]nly one woman and three men ... were absolutely convinced that no one but their partner knew about it. However, two of the men had wives who had told a close friend [about the DI] without their husband's knowledge.'³⁴⁵ Lalos et al also report that it was most common for both relatives and close friends to be told about the DI. However, 'quite often' this information was also known by 'some neighbours and staff at the day care centre and school.'³⁴⁶ They were able to conclude that, in relation to 18 of the 19 families, there was at least one person outside of the family who knew about the DI. In spite of this, the children in eight of these families had not yet been told themselves.³⁴⁷

What is apparent from the follow up study, above, is that the percentage of parents who told someone outside the family about the DI, *without telling*

³⁴⁰ See prop 1984/85:2, p 15; and prop 2001/02:89, pp 46–48. See also Part 5.2, below.

³⁴¹ Gottlieb et al, above n 260, p 2054. The highest frequency of disclosure to people other than the child was reported to be amongst those who most recently had their children. In fact, in each of the four sub-groups, divided according to the age of the child, ie 1–3 years, 4–7 years, 8–11 years, 12–15 years, the percentage of parents telling others about the DI has increased with successive years.

³⁴² Ibid, p 2054.

³⁴³ Ibid.

³⁴⁴ Ibid.

³⁴⁵ Lalos et al, above n 273, p 1761.

³⁴⁶ Ibid.

³⁴⁷ Ibid.

the child, had in fact decreased by the time the second study was performed. It was also evident that the children in five of the eight families who did not yet know about the DI had parents who planned to tell them about it in the future.³⁴⁸ Since the combined actual and intended disclosure rate of 83 per cent³⁴⁹ is very close to the overall percentage of parents who had already told other people about the DI, ie 89 per cent, there appears to be a high probability that most of the children from this group have either heard, or will hear, about their donor conception from their parent or parents. Moreover, the corresponding risk that they will first hear this news from an outside source would appear to be considerably smaller for these children than for the other remaining children whose parents participated in the first study.

In the Linköping study, 88 per cent of the couples had talked to other people about the DI. Considering the combined actual and intended disclosure rate of the group was 75 per cent at the time of the report, this figure indicates that at least 13 per cent of parents who do not intend to tell their child have told others about the DI. In turn, there is a strong possibility that some of these children will hear about the DI from a source outside the family.

4.4.2 Studies from other jurisdictions

In the 1997 study reported in by Brewaeys et al, above, 50 per cent of the DI parents had told at least one other person about the DI; either family or friends or both.³⁵⁰ Twenty-six per cent of the insemination families had been open about the donor insemination to others, even where they were not in favour of disclosing this information to their child.³⁵¹ There is thus a real possibility that the child might hear of this secret from a third person. According to Brewaeys et al, these findings that show a discrepancy between information revealed to others and information revealed to the child are consistent with research previously undertaken on insemination families.³⁵²

In Soderstrom-Anttilla's 1998 study, above, 73 per cent of egg donation parents, ie 36 of 49, had told other people about the donation. Of this group, 63 per cent had told family members or one or two good friends and 10 per cent replied that they had discussed the matter "openly". The remaining 27 per cent had not told anybody about the treatment.³⁵³ It is obvious that if 36 parents have told other people about their donor treatment but only 18 par-

³⁴⁸ Ibid, p 1762.

³⁴⁹ See Part 4.2.2.2, above.

³⁵⁰ Brewaeys et al (1997), above n 270, pp 1593–1594

³⁵¹ That is 10 out of 38 families. Ibid, p 1594.

³⁵² Ibid, p 1595. See also Golombok et al, above n 304, pp 2324–2331, who report that the Dutch data concerning the donor insemination group is consistent with the data collected in the three other European countries participating in the study, ie Italy, Spain and the UK, where only 12% of the parents had decided to disclose.

³⁵³ Söderström-Anttila et al (1998), above n 307, p 2013.

ents intend to tell their children about it, the possibility that this information will leak out to the child at some stage is quite high.³⁵⁴

In the study by Hunter et al, above,³⁵⁵ most of the couples interviewed had told others about the DI. All the women interviewed had told at least one person about the DI and only one of the men had not told anyone about it. Eighty-seven per cent of the men and 88 per cent of the women had told their own family³⁵⁶ while 84 per cent of men and women had told a close friend. Some men and women had also told their employers and their child's school.³⁵⁷ However, since this particular group of parents had either already told their child about the DI or were intending to do so, the fact that all but one had told someone outside of the immediate family about the DI should not necessarily pose a problem for the donor offspring in question, assuming the parents actually carry out their intention to disclose. In line with the children from the follow up Stockholm-Umeå study, above, the risk that these children will first hear about the DI from an outside source must be presumed small.

Even though it is difficult to draw firm conclusions about the results of this group of studies, what they do confirm is that most parents will tell others about the donor conception, even if they have no intention of telling their children.³⁵⁸ Where this occurs, there is a tangible risk that donor offspring will find out how they were conceived from another source which — in Sweden at least — is not consistent with Parliament's intention that they should hear this news from their parents.

³⁵⁴ Söderström-Anttila et al go so far as to suggest that '...such an arrangement seems hazardous.' They recommend that: 'If the parents do not plan to tell the child, they should be encouraged not to tell other family members or friends.' Ibid, p 2014.

Note that there are no results available about the disclosure by parents to others from the authors' 2001 study on donor embryos mentioned above. See Söderström-Anttila et al (2001), above n 310, p 1120.

³⁵⁵ See Hunter et al, above n 318.

³⁵⁶ Ibid, p 159. The percentages given above represent 34 of the 39 men in the study and 39 of the 44 women.

³⁵⁷ Ibid. Twenty-five per cent of men and 28% of women had told employers and 15% of men and 18% of women had told the child's school.

³⁵⁸ See also MacCallum and Golombok, above n 316, p 2888. This study showed that 72% of embryo donation mothers had told other family members about the donation. By comparison, only 9% of mothers had told their children about this and 24% planned to do so in the future.

4.5 Parliament's intention was that donor offspring should find out how they were conceived

It was shown in the previous chapter that the intention of the Swedish Parliament was that donor offspring should find out how they were conceived so that they could make their own choices regarding access to information.³⁵⁹

When the Swedish Parliament left the responsibility for disclosure with the parents of donor offspring in 1984, it was assumed that parents would disclose, thereby ensuring that the right to information would become a fully functional and genuine right. Clear indications of this can be found in the Government Bill on Artificial Insemination where the Government refers to donor offspring being able to turn to the Social Welfare Board in their home county for assistance when seeking information about the donor. In relation to this, it is acknowledged in the Bill that such assistance is dependent upon the child knowing or suspecting that he or she has been conceived through donor insemination. Moreover, it is evident from the wording of the Bill that the Government expected that parents should — in light of the recommendations regarding access to information for donor offspring — normally inform their children about the donor conception at a suitable time and that, as a rule, the children would also have been told where the insemination had taken place.³⁶⁰

The fact that parents are not disclosing as anticipated is inconsistent with Parliament's intention that donor offspring should be able to exercise their right to information about the donor when they are sufficiently mature. The legislation itself clearly reflects Parliament's intention by expressly stating that donor offspring have a right to know the identity of the donor.³⁶¹ The wording contained in the mirror provisions of the Insemination and IVF chapters of the Genetic Integrity Act is not in any way ambiguous. Nor is it open to speculation. It does not provide that donor offspring have a right to identifying information about the donor *subject to the discretion of their parents*. Rather, it expressly confers on donor offspring an unconditional right to identifying information about the donor. Moreover, there is no question that the policy behind the legislation was that donor offspring should have the opportunity to find out about their genetic origins.

³⁵⁹ As to Parliament's intention that donor offspring should know about the donor and that they should have a right to this information see further prop 1984/85:2, pp 15–16, 27; DS 2000:51, pp 25, 37, 44–45, 61–62; and prop 2001/02:89, pp 45–46, 86.

³⁶⁰ See prop 1984/85:2, p 27.

³⁶¹ See Genetic Integrity Act, Ch 6, s 5 (Insemination); Ch 7, s 7 (IVF).

4.6 Disclosure is assumed to be in the best interest of donor offspring

It has been shown above that the access to information provisions of the Swedish legislation were drafted on the assumption that satisfying the best interests of donor offspring is directly connected to disclosure. The preparatory works to the Act on Insemination contain many references to this.³⁶² Moreover, the right to identifying information contained in the Genetic Integrity Act³⁶³ reflects the assumption that it is in the best interests of donor offspring to have the opportunity to trace the donor — something which today is contingent upon disclosure.

This assumption is further reinforced by studies on donor offspring, although the question of whether there is *a need* for donor offspring to know about the donor is irrelevant from a legal standpoint in Sweden where the law is clearly settled in favour of the child's right to know. It is, however, important to recognise that there is a growing body of research which strongly suggests that disclosure is connected to the welfare and interests of donor offspring. Accordingly, two examples of the results of this research are highlighted below. It should also be remembered that gathering information from donor offspring is more difficult than obtaining information from parents or donors because it is often not possible to know who the donor offspring are or where they are located, particularly in relation to those born before record keeping was made mandatory. Yet it is this group, the pre compulsory-record-keeping group of donor offspring, which is of particular interest when it comes to studies seeking to evaluate the importance of disclosure since many of them are now adults.

In 2000, Turner and Coyle published the results of a qualitative study undertaken on donor offspring. One of the aims of the study was to consider the counselling needs of this group.³⁶⁴ Surprisingly, they were only able to recruit 16 participants via donor insemination support networks in Australia, the United Kingdom, USA and Canada.³⁶⁵ In their own words: 'Recruitment of participants was undertaken on an international basis because the secrecy

³⁶² See, for example SOU 1983:42, pp 117, 121; Prop 1984/85:2, pp 15, 24–27, 40; LU 1984/85:10, pp 21–23; SoU 1984/85:2 y, pp 5–6; And **note** that this assumption was later reinforced in eg DS 2000:51, p 27; and prop 2001/02:89, p 86. See also Part 3.4, above.

³⁶³ Ch 6, s 5 (Insemination); Ch 7, s 7 (IVF).

³⁶⁴ AJ Turner and A Coyle, 'What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy' (2000) 15 *Human Reproduction* 2041, p 2043.

³⁶⁵ The data from the questionnaire was qualitatively evaluated using interpretative phenomenological analysis (IPA), a method previously used in other health and well-being studies, which features a detailed, in-depth exploration of the experiences of participants. Because of its concern with detail, this method is used on smaller sample sizes and the authors of the study report that they '... were therefore pleased to have been able to apply our [ie their or this] method to a sample of 16, which is certainly not an atypical sample size for many qualitative research studies.' *Ibid*, p 2043.

surrounding the practice of DI has meant that there are very few individuals who know that they are donor offspring.³⁶⁶ The group comprised 13 females and 3 males aged between 26–55 years.³⁶⁷ All participants had been conceived in countries or jurisdictions where there was no legal right to know the identity of the donor.³⁶⁸

What Turner and Coyle were able to establish was that the right to know about their genetic origins was important for 15 of the 16 participants in the study, all of whom had made some initial enquiries in an attempt to locate their donors.³⁶⁹ However, the participants often felt that their need to have information and to search for the donor was not recognised by others.³⁷⁰ Turner and Coyle found that ‘participants continually reported that they needed to know their genetic origins and wished to search for their donors.’³⁷¹ Participants ‘consistently reported mistrust within the family ... lack of genetic continuity, frustration in being thwarted in the search for their biological fathers ...’ and a need to talk to someone who would understand their situation.³⁷²

The participants all had in common the feeling that, at some level, they knew that there was something within their families that was not right.³⁷³ In the words of one participant ‘Rachel’:

I always felt like I didn’t belong with these people—I searched for evidence of my ‘adoption’ for many years as a child ... It [the withholding of information] created a ‘shroud of secrecy’ and a ‘sense of shame’ about something I could sense, but of what I had no real knowledge—I always had suspected something wasn’t ‘kosher’—but I didn’t know what it was—there’s no way my sense of self-esteem could not have been damaged by that experience.³⁷⁴

Many participants’ also experienced ‘a feeling of loss about not knowing “their” donor.’³⁷⁵

³⁶⁶ Ibid.

³⁶⁷ Ibid, p 2044. **Note** that the abstract of the study states that the participants of the study comprised 13 males and 3 females (at p 2041). However, from the given names in the text it is clear that there are 13 females and 3 males.

³⁶⁸ Ibid, p 2043.

³⁶⁹ This is consistent with a study undertaken on 29 donor offspring from the USA who knew about their conception. The offspring were 12–17 years of age at the time of the study. The results revealed that 86.2% of the donor offspring questioned replied that they would be at least ‘moderately likely to request’ identifying information about the donor in the future. See JE Scheib et al, ‘Adolescents with open-identity sperm donors: Reports from 12–17 year olds’ (2005) 20(1) *Human Reproduction* 239, p 246.

³⁷⁰ Turner and Coyle, above n 363, pp 2046–2047.

³⁷¹ Ibid, p 2049.

³⁷² Ibid, p 2041.

³⁷³ Ibid, p 2045.

³⁷⁴ Ibid.

³⁷⁵ Ibid, p 2046.

The results of Turner and Coyle's study are consistent with those found by McWhinnie who reports that:

[b]ecause of the extreme secrecy over the 60 years of this practice, it has not been possible to undertake any kind of systematic study of DI adults and their experiences. However, by scanning the findings from small studies available and the literature about personal biographies in newsletters and elsewhere, it is possible to gain access to the experience of approximately 80–90 DI adults.

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The data above supports the notion that many donor offspring who know about their conception do in fact have a personal need to trace the donor. Knowledge of their conception, as a result of disclosure, is, of course, fundamental in this connection. While Swedish donor offspring already have a legal right to identifying information about the donor, studies such as those undertaken by McWhinnie, and by Turner and Coyle, above, are important reminders that the realisation of the right to identifying information is of great significance to donor offspring. This in turn should increase the resolve to ensure that the law which confers this right is fully functional, as intended.

4.7 Concluding remarks

This chapter has attempted to show that a donor offspring's legal right to identifying information about the donor is not an effective legal right because it is conditional upon the parents' will to disclose and because many parents do not tell their children how the child was conceived. It is also apparent that one of the reasons why parents of donor offspring do not disclose is because they find it difficult to do so. All of the available literature which has explored questions about parental disclosure — in addition to the studies discussed in this chapter — confirms this. Moreover, it highlights the need for parents to have access to effective support services in order to assist them to manage disclosure, irrespective of whether a jurisdiction has abolished anonymity or not. In jurisdictions such as Sweden, where Parliament has made a positive decision to abolish anonymity via law, organised support mechanisms for parents may be the key to the effective implementation of the right to information.

The fact that so many parents do not disclose and have no intention of doing so in the future is clearly at odds with existing ART law in Sweden. While the results of the follow up Stockholm-Umeå study published in the 2007, and the Linköping study published one year earlier, are certainly posi-

³⁷⁶ See A McWhinnie, 'Gamete donation and anonymity: Should offspring from donated gametes continue to be denied knowledge of their origins and antecedents?' (2001) 16 *Human Reproduction* 807, p 811.

tive in relation to intended disclosure, the chance that all, or even most, donor offspring will find out how they were conceived from their parents today is by no means high. If the right to information cannot be exercised by donor offspring because parents are not disclosing, it would seem logical to address the issue of parental disclosure as a matter of urgency; particularly if the responsibility for both steps of disclosure, ie the moral and the legal components, is to be left to parents. If not, Parliament's intention that donor offspring should have a right to know the identity of the donor, and that they should find this information out from their parents, may be an unattainable goal.

5 Facilitating the right to information

5.1 Introductory remarks

Having established that parents of donor offspring are not disclosing to the extent expected, the main purpose of this chapter is to identify and explore a number of alternative measures, both supportive and invasive, that could be implemented to facilitate the right to information. Since the 1980s Swedish policy in relation to the responsibility for disclosure has been unwavering: Donor offspring should find out how they were conceived from their parents because it is the parents who are best equipped to deliver this information at a suitable time, and in a way which will be of the greatest possible benefit to the child.³⁷⁷ An appropriate starting point for promoting access to information, then, should be with the parents of donor offspring; to offer them greater support in order to make it easier and more natural for them to manage disclosure.³⁷⁸ To this end, supportive measures are examined first. These measures include the introduction of compulsory counselling; making professional counsellors responsible for the psycho-social investigation; the implementation of more effective follow up and support programs for parents; clarifying the child's right in the Children and Parents Code; and giving donors a right to apply for identifying information about adult donor offspring. In addition to increasing disclosure, the implementation of these measures takes into account the interests of parents and donor offspring. The last-mentioned measure also considers the possible interests of donors. Its inclusion here, however, is due to its potential as a tool for promoting disclosure in order to satisfy the best interests of donor offspring.

After highlighting the importance of a central donor information register for Sweden, two invasive alternatives for promoting access to identifying information are explored. These alternatives — entering information about the donor on the population register and notifying adult donor offspring about the donor — would virtually guarantee that all donor offspring will find out how they were conceived even if the parents do not disclose.

³⁷⁷ See prop 1984/85:2, p 15; prop 2001/02:89, pp 46–48. See also SOU 1983:42, p 116; SOU 2007:3, p 92.

³⁷⁸ The need for greater support for parents was raised in Part 3.5.3, above, particularly in the context of counselling.

Finally, whether the measures put forward could be applied retrospectively is briefly addressed before considering the possibility of a voluntary register for Sweden.

5.2 Make counselling compulsory

One way to facilitate the right to information would be to introduce counselling as a compulsory component of all donor treatment procedures. At present, there is no requirement for parents to participate in pre-treatment counselling under the Genetic Integrity Act or its regulations.³⁷⁹ This requirement was also absent under the Act on Insemination. Yet already in 1984, the importance of psycho-social support for parents was emphasised in the Government Bill on artificial insemination.³⁸⁰ Several years later in the Government Bill on the treatment of unintentional childlessness, the Government — in light of what it regarded as the “discouraging” results of the first Stockholm-Umeå study³⁸¹ — considered how it could increase the tendency of parents to disclose. There it stated that:

[t]he Government takes seriously the fact that so many of the children do not find out about their biological origins.³⁸²

Reiterating its position that it was best for the child to find out this information from his or her own parents as early as possible, the Government expressed the view that it was most urgent to find ways to promote this. According to the Bill, a pre-condition for parents taking up this question with their children is that they are actually aware that they should do so. To this end, it was re-confirmed that prospective parents should be advised about the importance of openness with their child and emphasised that this should be included in the psycho-social investigation prior to treatment.³⁸³ The Bill also provided that:

³⁷⁹ See further Part 3.5.3.4 above.

³⁸⁰ Prop 1984/85:2, pp 15, 24–25. Since then the importance of psycho-social support for parents has continued to be discussed and acknowledged both by the Government and Parliament, and in subsequent investigations so its view is well established. See, eg, prop 2001/02:89 om behandling av ofrivillig barnlöshet, pp 46–48. [Trans: Government Bill on the treatment of unintentional childlessness.]; SOU 1983:42, p 116; SOU 2007:3, p 92.

³⁸¹ That is, that only around 10% of parents who answered the questionnaire had told their donor offspring children how the child was conceived, prop 2001/02:89, p 47; See also Part 4.2.2.1 above, where this study is discussed.

³⁸² Prop 2001/02:89, p 48. [Author’s translation.]

³⁸³ Prop 2001/02:89, p 48. This was essentially a reinforcement of the Government’s comments made in prop 1984/85:2, above, but, given its new-found knowledge that many parents had not yet told their children about the donor conception, placed more emphasis on the importance of finding ways to increase disclosure.

[t]he National Board of Health and Welfare should contribute to the development of routines and methods so that prospective parents can receive help with how they, early and in a good and adequate way, can inform their child about how the child came into existence.³⁸⁴

Since this was not questioned by the Swedish Parliament it is reasonable to assume that, in its view, parental support should not only be required; it should be an ongoing process in order to maximise disclosure. If this is to be effective, some form of assistance should be offered to help parents of donor offspring with disclosure *after* the child is born in addition to counselling them for openness during the psycho-social evaluation prior to the donor treatment procedure.

Attempts to achieve the latter appear to have been made through the guidelines on assisted reproduction.³⁸⁵ In spite of this, however, there are indications that some parents are not receiving pre-treatment counselling at all and being counselled for openness is not necessarily routine prior to donor treatment procedures. Moreover, there is no evidence that routines or methods have been developed to assist parents with disclosure *after* their children have been born.

In order to promote access to identifying information in line with Parliament's intention, above, there should be, at an absolute minimum, a requirement that the psycho-social investigation prior to donor treatment procedures includes counselling parents for openness. The framework for such counselling already exists in the guidelines on assisted conception. Moreover, the National Board of Health and Welfare has the full support of the Swedish Parliament, if not a mandate, to develop this process further. It is simply a matter of pursuing it, and in such a way to ensure that counselling will in fact take place. If new regulations were drafted to reflect the intention that counselling for openness should be a mandatory component of the psycho-social evaluation, it should not be necessary to amend the Genetic Integrity Act to give effect to this. The Act already provides that donor treatment procedures may only be carried out if it can be assumed that the prospective child will grow up under good conditions. Counselling could therefore be regarded as an appropriate and necessary step to take in order to fulfill the requirements of the pre-treatment evaluation process. On the other hand, if the intention would be to guarantee that counselling became a compulsory part of the pre-treatment process, such that prospective parents would be compelled to participate, this should be expressly provided for in the legislation.

³⁸⁴ Prop 2001/02:89, p 45. [Author's translation.]

³⁸⁵ SOSFS 2002:13, Ch 4 (Guidelines). See also Ch 10 (Guidelines) which provides that parents should be offered counselling.

5.3 Clarify responsibility for counselling

5.3.1 Introductory remarks

Another way to promote the right to information, which would also complement the measure of mandatory counselling, would be to clarify the responsibility for the psycho-social investigation with a view to giving the responsibility for counselling to professional counsellors. It was shown in Chapter Three, above, that the responsibility for the psycho-social investigation of prospective parents prior to donor treatment procedures lies in the hands of the medical doctor. Even though there are expectations, in line with Parliament's intention, that this investigation should be jointly undertaken between the doctor and a professional counsellor, it is ultimately the doctor who determines whether or not a given couple is suitable for treatment, both from a medical and psycho-social perspective.³⁸⁶

Although the National Board of Health and Welfare's guidelines elaborate on what should be taken into account with the psycho-social assessment, and state that it "should" always be carried out jointly,³⁸⁷ the guidelines are not binding. Moreover, both the Genetic Integrity Act and the regulations are silent about the involvement of a counsellor. Accordingly, the risk that some prospective parents will not have the opportunity to effectively work through the important psychological issues associated with their treatment remains real. If doctors are to satisfy themselves that future donor offspring are to grow up under good conditions, as required under the legislation,³⁸⁸ all prospective parents should be adequately assessed and provided with sufficient support and information prior to treatment. While medical doctors are best-equipped to determine whether a couple is suitable to undergo treatment for medical reasons, it is unreasonable to expect them to take responsibility for the psycho-social aspects of the investigation.

In light of recent studies which indicate that some prospective parents are not receiving counselling at all prior to donor treatment procedures, and that not all doctors are positive about promoting openness,³⁸⁹ the opportunity should now be taken to review and clarify the existing division of responsibility for the psycho-social investigation of prospective parents.

If counselling is to become an effective tool for the purpose of facilitating disclosure, it would seem logical to place the pre-treatment psycho-social investigation, along with any follow up counselling, in the hands of a competent professionally-trained counsellor who is supportive of and understands the intentions of the legislation.

³⁸⁶ See Part 3.5.3.4, above. See also Genetic Integrity Act, Ch 6, s 3 (Insemination); and Ch 7, s 5 (IVF).

³⁸⁷ SOFS 2002:13, Chapter 4, Guidelines. See also Part 3.5.3.4, above.

³⁸⁸ See SFS 2006:351, Chapter 6, s 3 (Insemination); Chapter 7, s 5 (IVF).

³⁸⁹ See further Part 5.3.3, below.

5.3.2 Parliament's intention was that the psycho-social investigation should be shared

Leaving the ultimate decision about a couple's suitability for treatment in the hands of the doctor alone was something that the Insemination Committee was strongly opposed to. This was mainly due to its finding that the psycho-social advice given by doctors performing insemination at that time was not sufficient to ensure that any prospective child would grow up under good conditions.³⁹⁰ In the Committee's view, personnel involved in the advice and investigation process prior to donor treatment procedures must have special competence. It believed that the Social Welfare Board would be well suited for this task because the Authority's staff were already familiar with adoption matters and associated problems.³⁹¹ The Insemination Committee also believed that the Authority would provide a good and complete assessment of prospective insemination parents.³⁹² Accordingly, it recommended to the Swedish Government that all prospective parents must undergo a psycho-social evaluation by the Social Welfare Board in order to assess whether they would be suitable candidates for a donor treatment procedure.³⁹³

The Insemination Committee's recommendation was heavily criticised during the consultation process and subsequently rejected in the Government Bill. A clear majority of the remitted opinions considered that the evaluation of a couple's suitability as prospective insemination parents should occur, instead, where the insemination takes place.³⁹⁴ The Government shared the Committee's view that some form of psycho-social investigation of the prospective parents was necessary to ensure that a prospective insemination child would be able to grow up under good conditions. It was not convinced, however, that the responsibility for the medical and the psycho-social evaluations should be split up between two separate institutions — particularly since most hospitals already had access to social workers, psychologists and psychiatrists who could easily assist the doctor with an assessment of the suitability of the prospective parents. Thus, the Government instead proposed that both the medical and the psycho-social investigation take place at

³⁹⁰ SOU 1983:42, p 87. It should be recalled that the Committee's starting point was that donor insemination shall be approved only to the extent that it could be assumed that the prospective child would be able to grow up under good conditions.

³⁹¹ SOU 1983:42, p 96.

³⁹² SOU 1983:42, p 97. The Committee considered in the first instance, the hospital welfare officers as well as the hospital employed psychologists and psychiatrists. It believed that an advantage with leaving the advice and investigation responsibility to such personnel was that the whole activity of donor insemination would be able to stay within the hospital. A smooth and easy procedure should then presumably arise. However, the Committee found that there were also disadvantages with such a system. Most importantly, these people were not usually working with this activity. Accordingly, it opted for the Social Welfare Board. See SOU 1983:42, p 96.

³⁹³ SOU 1983:42, p 162 s 7.

³⁹⁴ Prop 1984/85:2, p 11.

the hospital concerned, under the supervision of the responsible doctor who would also make the final decision about whether or not to approve the treatment. Any such decision of the doctor could subsequently be appealed to the National Board of Health and Welfare.³⁹⁵

Although it was Parliament's intention that a joint investigation be undertaken this is by no means clear from the wording contained in the insemination and IVF chapters of the Genetic Integrity Act.³⁹⁶ Moreover, no regulations have been drafted on this issue. The guidelines only briefly refer to the involvement of the counsellor, clearly reinforcing the doctor's role as decision maker, even with respect to the psycho-social factors about which a professional counsellor is more competent to make a determination.³⁹⁷

5.3.3 Give responsibility for psycho-social investigation to professional counsellors

A recent study about the attitude of Swedish obstetricians and gynaecologists in relation to gamete donation has revealed that approximately 40 per cent of doctors questioned were opposed to donor offspring receiving any information about the donor when they reached maturity.³⁹⁸ Moreover, while the majority of doctors responded that parents should be honest with their child about the child's origins,³⁹⁹ only 41 per cent of male doctors and 51 per cent of female doctors agreed that it was in the best interests of adult donor offspring to be able to find out the identity of the donor.⁴⁰⁰ The authors of the study point out that 'negative attitudes towards disclosure may influence patients' ability to discuss their thoughts and feelings about donation.'⁴⁰¹ Assuming this is true, it is likely that some prospective parents will not find

³⁹⁵ Prop 1984/85:2, p 12. The relevant provision can be found on p 4 of the Government Bill (s 3, ss 2).

³⁹⁶ See Genetic Integrity Act Chapter 6, s 3 (Insemination); Chapter 7, s 5 (IVF).

³⁹⁷ Section 11 of the Victorian Infertility Treatment Act 1995 (Vic) by contrast, expressly requires that all couples undergo counselling, prior to treatment. This process, could be seen as analogous with the psycho-social investigation in Sweden; the stage prior to the infertility treatment process where the so-called compulsory counselling occurs. There are two main differences, however. First, the Victorian Act specifically provides that this process must be undertaken by a counsellor approved under the Act — a counsellor who has been trained and equipped to assist patients with infertility problems and associated issues. Secondly, the process in Victoria is complementary to, but completely independent from the medical investigation.

³⁹⁸ See A Skoog Svanberg et al, 'Attitudes towards gamete donation among Swedish gynaecologists and obstetricians' (2008) 23 *Human Reproduction* 904–911, p 904. See also p 906 which provides that more than 30% of doctors did not support disclosure. 854 of 1230 gynaecologists and obstetricians whose names were contained in a commercial register of all gynaecologists and obstetricians working in Sweden, participated in this questionnaire study. The response rate was 69% (see p 904).

³⁹⁹ That is, 72% of men and 86% of women. *Ibid*, p 907.

⁴⁰⁰ *Ibid*.

⁴⁰¹ *Ibid*, p 904. See also p 911.

the support they need in relation to disclosure issues from their attending doctor. Since medical doctors are currently responsible for the psycho-social investigation, a part of which should include encouraging openness during pre-treatment counselling, these results further strengthen the case for giving this task to professional counsellors instead.⁴⁰²

The second Stockholm-Umeå study, published in 2007,⁴⁰³ also showed that the attitude of healthcare staff had an impact on parents' decisions about whether or not to be open with their child, even to the extent where the majority of parents who had been encouraged to disclose had in fact done so.⁴⁰⁴ In this study, 20 parents out of 36 felt that they had not been encouraged to be honest with their child about the DI treatment. The remaining 16 felt that they had been directly or partly encouraged to do so.⁴⁰⁵ It was also found that the willingness of parents to disclose was lower when openness was not consistently encouraged by staff. Moreover, a great majority of the couples (12 of 19) had been told to 'do as they wished.' Lalos et al thus conclude that staff should be better educated about the implications of the legislation and trained to give a 'congruent and positive attitude vis-à-vis disclosure.'⁴⁰⁶ Importantly, when the study participants were asked to give advice to health personnel who were involved in meeting or treating prospective parents, several of them emphasised the need for contact with social workers and counsellors.⁴⁰⁷ Some parents also said they needed more guidance in relation to disclosure issues,⁴⁰⁸ something that was also found in the first Stockholm-Umeå study where 8 sets of parents who had disclosed expressed that they, in the first place, would have appreciated help with information or advice. Three couples specifically responded that they would have liked to have had help to tell their child about how the child was conceived.⁴⁰⁹ While the majority of the parents in the second Stockholm study had already told their children about the DI, many of them reported that they had, and still have, the need for advice and assistance regarding *when* and *how* to discuss the DI with their children.⁴¹⁰ These parents referred to the necessity of being offered counselling and support from a child psychologist or social worker and some parents had organised such contact themselves.⁴¹¹ These responses indicate that not all parents questioned had received counselling from a professional

⁴⁰² See Skoog Svanberg et al, above n 398.

⁴⁰³ This study was discussed in Part 4.2.2.2, above.

⁴⁰⁴ See Lalos et al (2007), above n 273, p 1759.

⁴⁰⁵ Ibid, p 1764.

⁴⁰⁶ Ibid, pp 1764, 1767.

⁴⁰⁷ See Lalos in SOU 2007:3, p 150; and Lalos et al (2007), *ibid*, p 1765.

⁴⁰⁸ SOU 2007:3, *ibid*.

⁴⁰⁹ See SoS-rapport 2000:6, p 35.

⁴¹⁰ See Lalos et al (2007), above n 273, p 1764.

⁴¹¹ Ibid, pp 1764–1765. Some parents also indicated that they would have appreciated contact with other families in a similar situation and many felt that there was a lack of resources by way of books and films to assist them with disclosure (p 1765).

counsellor as part of the psycho-social investigation and that some parents would welcome additional support that would assist them with disclosure.

The guidelines on assisted conception clearly provide that ‘the doctor should, as far as possible, satisfy him- or herself that the couple ... will tell the child about his or her origins’.⁴¹² If approximately 20 per cent⁴¹³ of obstetricians and gynaecologists questioned did not believe that parents should be honest with their children about the child’s conception, and if less than half agreed that it was in the best interests of donor offspring to have a right to identifying information about the donor, there must be an associated risk that some of them will not encourage prospective parents to be open with their children. Knowing this, it is difficult to accept that the responsibility for the psycho-social evaluation of prospective parents should remain with doctors, particularly when Swedish law and policy is unequivocal that donor offspring have a right to this information.

Since the psycho-social evaluation is directly connected to the best interests of future donor offspring, it would make more sense if the responsibility for this component of the pre-treatment evaluation were given to professional counsellors who are both familiar with and supportive of the law and the guidelines set out by the National Board of Health and Welfare. To avoid any misunderstanding, the division of responsibility between the medical evaluation and the psycho-social evaluation, and the fact that pre-treatment counselling is mandatory, should be expressly reflected in the Act itself.

5.4 Establish a follow up program for parents

5.4.1 Introductory Remarks

In order to further enhance disclosure, the implementation of a follow up program for parents of donor offspring should be considered. Such a program would serve as a valuable complement to the pre-treatment counselling undertaken in the psycho-social investigation by providing on-going support for parents as their child develops. There are already indications from the two Stockholm-Umeå studies, above, that some form of follow up would be welcomed by parents. Already in the first study, several couples said they would have appreciated some form of help or advice at the time when disclosure was likely to be imminent.⁴¹⁴

⁴¹² See Regulations and Guidelines on Assisted Conception, Ch 4 “The psychological and social examination” (Guidelines). [Author’s translation.]

⁴¹³ See figures from Skoog Svanberg et al, above n 398, p 907: 72% of men and 86% of women.

⁴¹⁴ One couple gave the child’s age 2–3 as a guide. One couple also suggested that the clinic could bring about contact when children have been born following insemination. See SoS-rapport 2000:6, p 35.

To be most effective, any follow up program introduced for parents should — as far as possible — be standardised so that the nature of support and information provided would be similar for all families. Moreover, a public authority should be made responsible for establishing appropriate procedures and co-coordinating, at a national level, any additional programs necessary for its implementation.⁴¹⁵ This would make it easier to monitor the effectiveness of follow up. It would also help to ensure that processes and standards were consistent. Presumably, the National Board of Health and Welfare would be the body of choice for this role. If it, in turn, delegated the responsibility for the day to day administration of any program/s to the local offices of the Social Welfare Board, families of donor offspring would not have to travel out of their home municipality in order to take part in any of the counselling or support features offered or required.

Under this option, it is anticipated that the Social Welfare Board would systematically follow up and support the parents of minor donor offspring in order to offer them support so that parents would find it easier to manage disclosure. It is envisaged that this would involve a combination of parental contact and counselling at regular, pre-determined intervals throughout the donor offspring's childhood and adolescence. In addition, it should be left open for parents to initiate contact with the Board on their own motion if they require or desire additional support.

5.4.2 Possible structure for a follow up program

Since counselling is already presumed to be an integral part of the donor treatment procedure, it should be possible to extend its scope so that it may also be used to support parents in the intervening years between the donor offspring's conception and maturity.

Although the nature and frequency of any additional contact and support would have to be determined by experts, an example of how such a process could possibly be structured is set out below:

All parents of donor offspring would be contacted at least three times during the donor offspring's childhood and adolescence. On each of these occasions the objectives should be, *inter alia*, to find out whether the parents have told their child about his or her origin and if not whether they need any help to do so; to assist those parents who have not yet disclosed to plan for disclosure; to support those parents who have disclosed with any other matters that may have arisen due to the fact that they are part of a donor family; and to provide support for donor offspring where appropriate.⁴¹⁶

⁴¹⁵ For example the training and/or approval of counsellors, collection of information etc.

⁴¹⁶ Arguably, donor offspring have the greatest need for counselling because they have no opportunity to participate in pre-treatment counselling like their parents or donors. Accordingly, it is important that counselling services are made available to them. The issue of donor

Suitable times to be established for the contact and follow up of the parents of donor offspring could be, for example, when the child is 5, 10 and 15 years old. To this extent, it is important that the same times apply to all families of donor offspring. If the child has not yet been told about the donor conception by the time he or she is 15 years of age, the scheduled follow up could serve to reinforce the importance of making a disclosure plan and carrying it out, with any support and assistance necessary, before the child turns 18.

If the Social Welfare Board in each county was authorised to pursue a continuing relationship with the parents, where counselling and follow up were combined in a structured way, parents would not only feel more supported, they would be better equipped for the task of disclosure. An on-going relationship would also make it easier for the Board to provide support for minor donor offspring where appropriate.⁴¹⁷

5.4.3 Encouraging compliance

A foreseeable problem with the implementation of a compulsory follow up program for the parents of donor offspring would be that some families may be reluctant to participate. A follow up program run by the State could be perceived as intrusive, irrespective of the degree or support offered. Even if parents were to agree to such a program when they consented to the donor treatment procedure, it would not be possible to force them to participate. It would thus be essential for prospective parents to thoroughly understand the process and intentions of the program before they commenced their treatment.⁴¹⁸ To give effect to this, current counselling procedures could be adapted to ensure that these issues were discussed with the parents during the psycho-social investigation. In most cases, a reluctance to participate should be possible to overcome if the pre-treatment counselling sessions carefully addressed the importance of continuing counselling and support. It would also be important for parents to understand that one of the main pur-

offspring counselling, albeit in the context of access to identifying information, was discussed in Part 3.6.2, above.

⁴¹⁷ Turner and Coyle, in their study of adult donor offspring found that a common theme amongst the participants of the study was that they found it therapeutic to discuss their experiences as donor offspring. See Turner and Coyle, above n 363, pp 2043, 2050.

⁴¹⁸ It is important that any such program is perceived to be a legitimate component that follows up the treatment so that all parents can be contacted after the child is born. It cannot be assumed that all parents would otherwise volunteer to be supported and followed up. In the New Zealand study from 1999 by Rumball and Adair, eight of the 154 couples who were invited to participate in a study about parents' experiences in respect of disclosure and non-disclosure actually denied permission to be contacted by the clinic in the future. See Rumball and Adair, above n 311, p 1394. While this situation can be distinguished from that proposed it nevertheless demonstrates the reluctance of some parents to be contacted by an outside body in relation to their donor offspring children. This issue would have to be addressed before any follow up program could be successfully implemented.

poses behind Swedish ART legislation is to, as far as possible, satisfy the best interests of donor offspring, and that these interests include a donor offspring's right to know the identity of the donor. If prospective parents were thoroughly prepared and informed about the requirement of follow up, and understood why it was important — from their own future child's perspective — they may be happy to agree to participate in such a program, perhaps even as a condition of treatment.

The effective implementation and success of this alternative would depend on the ability of a delegated authority to locate and contact the parents of donor offspring. This would not be a problem in Sweden, due to the existence of the population register.⁴¹⁹ If other jurisdictions were to consider the option of establishing a follow up program, however, particularly in the absence of a national registration system, this potential problem and how to circumvent it would need to be borne in mind.

Finally, if it were to be considered appropriate by the Swedish Parliament to compel parents to participate in a follow up program, the Genetic Integrity Act should be amended to clarify the obligation of the National Board of Health and Welfare to create and supervise a suitable program. If the program were to be voluntary, on the other hand, it could be implemented without legislative amendment since there would be no obligation to participate. However, an express provision in the Act itself would make Parliament's intention absolutely clear, thereby ensuring that any attempts by the Social Welfare Board to contact parents would not only be accepted but also regarded as legitimate.

5.5 Clarify the child's right in the Children and Parents Code

Another way to facilitate the right to information could be to use the Children and Parents Code to confirm the child's right by law. This, at least, was one of the conclusions made from the 2007 investigation into parenthood with assisted reproduction. In this connection, the report of the investigation recommended that the Code be amended to expressly declare that donor offspring have a right to information about their genetic origins and that parents have a corresponding responsibility to tell them how they were conceived.⁴²⁰ The main aim of these recommended amendments is to make it clear that the parents are responsible for informing their child about the do-

⁴¹⁹ See further, Part 5.8.2, below.

⁴²⁰ See SOU 2007:3, p 21, s 11. The proposed changes to the Children and Parents Code may be found at pp 15–24. **Note** also the alternative wording recommended by Anna Singer in relation to the proposed changes. See pp 123, 129–133. On the issue in question see esp p 133 (s 14).

nor conception and, where information exists, about their right to know the identity of the donor.⁴²¹ Importantly, the report also emphasised that the provisions referring to parental responsibility and disclosure should be in the Children and Parents Code because their application should not be limited to children who have been born under ART law.⁴²² That is to say, all donor offspring, irrespective of the circumstances of their conception, have a right to be told the truth about their genetic origins.⁴²³

This measure would be an important step forward in acknowledging the rights of donor offspring children to information but it should not be expected to bring about a significant change in the actual disclosure patterns of parents. Essentially, it is a passive measure designed in part to remind parents that society expects them to be open with their children about the child's origins and to this extent it does little more than repeat what is already stated in the Genetic Integrity Act.

In combination with other measures, however, clarifying the child's right and the parents' responsibility in the Code, if implemented, may contribute to an increase in the tendency of parents to be open with their children.⁴²⁴ Even so, while it could possibly increase the rate of parental disclosure over time, it needs to be accepted for what it is: a declaration of an already-existing right that cannot, on its own, be expected to solve the problem of non-disclosure.

5.6 Give donors a conditional right to apply for identifying information about donor offspring

Another, albeit controversial, way to encourage parents to disclose, thereby promoting access to information, would be to give donors a right to apply for identifying information about adult donor offspring. Unlike the unconditional right conferred on donor offspring, however, donors should not be permitted to exercise this right without the consent of the donor offspring in question.

A similar right for donors has existed in Victoria since 1998 when the access to identifying information provisions of the Infertility Treatment Act

⁴²¹ SOU 2007:3, p 96.

⁴²² SOU 2007:3, p 96.

⁴²³ It should also be mentioned that the report was criticised for not taking into account the fact that *all* children, ie not just those born following ART or those who have been adopted, should have the same right to know the truth about their genetic origins. See 2007-09-04 Remiss, Föräldraskap vid assisterad befruktning (SOU 2007:3), Dnr: JURFAK 2007/23, Juridiska fakultetsnämnden, Uppsala universitet, p 3.

⁴²⁴ The investigation held a similar view but it was more confident that the measure *would* increase parental disclosure. See SOU 2007:3, p 96.

came into effect.⁴²⁵ The Act also enables donors to apply for identifying information about minor donor offspring subject to the consent of the parents or guardian of the child. These provisions had been the subject of some controversy over the years and in June 2007, after considering the competing arguments, the Victorian Law Reform Commission recommended to the Victorian Government that donors should no longer have the right to apply for identifying information about donor offspring.⁴²⁶ In the view of the Commission:

[O]nce a donor-conceived person reaches adulthood, she or he should be the only party able to apply for information on the central register. The donor registers have been established for the benefit of donor-conceived people, who should have ownership of the process of information exchange. A donor should therefore not have the right to apply for identifying information about a person conceived with their gametes.⁴²⁷

This position, and the recommendation of the Victorian Law Reform Commission, above, is consistent with the view that has existed in Sweden since the Act on Insemination came into effect.

The Victorian Government, however, had a different opinion and rejected the Law Reform Commission's recommendation in relation to this issue.⁴²⁸ The Government did not provide any reasons for its decision and details of Cabinet meetings are not released to the public. However, in a letter dated 27 March 2008 reference was made to fact that 'the VLRC identified the arguments in relation to this issue on pages 153 to 155 of its report.'⁴²⁹ This implies that the arguments put forward in favour of retaining the provision were, for whatever reason, regarded as more convincing by the Victorian Government. One of those arguments was that the 'provision serves an important purpose in supporting the child's right to know about his or her genetic origins.'⁴³⁰ The report went on to say that:

Because so many parents have not informed their children they are donor-conceived, being contacted by the ITA [to consent to the release of identifying information to the donor] may be the only way the child will find out ... [This] may also act as an incentive for parents to inform their children from an early age ...⁴³¹

⁴²⁵ See Infertility Treatment Act (1995) Vic, ss 76–77.

⁴²⁶ See further Victorian Law Reform Commission, Assisted Reproductive Technology and Adoption: Final Report, June 2007, Vic, pp 153–154.

⁴²⁷ *Ibid*, p 154.

⁴²⁸ See Media Release from the Office of the Attorney-General, 'New laws on assisted reproductive technology and surrogacy', Friday, December 14, 2007.

⁴²⁹ Letter to Jane Stoll from Ruvani Wickremesinghe, Acting Director, Department of Justice, Civil Law Policy, following a request for further information, 27 March 2008.

⁴³⁰ Victorian Law Reform Commission, Assisted Reproductive Technology and Adoption: Final Report, June 2007, Vic, p 153.

⁴³¹ *Ibid*. **Note** that the 'ITA' refers to the Victorian Infertility Treatment Authority.

This reasoning is interesting and could also be considered in Sweden. If donors were able to apply for identifying information, and if the release of such information was subject to the consent of the donor offspring in question, it could promote parental disclosure. This would, in turn, facilitate the right to information, without the need to introduce more invasive measures than those discussed above. If this measure were to be implemented in Sweden, however, it would also be necessary to incorporate additional requirements for the counselling of donor offspring and donors.

5.7 Establish a central donor information register

When taking into account the various ways to promote the right to information, it is impossible not to consider the importance of establishing a central register in Sweden. It is anticipated that such a register would contain relevant, prescribed information about donors, parents and donor offspring in one location and would, *inter alia*, streamline the process of access to information considerably, both for donor offspring and for the administering authorities. Central registers have already been successfully set up in several jurisdictions including Victoria, Australia; Western Australia; the United Kingdom; and New Zealand.

As indicated in Parts 3.2.2 and 3.6.2, above, the processes established for access to information in Sweden are by no means efficient. Donor offspring who wish to exercise their right to information about the donor are generally expected to turn to the Social Welfare Board in their home county in the first instance.⁴³² The Board must subsequently contact the hospital where the donor treatment procedure took place in order to access the information about the donor which is contained in a special case record. After locating the information, the hospital gives it to the Board which in turn is able to pass it on to the donor offspring. If the donor offspring does not know whether they were born from donor gametes, or where they were conceived, the Social Welfare Board's task will be more time consuming. Although this process is fully capable of functioning,⁴³³ it would clearly be simplified if certain prescribed information capable of linking all Swedish donor offspring and donors was contained in a single register. The National Board of Health and Welfare would be the appropriate institution to administer and maintain the register.

A register was in fact proposed in the 2007 report of the investigation into parenthood with assisted reproduction. It recommended that a "special regis-

⁴³² Adult donor offspring, assuming they know where they were conceived, may approach the hospital directly but this option is not available to mature minors.

⁴³³ It hasn't been put to the test yet, however. When the report of the 2007 investigation into parenthood with assisted reproduction was published there had been no known applications for information. See SOU 2007:3, pp 97, 102.

ter” be created to facilitate access to information for donor offspring.⁴³⁴ The investigation regarded such a register as a preferable alternative to entering information about the donor on the Swedish Population Register, particularly because it would be easier to protect the information stored in a “special register” by restricting the number of people who had access to it. Moreover, it was anticipated that the existence of a “special register” would make it easier for donor offspring to find out about their origins and where the information about the donor was stored.⁴³⁵ It should be pointed out that some aspects of the recommendation do not appear to have been well-considered.⁴³⁶ In part, this can be attributed to time limitations. This problem was acknowledged in the report and, to this end, the investigation was unable to prepare a proposal for a draft bill in respect of the establishment of a register.⁴³⁷ In particular, the report provided that a more thorough analysis was required in relation to the sensitive issue of how personal information should be managed so that the interests of all parties can be protected, while at the same time making the information easily accessible for the child.⁴³⁸

It is also important to recognise that the “special register” recommended by the investigation, above, has little in common with the central registers that are characteristic in some other jurisdictions. In light of this, if the goal is to set up a central register, it could be useful for the Government to take a closer look at how some of the older established registers in other jurisdictions — eg those in Victoria, Australia, and the United Kingdom — have been built before taking on or further exploring the recommendations made by this investigation.

Victoria, for example, has had a central register for 20 years. Its experience could therefore be particularly useful for Sweden. Its first register was established in 1988,⁴³⁹ ten years before the right to identifying information about the donor came into effect. Its current register, set up under the Infertility Treatment Act 1995, contains information about all births which have

⁴³⁴ See further SOU 2007:3, pp 100–103.

⁴³⁵ SOU 2007:3, p 100.

⁴³⁶ See for example the recommendation to centre the register on the mother who has given birth to the child. On this see further 2007-09-04 Remiss, Föräldraskap vid assisterad befruktning (SOU 2007:3), Dnr: JURFAK 2007/23, Juridiska fakultetsnämnden, Uppsala universitet, pp 3–4. At p 100 of SOU 2007:3, the report also refers to the establishment of a register which contains information about the mother and ‘information about where the information about the donor’s identity is stored ...’ [Author’s translation.] Accessing such information would then become a two-step process which is exactly how it is today.

⁴³⁷ See further SOU 2007:3, p 102. See also 2007-09-04 Remiss, Föräldraskap vid assisterad befruktning (SOU 2007:3), Dnr: JURFAK 2007/23, Juridiska fakultetsnämnden, Uppsala universitet pp 3–4.

⁴³⁸ SOU 2007:3, p 102.

⁴³⁹ Under the repealed Infertility (Medical Procedures) Act 1984 (Vic). This register is now referred to as the 1984 Central Register.

taken place following donor treatment procedures since 1 January 1998.⁴⁴⁰ Both identifying and non identifying information about donors, donor offspring, and parents of donor offspring, is contained in the central register at the Infertility Treatment Authority. Donor offspring and their descendants, parents of donor offspring, and donors are all entitled to apply to the Authority for information contained in the register in accordance with the Act. The Infertility Treatment Authority currently oversees the operation of both central registers.⁴⁴¹

A central donor information register would promote the right to identifying information by making information about the donor easier to access. It could also facilitate any follow up program introduced because the National Board of Health and Welfare would have information about the parents of donor offspring in a single location. This could be particularly useful for planning in addition to contact.

Assuming such a register were to be established in the future, there is no reason why it could not include the records of donor offspring births dating back to 1985, when ART legislation was first introduced, since this information is available. Parliament would, however, have to authorise the National Board of Health and Welfare to collect this information from the hospitals and clinics in question. If a central donor information register were to be combined with one or several of the other measures outlined above, it could become a very effective means to promote access to information for donor offspring.

5.8 Enter information about donor on the population register

5.8.1 Introductory remarks

An effective — albeit quite intrusive — way to facilitate the right to information would be to enter information about the donor on the population register. The idea of using the population register as a way to promote access to identifying information about the donor is not new. Already in 1983, the

⁴⁴⁰ This register is referred to as the 1995 Central Register in order to avoid confusion between the two central registers. Section 68 of the Infertility Treatment Act 1995 (Vic) provides that '[t]he Authority must, in the prescribed manner, keep a central register containing the information given to the Authority under this Division and the prescribed information (if any).' The Infertility Treatment Regulations 1997 (Vic), rr 13–18, set out the prescribed information that must be kept by the doctor performing the donor treatment procedure and the information that must be sent to the Authority. The process of access to information from the central register is governed by Part 7, Division 3 of the Act (ss 74–82). This Division also provides for the establishment of a voluntary donor treatment procedure information register, which is not part of the central register (s 82 of the Act).

⁴⁴¹ It is also responsible for the operation of two voluntary registers. See Part 5.11, below.

Insemination Committee recommended that there should be a requirement that the hospital give notice to the then Parish Civil Registration Office when a child had been born following donor insemination.⁴⁴² This was considered by the Swedish Government prior to the enactment of the Act on Insemination but was not supported. The reasons given for rejecting the Insemination Committee's recommendation were first, because virtually all submissions received in response to the issue had been opposed to the idea; and secondly, because the Government considered that registering such information with the Parish Civil Registration Office would not fulfill any real function.⁴⁴³

In 2002, the Government took the opportunity to clarify its view about this issue in the Bill on the Treatment of Unintentional Childlessness.⁴⁴⁴ There, in reference to previous suggestions that had been made to enter information about the donor on the population register, it emphasised that the starting point for the current law is that the social father is the legal father. Since the donor is not regarded as the parent of the child, the donation has no connection to the child's legal status.⁴⁴⁵ These factors, thus, weighed against the suggestion that information about the donation should be registered in the population register. The Government did, however, indicate that one factor in favour of such a registration would be where it was of benefit to the child.⁴⁴⁶

The issue has recently been raised again in the investigation on parenthood with assisted reproduction.⁴⁴⁷ While the report of the investigation has placed the issue back on the public agenda, however, the alternative of entering information about the donor on the child's birth record via the population register was not ultimately proposed. Instead, the creation of a "special register" was recommended in the first instance.⁴⁴⁸ Accordingly, it is unlikely to

⁴⁴² SOU 1983:42, p 145. Note that the Parish Civil Registration Office is now the Swedish Population Register.

⁴⁴³ Prop 1984/85:2, p 17. The reasons for this were not elaborated on in this Bill although there are indications from the wording of the Bill that it was, in part, due to the fact that the special journal notes on the donor would be required to be preserved for 70 years anyway. See p 17. It should be pointed out that this view, ie that such a registration would not fulfill any real function, has been reinforced over the years in connection with various amendments made to ART legislation. The issue of registering information about the donor on the population register was also raised again, inter alia, in SOU 2001:10, pp 171–172, 180; and prop 2001/02:89, pp 45–48. See esp p 47 where the Government was quite clear about its view that the population register was not an appropriate place to register information about the donor.

⁴⁴⁴ Prop 2001/02:89.

⁴⁴⁵ Prop 2001/02:89, p 47. See further, Singer above n 43, p 332.

⁴⁴⁶ Prop 2001/02:89, p 47.

⁴⁴⁷ See SOU 2007:3, pp 99–102.

⁴⁴⁸ See SOU 2007:3, pp 100–101. This issue is discussed above in Part 5.7. An interesting observation about the report on parenthood with assisted reproduction is that it treats these two measures, ie population register notation and "special register", as distinct alternatives, leaving the impression that it is necessary to choose one or the other. It is submitted here that this approach is not the only way to manage the issue in question and that both measures ie a register and a notation about the donor on the population register, could operate side by side.

be considered by the Government as an option to promote access to information in the near future. Since the issue has been raised so often during the last 25 years, however, the use of the population register as a possible tool to facilitate the right to information is explored below.

5.8.2 Special features about Swedish birth certificates relevant for access to information

Birth certificates are used, inter alia, to prove or establish a person's identity. To this extent they contain, as a rule, the full name and date of birth of the person in question. These features are standard in most, if not all jurisdictions. However, the amount and nature of information contained on birth certificates, and the way in which such information is recorded and administered, varies from country to country. The Nordic countries, for example, have very advanced population registration systems. This, in turn could be significant in determining whether an express notation about the donor on the birth record of the donor offspring would be a viable alternative for promoting access to information.

Since some foreign readers may be unfamiliar with the Swedish Population Register and the way in which it issues birth certificates, a few things in this connection should be mentioned. The authority responsible for administering the population register is the Swedish Tax Agency. The registration of births and the issuing of birth certificates is governed by the National Registration Law (SFS 1991:481). Information registered in the population register about each citizen includes their name, unique personal identity number, place of birth, citizenship and family connections — which includes adoption.⁴⁴⁹ Another feature of the Swedish population register is that Swedish citizens do not receive the equivalent of a single birth certificate which is valid for them to use throughout their life whenever it is necessary to produce a document to establish their identity. Instead, each time citizens or permanent residents are required to prove their identity they contact the Swedish Tax Agency which in turn sends to them, at their registered address, the appropriate birth certificate, known in Sweden as a *personbevis*.⁴⁵⁰ In most cases, an up to date certificate must be produced for each new matter where proof of identity needs to be established and the validity of these cer-

They should, rather, be seen as complementary measures that could, together, help solve the problem rather than as separate potential solutions.

⁴⁴⁹ See further Swedish Tax Agency 'Population Registration in Sweden' SKV 717B, edn 4, Dec 2007, p 3. **Note** that this document is in English and provides an excellent overview about how registration in Sweden works. It can also be found on the internet at <<http://www.skatteverket.se/download/18.b7f2d0103e5e9ecb08000127/717b03.pdf>> last checked 2008-06-18.

⁴⁵⁰ The dictionary definition of *personbevis* is a [copy of a] birth certificate. However, a *personbevis* is, in fact, an extract of a specified part of the population register and to this end fills the function of a birth certificate.

tificates expires after a few months. Accordingly, it is not possible for a Swedish person to use the same certificate over and over in the way that citizens of some other countries do with their original birth certificate.⁴⁵¹

At the time of writing, the website of the Swedish Tax Agency lists 41 possible categories of birth certificate which may be ordered.⁴⁵² The nature and amount of information on each certificate varies depending upon the purpose for which it is required. Birth certificates issued for citizenship applications, or certified identity cards,⁴⁵³ for example, require a full extract from the population register. This extract contains all of the information that has been registered about an individual in the population register.⁴⁵⁴ Other birth certificates, such as those required in order to obtain a parking permit or to open a bank account reveal the name and date of birth of the person in question but contain no additional information that is not necessary for the administration of the matter at hand.⁴⁵⁵

⁴⁵¹ Australia is an example of one such jurisdiction where each citizen has only one birth certificate which applies throughout his or her lifetime. The information originally recorded at birth is generally not updated as an individual's life situation changes, in the way that it is via the population register in Sweden. In Australia, births are registered with the appropriate authority in each state which in turn issues the birth certificate. To take the example of the State of Victoria, the administering authority is the Registry of Births, Deaths and Marriages and the registration and administration of birth certificates is governed by the Births, Deaths and Marriages Registration Act 1996 (Vic). Information contained on all Victorian birth certificates includes, inter alia, the name and gender of the person born, their date and place of birth and the name and occupation of each parent. If a person loses their birth certificate they may order a replacement certificate and the information contained on the new birth certificate will be identical to that contained on the original one. Thus, if the name of or existence of the donor were to be entered on to the birth certificate of Victorian donor offspring, it would be visible for all to see each time the birth certificate was required to be produced. Accordingly, in jurisdictions where birth certificates are issued in this way, the alternative of making a notation about the donor in the population register and thereby on the birth certificate of the donor offspring, would be more difficult to implement than in Sweden where the population register is able to filter the nature and amount of information contained on different types of birth certificates depending on the purpose for which the information is required.

⁴⁵² It is possible to order a birth certificate from the Swedish Tax Agency over the telephone. The certificate is mailed to the registered address of the person in question. A birth certificate may also be ordered on the website of the Agency, using the link below. This link reveals the diverse range of certificates available and, in some cases, the nature of information contained in each. If one has a purpose which is not listed, it is possible to order an extract from the population register either in Swedish or English. <<http://www.skatteverket.se/servicetjanster/bestallningstjanst/personbevis.4.5098f9104ec1b57328000231.html>> last checked 2008-06-18.

⁴⁵³ **Note** that a Certified Identity Card is available to anyone who is registered in the Swedish Population Register. This identity card is not the same as the National Identity Card issued by the police, and only available to Swedish citizens. Where it concerns that latter, no birth certificate is required and identity is established via an individual's Swedish passport.

⁴⁵⁴ SKV 717B, edn 4, Dec 2007, p 3.

⁴⁵⁵ Some other reasons for which a Swedish birth certificate is required include applications for various studies; employment; drivers' licences; residence permits; and foreign passports. A birth certificate is also required, inter alia, prior to marriage, divorce, and for child custody matters.

Since the Swedish Tax Agency is able to filter the extent of personal information visible on birth certificates, depending on their intended purpose, it should be possible to tailor-make a birth certificate for donor offspring, completely in line with Parliament's intentions. To this end, however, a foreseeable challenge would be to determine where to make the information about the donor visible on the population register. It could, for example, be entered such that it would only be seen when a full extract of the register was ordered by the donor offspring in question. In doing so, access to this private and sensitive information could be restricted, and thereby protected, to the maximum extent possible.

While registering information about the donor on the population register could not completely guarantee that all donor offspring will find out how they were conceived, it would come close. Much would depend upon where Parliament saw fit to include the information about the donor. If the information were to be included only on a full extract of the register, most donor offspring would eventually have access to this information, although there would always be a small risk that some could go through life without requiring such an extract. It is unlikely, however, that Parliament would deem it appropriate to include information about the donor on each of the current 41 varieties of birth certificate connected to donor offspring simply in order to eliminate this risk. To do so would create additional problems that would not necessarily be in the best interests of donor offspring.

From a purely technical perspective, however, it would seem that the population register could be used to promote access to identifying information about the donor by donor offspring.

5.8.3 Identifying information or simply a notation?

If using the Swedish Population Register were to be seen as an appropriate means to promote the right to information, the first challenge to surmount would be to determine whether or not the donor should be identified on the birth record of the donor offspring.

On this issue, the position of the Swedish preparatory works to date points towards making a notation about the *existence* of the donor on the register. Such a notation would, assuming it was subsequently seen by the donor offspring, alert them to the fact that a donor exists, thus enabling them to investigate the matter further if they wish to do so. Another alternative would be to enter identifying information about the donor onto the register but prevent the information, to the greatest extent possible, from being accessed by anyone other than the donor offspring. Both of these options could be further enhanced — or complicated as the case may be — by making the notation first visible when the child turns 18, something which was mentioned by the

investigation on parenthood with assisted reproduction in relation to the first-mentioned option, above.⁴⁵⁶

The position taken in this thesis is the same position as the Swedish preparatory works, above. That is, if the option is implemented at all, the information recorded in the population register should comprise a notation about the donor's existence. Moreover, the notation should only be visible on selected birth extracts to the extent necessary to promote the child's right to information. To this extent, it should also be possible to completely remove any notation made on the register once it has filled its purpose.

An argument in favour of keeping the information invisible until the child is an adult, is that, in accordance with the child's best interests, the parents should be the ones to tell them about the existence of the donor, if at all possible. If information about the existence of the donor is not visible before the child turns 18, the parents will be able to select the appropriate time for disclosure, in line with what they consider is best for their child, knowing that the child will not accidentally stumble across this information on a birth certificate before being adequately prepared.

Nothing further would be gained for donor offspring by identifying the donor on the population register since this information is already available to them via the Social Welfare Board. The intention behind the legislation is that it is in the best interests of donor offspring to have the opportunity to exercise their right to information about the donor. To this end, the Genetic Integrity Act provides that donor offspring have a *right* to know the identity of the donor, not that they *must* know the identity of the donor. By entering information about the existence of the donor on the population register, donor offspring would receive sufficient information to enable them to exercise their right, no more. Because it cannot be assumed that all donor offspring would appreciate being forced to know the identity of the donor, even though they may feel strongly about having the right to know how they were conceived, this option would leave it open for donor offspring to follow up the identity of the donor themselves if they wished to do so and would therefore be a more appropriate option than identifying the donor on the register.

⁴⁵⁷ A central register would further facilitate this process.

Even so, and particularly in light of what was provided by the Government in the Bill on the Treatment of Unintentional Childlessness, above, a notation of this kind could nevertheless be seen as an improper use of the

⁴⁵⁶ See SOU 2007:3, p 99. Still another possibility which is not considered in this chapter would be to enter the information onto the register in code form.

⁴⁵⁷ This situation can be distinguished from entering on the population register information about the genetic parents of adopted children, where known, because the genetic parent/s have at one time also been the legal parents of the child. In the case of donor offspring, by contrast, there is no past legal relationship between the donor and the donor offspring. For a discussion on the establishment of genetic origins following adoption and insemination, see Singer, above n 43, pp 407–411.

population register since its purpose would be to simply alert donor offspring about how they were conceived rather than to provide any concrete information about legal or genetic parentage. On the other hand, as mentioned above, the Bill also provided that a factor in favour of such a registration would be where it would benefit the child.⁴⁵⁸ The option of entering information about the donor's existence on the register could be persuasive in this regard, whereas identifying the donor would be more difficult because it compels information on donor offspring that they may not wish to know.

Irrespective of which alternative were to be chosen, however, it must be remembered that using the population register in this way is closely connected to an individual's personal integrity and their right to privacy. To this end it would be essential to carefully investigate ways in which to collect and store the information to ensure that the privacy of all parties is protected. While an examination of these aspects is beyond the scope of this chapter, the privacy implications, along with any relevant law in this connection would have to be very carefully examined and considered if and when the practicalities of implementing this option were to become imminent.⁴⁵⁹

Because of the way in which the population register has been set up in Sweden, and the unique way in which birth certificates are issued, making a notation about the donor on the register would not have to mean that identifying information would automatically be visible on the child's birth certificate. Moreover, it should be possible to enter the information such that it would appear only on certain documents or certificates, thus protecting the privacy of both donor offspring and donor. At the same time it would increase the opportunities for the child to exercise their right to information in the future.

5.8.4 Some advantages and disadvantages

The main advantage of entering information about the existence of the donor on the population register would be that more donor offspring could exercise their right to information about the donor if they wished to do so. Moreover, children who would not otherwise be told about how they were conceived, would have a greater chance of finding out about the existence of the donor.

Another advantage of this measure is that it could also prove to be an economical solution in the long term. After the initial set up costs were taken into account it would involve very little maintenance both administratively and from a human resources perspective. Once the information about the existence of the donor was entered on the population register, the birth records of the donor offspring should not require any more attention than other

⁴⁵⁸ Prop 2001/02:89, p 47.

⁴⁵⁹ It may be recalled that the importance of protecting the individual's privacy was highlighted in SOU 2007:3, p 102. See Part 5.7, above.

records. Moreover, because this information would be on the register already from the child's birth, there would be no need for the authorities to check whether or not parents had disclosed.

Such a measure would not, however, be disadvantage-free. An entry on the population register about the donor's existence, would sooner or later appear on the birth certificate of the child or adult donor offspring as the case may be, highlighting the differences between donor offspring and other children. For donor offspring, this could prove to be both embarrassing and unwelcome because it would reinforce their unique situation and set them apart from most other individuals who only have a reference to their two legal parents on the register.⁴⁶⁰

From the perspective of the parents of donor offspring, it may not be welcomed either since the compulsory inclusion of information about the existence of the donor on the register would be tantamount to a public statement of their infertility. Moreover, the families of donor offspring could feel that they are publicly exposed or labeled as "different" when compared with families who have had no need to use a donor in order to create a child.⁴⁶¹

Assuming that all donor offspring would subsequently be able to choose whether to exercise their legal right to information, it could be seen as reasonable to enter information about the existence of the donor on the register in order to ensure that their interests are protected. It should be remembered, however, that not all parents fail to disclose.⁴⁶² Where openness about the donor is the rule rather than the exception, even a notation about the donor's existence on the population register could be regarded as totally unnecessary. And in the words of the Government Bill on Insemination, albeit in a slightly different but connected context 'would [not] fill any real function.'⁴⁶³

5.8.5 Preparation for parents and donors

If the alternative of entering information about the donor on the Swedish Population Register were to be implemented to promote the right to information, it would also be necessary to find a way to guarantee — most likely

⁴⁶⁰ That is, with the exception of adopted children whose original legal parents — often also the genetic parents — are, where possible, listed on the register. This situation, however, is distinguishable from donors who are only very rarely regarded as legal parents. See also fn 457, above.

⁴⁶¹ In this connection, it should be borne in mind that the Government also has an obligation under Article 8 of the ECHR to ensure that there is no unnecessary interference with respect to the parents' right to private life.

⁴⁶² In line with what is mentioned in the preceding footnote, if entering information about the donor on the population register would not be necessary in order to achieve the objectives of the legislation, it is possible that this measure could be regarded as a breach of the right to private life of parents, donors, and even donor offspring.

⁴⁶³ Prop 1984/85:2, p 17.

via the regulations and guidelines⁴⁶⁴ — that all parents, prior to consenting to a donor treatment procedure, were totally clear about the fact that information concerning the donor would appear on the population register and, subsequently, on one or several of the child's birth certificates. Pre-treatment counselling would thereby have to be tailored to take this into account. To this extent it would also be prudent to make any donor treatment procedure subject to a written acknowledgement from both prospective parents and the donor, obtained at the same time as the pre-treatment consents, which would confirm that all participants understood where and to whom the information would be visible.

5.8.6 Concluding remarks

A notation about the donor's existence on the Swedish Population Register would almost guarantee that the right to information could be exercised by all Swedish donor offspring. Even so, this alternative has been on the public agenda for many years and has not yet been regarded by the Swedish Government or Parliament as an appropriate solution in response to the problem. Although the Government has acknowledged that a factor in favour of such a registration is where it would benefit the child,⁴⁶⁵ it has also taken the opportunity on several occasions to confirm its overriding view that registering information about the donor on the population register would not fill any real function.⁴⁶⁶ Thus, while the Government has not ruled out the possibility of such a measure in the future, it appears to be firmly of the opinion that the population register is not the appropriate location to include information about the donor. If this policy continues it is probably unlikely that such a measure will be implemented in the near future.

5.9 Notify adult donor offspring about their right to information about the donor

Another intrusive measure that would facilitate the right to information would be to authorise the National Board of Health and Welfare to notify donor offspring in writing about the donor's existence and about the donor offspring's right to identifying information. Such a notification could occur when donor offspring are 18 years of age. For this measure to work effectively, a letter would need to be sent to donor offspring at their registered

⁴⁶⁴ That is, assuming the Genetic Integrity Act is amended to expressly provide for the requirement of pre-treatment counselling for prospective parents, preferably combined with follow up.

⁴⁶⁵ Prop 2001/02:89, p 47.

⁴⁶⁶ Here it referred to the original preparatory works to the Act on Insemination which had come to the same conclusion, stating that nothing had changed in relation to this issue.

address. In order to ensure that donor offspring themselves collected the letter from their local Post Office, it could be sent via registered post. This would not only provide the National Board of Health and Welfare with confirmation that the donor offspring in question received the information;⁴⁶⁷ it would also make it difficult for anyone else to tamper with the letter in order to prevent the information from reaching the donor offspring.

From an administrative point of view this alternative would be easier to implement than the option of entering information about the donor on the population register, above because there would be no need to make any changes to the population register or to the birth certificates of donor offspring; no need to maintain different categories of information on the register for each donor offspring, ie secret and visible; and no need to use the population register as a tool to link information about donors and donor offspring.

An additional advantage of this alternative would be that donor offspring and their parents would not be subject to unnecessary embarrassment caused by the presence of information about the donor on the child's birth certificate. If all donor offspring received a letter from the National Board of Health and Welfare when they turned 18, there would be no need to enter information about the donor on the population register which in turn would mean that no information would ever be visible on the birth certificates of donor offspring.

Sending a letter to adult donor offspring advising them of the donor's existence, however, could be seen as a significant intrusion into the private lives of families. In effect, this measure would issue an ultimatum to the parents that if they did not disclose, information about the donor would nevertheless be delivered to their child via the authorities. Even so, the risk that parents and children would feel publicly exposed and embarrassed would be less likely if this measure were employed compared with entering information about the donor on the population register.⁴⁶⁸ It would be important, however, to combine this alternative with counselling and an organised follow up program in order to ensure that parents received the support they needed so that disclosure became as easy and natural as possible before their child turned 18. The availability of follow up support for donor offspring would also have to be taken into account.

The success of this alternative would depend upon the ability of the relevant authority to know who, and where, the adult donor offspring were so that they could be advised about the existence of the donor. To this end, a central donor information register maintained by the National Board of

⁴⁶⁷ That is, because the donor offspring would have to go to a Post Office and establish his or her identity before the letter could be released to them.

⁴⁶⁸ Although see comments made above in footnotes 461 and 462, above.

Health and Welfare would be a great advantage because it would contain all of this information in one location.⁴⁶⁹

If this measure were to be implemented, it should be clearly provided for in the Genetic Integrity Act. As indicated above, using donor offspring notification as a way to promote the right to information could be perceived as an unreasonable intrusion into the private life of donor offspring families, particularly by the parents. If the National Board of Health and Welfare were to suddenly issue regulations and guidelines on this matter and commence sending out letters to adult donor offspring without clear directions from Parliament, and without a corresponding obligation to prepare families well in advance, it could result in a great deal of trauma. In addition to creating difficulties for the families in question, this would not ultimately serve the interests of donor offspring. An amendment to the Act would thus make Parliament's intention absolutely clear, both for parents of donor offspring and for the relevant authorities.

5.10 Retroactive application of measures

An important question relevant to the implementation of measures that promote the right to information is whether they could, or should, be applied retroactively. Before determining whether or not a given measure could be applied in this way, however, the consideration and balancing of a number of legal principles would be required. While it is not possible to undertake such an analysis in this chapter, a number of factors that could be taken into account in this connection are briefly highlighted below.

The issue of retroactive application would be particularly relevant in relation to the implementation of the more invasive measures discussed, ie entering information about the donor on the population register and notifying donor offspring about the donor's existence. It may also need to be raised if parents were expected to participate in a compulsory follow up program.

An argument that could be made in favour of applying these measures retroactively is that a donor offspring's right to know the identity of the donor has existed since 1 March 1985. Accordingly, all donor offspring born from gametes donated after this date should be entitled to benefit from any subsequent decision made to promote this right. It could even be alleged that retroactive application in this context would not only be acceptable but essential in order to ensure that the best interests of donor offspring are, as far as possible, satisfied as intended under Swedish ART law. In line with this argument, all parents of donor offspring conceived after the access to infor-

⁴⁶⁹ Locating Swedish donor offspring should not be a problem for the reasons already highlighted above. However, it would still be necessary to know who the donor offspring were; something that could be facilitated by a central donor information register.

mation provisions came into effect should be prepared to accept retroactive measures that would support their child's already-existing right to identifying information about the donor.

A compelling argument against retroactively applying measures to promote the right to information, on the other hand, is that the parents in question never had the opportunity for counselling that was specifically directed towards any changes that may be implemented. This argument would be most persuasive in relation to the more intrusive measures mentioned above because the implications associated with such alternatives are more far reaching than, for example, implementing a follow up counselling program. An additional argument against applying the population register measure retroactively is that this issue was considered and rejected before ART legislation was enacted in 1984 and it has continued to be regarded as inappropriate on several occasions since that time.

Even so, where it concerns donor offspring conceived after 1 March 1985, it must be assumed that parents consented to treatment only after being advised that any child subsequently born would have a right to identifying information about the donor in the future. Despite the recent study results in relation to the attitudes of doctors, above, it is still reasonable to expect that all parents were at least made aware of their future child's right to information even if they were not actively encouraged to disclose. Moreover, the right to know the identity of the donor exists to promote the child's interest, not the interests of the parents. Thus, it could be argued that the retroactive application of measures that promote the child's interest would not necessarily be unreasonable assuming careful attempts were made to advise the parents in question about any imminent changes to the law which would affect them, and provide them with additional opportunities for support in relation to disclosure issues.

5.11 A voluntary contact register

The intention of this chapter has been to consider ways to advance the right to information for donor offspring born under the Genetic Integrity Act. If Sweden also has obligations to its donor offspring under international law, however, it should take active steps to promote access to information for donor offspring who are not born under the Act in addition to those conceived before ART legislation came into effect.⁴⁷⁰ One way this could be achieved would be to establish a voluntary contact register to facilitate the exchange of information, or contact, between donor offspring and donors.

In theory, a voluntary contact register could also be utilised by a wide range of other individuals who may be connected through a donor treatment

⁴⁷⁰ See further Part 3.7, above.

procedure, but who would otherwise have no other way of locating each other. In Victoria, for example, it is possible for donor offspring, descendants of donor offspring, donors, recipient couples and relatives of these people to ask the Infertility Treatment Authority to enter their names and addresses on the voluntary registers along with their wishes in respect of obtaining information about another person whose name is, or may later be, entered on the register, or about allowing information about themselves to be released to others.⁴⁷¹ To this end the existence of the Victorian registers acknowledges the information needs of all those people who may have close links to donor offspring.

Whether the Victorian model would be considered appropriate in Sweden, however, is unlikely. Swedish law is unequivocal that the right to information should be exercisable only by donor offspring. Thus, a register that accepted entries from — and facilitated contact between — other individuals connected to the donor or donor offspring would probably not be regarded as consistent with the donor offspring's best interests. It is also possible that such a register could conflict with the privacy rights of other individuals under Article 8 of the ECHR. Even if a Victorian-style register were to be regarded as suitable for Sweden, however, such a register would be difficult to establish because records containing information about donor treatment procedures prior to 1985 would be difficult, if not impossible, to obtain.⁴⁷² Even so, a register that promoted contact between donors, and donor offspring who have no right to information under Swedish ART law, and between genetically related siblings, would presumably be welcomed.

In light of the dearth of medical records about donor treatment procedures in Sweden prior to 1985, the establishment of a voluntary DNA contact register may be regarded as a more suitable alternative for Sweden than the Victorian-style registers, above. One example of a successfully-operating DNA register is the UK DonorLink Register.⁴⁷³ This register, launched by the United Kingdom Department of Health in 2003, was established to facilitate contact between adults affected by donor treatment procedures that took place before the UK's record-keeping provisions came into effect in 1991.⁴⁷⁴ The UK DonorLink Register, enables adult donor offspring, their genetically

⁴⁷¹ See further Infertility Treatment Act 1995 (Vic), s 82 in relation to the Post 1988 Voluntary Register and s 92C in relation to the Pre 1988 Voluntary Register.

⁴⁷² This situation can be distinguished from the situation in Victoria where the a central register was already in operation 10 years before the right to identifying information about the donor came into effect.

⁴⁷³ This register is also known as the UK DonorLink Voluntary Information Exchange and Contact Register Following Donor-Conception pre 1991.

⁴⁷⁴ Information about the UK DonorLink Register was obtained from the DonorLink website <<http://www.ukdonorlink.org.uk/>>; and from the home page of the Human Fertilisation and Embryology Authority <<http://www.hfea.gov.uk/en/1185.html>> both links checked on 27 June 2008. DonorLink has also produced an informative brochure for donor offspring and donors which may be found at <<http://www.ukdonorlink.org.uk/assets/documents/leaflet.pdf>> last checked 27 June 2008.

related half or full siblings, and donors to exchange information with each other. DNA testing is used to confirm that individuals registered with UK DonorLink are genetically related.⁴⁷⁵ Such a register would not be inconsistent with Swedish law provided the scope of individuals who could place their information on the register was confined to those mentioned above; thus ensuring that information could only be shared with the full consent of the donor offspring in question.

To conclude, a voluntary contact register would help facilitate access to information for *all* Swedish donor offspring, in line with the right to privacy under Article 8 of the ECHR. Although it is unlikely that Sweden has a positive obligation under the Convention to establish a voluntary contact register — given the margin of appreciation afforded to independent contracting States — such a register would, nevertheless, be an important and valuable complement to the current regulatory framework for access to information in Sweden.⁴⁷⁶ It would also send a clear message to the international community that Sweden's commitment to its donor offspring extends to all donor offspring, not only those born under ART legislation.

5.12 Concluding remarks

Although there are positive indications that more parents are telling their donor offspring child how the child was conceived, Swedish ART law is still struggling to achieve its aims in relation to access to information for donor offspring. Unless donor offspring are told how they were conceived they cannot know that they have a right to identifying information about the donor. And unless new measures are implemented either to increase disclosure or advise donor offspring about the donor in some other way, there will always be some donor offspring who will not find out how they were conceived. A number of measures that can help solve this problem have been presented in this chapter.

Each measure considered above could be implemented on its own or together with one or more of the other alternatives to facilitate the right to information. If more donor offspring are to find out about their right to information, however, it would appear necessary to, at a minimum, introduce a

⁴⁷⁵ That is to say, before the Human Fertilisation and Embryology Act 1990 came into force.

⁴⁷⁶ An argument that the UK's Human Fertilisation and Embryology Authority had an obligation to establish a contact register in the UK was in fact put forward by the applicants when they sought judicial review in *Rose and Another v Secretary of State for Health* (2) Human Fertilisation and Embryology Authority [2002] EWHC 1593 (Admin) 26 July 2002. Interestingly, while the case did not proceed to final judgment, as a result of this case the Government agreed to support the establishment of a voluntary contact register for donors and their offspring, ie the UK DonorLink Register mentioned above. (Information confirmed via e-mail from Melissa Cummins, Policy Officer, Human Fertilisation and Embryology Authority, 28 January 2008.)

mandatory requirement for pre-treatment counselling and give the responsibility for such counselling to professional counsellors. Combining this with a follow up program for parents would further promote the right because parents would have access to more resources and support which should in turn make it easier for them to disclose.

A central donor information register would be a valuable complement to the entire access to information process, making it easier for donor offspring to obtain information and for the authorities to locate information. In addition, it would make it easier for the authorities to contact parents and donors if and when required. It would also make it possible for the National Board of Health and Welfare to better monitor the effectiveness of any new programs or measures implemented.

If new programs were put into place to improve counselling and follow up for the parents of donor offspring, it is likely that, over time, there would be a marked increase in the number of parents who would feel comfortable with the decision to disclose. Accordingly, more donor offspring would be able to exercise their right to identifying information about the donor. In the unlikely event that this would not happen, it may be necessary to consider more invasive means to promote the right to information such as entering information about the existence of the donor on the population register or sending a letter about the donor's existence to adult donor offspring. These measures are more likely to secure the right to information, and with much greater speed, than counselling and following up the parents. If Parliament's main objective is to ensure that the right to information about the donor should, at all costs, be realisable for all donor offspring, irrespective of whether they find out about it from their parents or from a public authority, implementing invasive measures could be the best way to achieve this. On the other hand, such measures intrude significantly into the private sphere of donor offspring families and to this extent may not be appropriate unless all other possible alternatives have first been explored and exhausted.

To date, no structured support programs have been implemented or tested in Sweden, particularly in relation to follow up support for parents. Since recent Swedish studies indicate that the tendency of parents to be open with their donor offspring children is increasing, it would seem premature to immediately attempt to solve the problem by using the most intrusive alternatives available. To this end, supportive measures could be applied for a pre-determined period — say 5–10 years — to see whether this trend continues. If clear, compulsory and consistent procedures are put into place to help parents with disclosure, and if the effect of these measures is monitored and adjusted in order to meet the objectives of the access to information provisions of the Genetic Integrity Act, it may be possible to avoid invasive measures completely.

6 Closing reflections

Although the focus of this thesis has been on identifying and counteracting some of the problems associated with Sweden's access to information laws, it is important not to forget Sweden's impressive record as a world pioneer in reproductive regulation. Moreover, for almost one-quarter of a century, Sweden has paved the way in relation to access to identifying information and, throughout this time, its determination to protect the best interests of donor offspring has been unwavering. In addition to giving donor offspring a right to know the identity of the donor, Sweden has taken active steps to ensure that the right may be secured by introducing compulsory record keeping and prohibiting certain practices such as the mixing of gametes from two donors and the importation of gametes without authorisation.

In spite of the efforts made to facilitate access to information in Sweden to date, however, it is now established that many donor offspring never find out how they were conceived because their parents do not tell them. As long as this situation is permitted to continue, there will always be some donor offspring who will be unable to exercise their unconditional right to access information about the donor. This is inconsistent both with Parliament's intention and the law itself and poses a dilemma for the Swedish Parliament. On the one hand, Parliament accepts that it is in the best interests of donor offspring to find out about the existence of the donor from their parents. On the other hand, however, there is no way to compel parents to disclose. Assuming Parliament's policy in relation to the best interests of donor offspring and access to information has not changed, new ways must urgently be found to promote disclosure by the parents. If these supportive measures prove ineffective, other more invasive ways to secure the right to information may need to be considered.

Presumably, measures that facilitate access to identifying information will promote the interests of donor offspring; the assumption being that it is in the best interests of donor offspring to know that they have a right to information about the donor. At the same time, however, other interests could be affected, some of which may be conflicting. Parliament has been unequivocal in its view that it is in the best interests of donor offspring to have a right to know the identity of the donor. The exercise of this right requires knowledge about the donor's existence. Parliament has also clearly provided that the best interests of donor offspring should, where possible, be satisfied. How relevant are the interests of others, then, and to what extent should

competing interests be considered when determining which measures are appropriate to implement? Some interests that may compete with those of donor offspring include the interests of parents, donors and the State.⁴⁷⁷ Even donor offspring may have competing interests of their own where it concerns access to identifying information about the donor. This could, in turn, be a problem when implementing some of the measures outlined in Chapter Five, above, particularly those alternatives that may be perceived as invasive.

Implicit in a donor offspring's right to know, for example, is that they have an interest in being told the truth about how they were conceived. In addition, donor offspring also have a corresponding interest in receiving this information from their parents, at a time that is optimum for their development. Satisfying these interests makes it possible for donor offspring to trace their genetic origins. Yet not all donor offspring wish to know the identity of the donor. For these donor offspring, the right *not* to know is a competing interest which should also be respected. Even those donor offspring who wish to exercise their right to information, may have an interest in keeping information about the donor private from others. These factors would all need to be borne in mind when implementing measures to promote the right to information. A measure that automatically identifies the donor in an attempt to promote disclosure, for example, may not be consistent with the best interests of those donor offspring who do not wish to have this information. Likewise, a measure that can completely circumvent parental disclosure, even if it serves the interest of genetic truth, will counteract the interest that donor offspring have in finding out how they were conceived from their parents.

Parent interests cannot be ignored either, even though the interests of donor offspring are regarded as paramount under the law. While donor offspring may have an interest in being told the truth about their conception, parents could have an interest in keeping this information secret. Parents may feel that they should be able to make decisions about private family matters, such as whether or not to share information about the donor treatment procedure with their child, without unnecessary interference from the State. Those parents who wish to disclose, have an obvious interest in receiving good quality support, both for their own benefit and for the benefit of the donor offspring child. This reinforces the need for the availability of professional counselling services. Some parents may also have an interest in

⁴⁷⁷ Extended family members of the donor offspring and the donor also have legitimate interests. As regards donors, Daniels et al suggest that there is a need to extend the scope of counselling services, with respect to the areas of information sharing and contact, to the partners and children of donors. According to Daniels et al, one situation where such counselling could be crucial is where donor offspring seek out the children or the partner of a donor, after the donor may have died; if this is the first the donor's family have heard about the donor offspring, it 'could cause considerable distress for all the parties involved.' See K Daniels et al, 'Families and Donor Insemination: the Views of Semen Donors' (1996) 5 *Scand J Soc Welfare* 229, p 235.

being permitted to take control over the time for disclosure. For these parents it could be important to determine when to take advantage of follow up assistance so they can manage disclosure effectively. Other possible interests parents may have could include a desire to have a personally-known donor, or the ability to select a donor rather than being allocated one, and the right not to have the donor interfere in the life of their family. The satisfaction of these interests, could impact on whether or not parents choose to have a donor treatment procedure under the State system and — even where they do — it could affect whether they comply with any disclosure expectations or obligations. Some parents, for example, may consider that a compulsory follow up program is too intrusive, preferring, rather, a voluntary follow up program. If Parliament were to disregard these interests, and implement a rigid compulsory program anyway, those parents who would otherwise have been prepared to have treatment in Sweden, using gametes from identifiable donors, may decide to visit a neighbouring jurisdiction instead. As a result, any donor offspring born following the treatment procedure abroad may never find out how they were conceived; nor would they have a legal right to know the identity of the donor, something regarded as fundamental under Swedish law. Moreover, even if they know about the donor's existence, they may never have the opportunity to find out who the donor is. Accordingly, ignoring parent interests in this way could counteract the intentions of the access to identifying information provisions of the legislation because Swedish ART laws cannot protect the interests of donor offspring conceived abroad. Yet to completely comply with the interests of parents in this respect, would also counteract the intentions of the legislation because parents who have not received ongoing counselling and support may be less likely to disclose.

An awareness of the possible interests of donors is equally as important as an understanding of other competing interests, particularly if the State has an interest in retaining sufficient numbers of donors in order to meet the demand for donated gametes. Failing to satisfy donor interests, however, is unlikely to impact on access to information in the same way as ignoring the interests of parents, even if it results in fewer donors who are prepared to donate. Over and above a possible interest in remaining anonymous, which is clearly not an option under Swedish law, donors could have an interest in knowing the identity of the donor offspring or extended family members. Some donors may also have an interest in *not* having information available to parents of donor offspring. In addition, donors may have a legitimate interest in being able to determine how their gametes are distributed. Being prepared for the implications of donation, including the possibility that donor offspring may want to meet them in the future, is an interest that applies to all donors. This interest is also consistent with the interests of donor offspring, particularly where offspring may choose to trace their genetic ori-

gins, because donors who are well prepared are more likely to respond to a request for a meeting in a positive way.

Finally, the State also has interests in the context of access to identifying information about the donor. These include, but are not limited to an interest in having an effectively functioning law and a public interest in preserving legal certainty. These interests will be difficult to satisfy if the State does not, to the extent possible, take into account the identifiable competing interests. Where a regulatory framework for access to identifying information has already been established, a State also has an interest in monitoring the implementation the law, maintaining accurate records, following up the law and amending it, if required, to ensure that it is effective. In this context, the State may have a more general interest in controlling the activity of ART, part of which includes satisfying the best interests of donor offspring by promoting the right to identifying information, and ensuring that each donor offspring born has two legal parents. Lastly, the State also has an interest in fulfilling its international obligations — real or perceived. In this connection, Sweden could be especially sensitive to criticism and pressure from other jurisdictions, particularly in light of its already-recognised standing in relation to access to identifying information about the donor.

The possible combination of interests is endless. Those mentioned above, however, illustrate Parliament's dilemma in creating and implementing measures that will facilitate access to identifying information while, at the same time, taking into account as many competing interests as possible. If the interests of one group are not met, some of the objectives of the legislation may end up being compromised. Although donor offspring interests are regarded as supreme, they may not necessarily be served in the long run if other interests, particularly those of parents, are neglected. It is no secret that parents can always choose to make their own arrangements for donor treatment procedures, thereby completely avoiding the access to identifying information provisions of the legislation. Even so, the fact that parents can, and do, avoid the legislation, does not justify inaction where it concerns facilitating the right to information because Parliament's primary obligation is to protect the interests of donor offspring. In finding new ways to make it possible for donor offspring to exercise their right to information, it may therefore be unavoidable to slight the interests of some parents.

Where to from here then? Clearly, facilitating the right to information requires more than clarifying and re-drafting the relevant provisions of the Genetic Integrity Act in accordance with Parliament's intention. Implementing measures to make the right more functional and effective requires an holistic approach which acknowledges that the problem of nondisclosure is embedded in a complex social context. Accordingly, any measure selected to promote the right to information for donor offspring should, as far as possible, attempt to find a balance between the various competing interests so that

the intention of the access to information provisions of the legislation — to protect the interests of the child — is not counteracted.

We already know that the effectiveness of the laws on access to information in Sweden currently hinge on the disclosure patterns of parents of donor offspring because parents bear the sole responsibility for advising their children about their right to information about the donor. We also know that professional counselling is by no means routine for prospective parents in Sweden today and that some parents have expressed a desire for professional guidance and assistance in relation to disclosure *after* their children are born. Knowing this, implementing measures that identify and satisfy both the interests of donor offspring and, as far as possible, those of parents, must be the best way to avoid compromising the objectives of the legislation.

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