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**The Genealogical Jigsaw Puzzle – A Missing Piece?**  
**The Right to Know for A.I.D. Children**

**Caroline Henaghan**  
**University of Durham – Department of Law**  
**2004**

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- 5 FEB 2007

## **The Genealogical Jigsaw Puzzle – A Missing Piece?** **The Right to Know for A.I.D Children?**

This paper examines current UK legal regulation relating to the provision of genetic background information to children born by donor insemination (DI) and argues in favour of changes to the existing law – the Human Fertilisation and Embryology Act 1990. The proposals for reform suggested in this paper would allow for Regulations to sanction the disclosure of both non-identifying and identifying information to DI children. These Regulations and the form they might take have been the subject of a recent government Consultation Paper, the response to which has been a majority in favour of the enactment of Regulations to allow disclosure of both types of information to donor offspring. This paper proposes that donor offspring should be granted the right to be told of their status and the right to receive information about their genetic background, whilst they are still children.

This paper analyses the issues raised in the Consultation Paper and the arguments for and against the enactment of Regulations. Existing sociological and psychological research demonstrates the importance of genetic heritage information for the development of a child's identity. The provision of genealogical information can also be justified by reference to the child's right to an identity under international human rights law. However, the concepts of secrecy and anonymity have thus far influenced this area of law allowing for the protection of the rights of the social parents of DI children and the donors respectively. Therefore, this paper advocates that the concept of openness should feature heavily in any future legislative measures. Based on evidence from other jurisdictions, this paper argues for the enactment of Regulations in the near future to allow for the protection of the rights of the DI child, which have until now been unjustifiably overlooked by the UK legislature.

*January 2004*

## Contents

<u>Chapter</u>	<u>Page</u>
1. Introduction to A.I.D.....	4
2. The Rights of the Child.....	16
3. The A.I.D. Child.....	28
Current UK regulation.....	28
The A.I.D. child.....	34
The rights of the A.I.D. child?.....	34
The welfare of the A.I.D. child?.....	37
The importance of identity.....	41
Social identity.....	41
Legal identity.....	55
The A.I.D. child's identity rights?.....	58
The right to be told.....	64
The right to receive information.....	67
4. The Social Parents.....	71
The parents of the A.I.D. child.....	71
Why the secrecy?.....	76
The infertile couple.....	81
The rights of the A.I.D. parents?.....	86
5. The Donor.....	91
The UK donor.....	91
Why the anonymity?.....	98
The rights of the donor?.....	106
6. The Way Forward?.....	110
The consultation paper.....	110
The rights of the adopted child - a comparison.....	112
The rights of the Australian A.I.D. child – a model for the UK?.....	116
The way forward for A.I.D.?.....	120
Bibliography.....	125
Appendix: article references.....	137

## 1. Introduction to A.I.D.

Children born by means of artificial insemination by donation<sup>1</sup> in the UK are in an unfortunate position. Many are unaware of the nature of their conception and almost all of them have no idea about their correct genetic background. This is because, under current UK legislation, AID children<sup>2</sup> are denied the *right to be informed of their status* and the *right to receive any information about their true genealogical background*.<sup>3</sup>

Assisted conception is not a new phenomenon,<sup>4</sup> although this does not prevent it from being referred to as one of the “*new reproductive technologies*.”<sup>5</sup> AID is thought to have been increasingly practised in the UK since the 1950’s, but it has only been regulated by law since the early 1990’s.<sup>6</sup> The practice is now generally widely accepted by the medical profession, the law and the public at large. What seems to have remained alien in some circles is the proposition that AID children should have the right to an *identity*.

This paper shall argue that, where a child is born following gamete and/or embryo donation by a third party, they should be entitled to be informed of their status and

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<sup>1</sup> Hereinafter referred to as AID. Also known as donor assisted conception, assisted conception by donation and gamete/embryo transfer by donation. However, the term DI (donor insemination) is preferred to avoid confusion with the AIDS virus. The acronyms “AID” and “DI” shall be the main terms of reference in this paper.

<sup>2</sup> Also referred to as “DI children” and “donor offspring”.

<sup>3</sup> The terms “genetic” and “genealogical” shall be used throughout this paper to describe the link between the donor/genetic parent and the donor offspring. These terms are to be preferred to the word “biological” because, in instances of egg donation, a biological link can be established during gestation, despite the absence of a genetic link between the carrying mother and the donor offspring.

<sup>4</sup> The first instance of human donor insemination allegedly occurred in 1884 at Jefferson Medical College in the United States – see R. Snowden & G. Mitchell, *The Artificial Family: a consideration of artificial insemination by donor*, London: Allen & Unwin, 1981, p13.

<sup>5</sup> See M. McNeil, I. Varcoe & S. Yearley (eds), *The New Reproductive Technologies*, Basingstoke: Macmillan, 1990.

<sup>6</sup> Human Fertilisation and Embryology Act 1990 – hereinafter HFEA – (in force August 1, 1991). Section 5 provides for the establishment of the Human Fertilisation and Embryology Authority (the HFE Authority), responsible for the licensing (HFEA, ss 9-22) of centres providing “treatment services” (defined in HFEA, s 2(1)).

have the right to access both non-identifying and identifying information in relation to that third party.<sup>7</sup>

It is estimated that there are approximately 1 500 – 2 200 live births<sup>8</sup> in the UK each year as a result of treatments using donated gametes and/or embryos.<sup>9</sup> Consequently, around 18 000 – 26 000 DI children have been born so far since the inception of the HFEA 1990. Add to this the number of children born prior to the advent of legal regulation (a figure which is impossible to quantify)<sup>10</sup> and we have a significant section of the population who have no means of knowing the complete truth about their conception.<sup>11</sup> Under the HFEA 1990, DI children merely have limited rights with regard to acquiring information relating to possible consanguinity with someone they intend to marry<sup>12</sup> and with regard to issues concerning inherited genetic illnesses and conditions,<sup>13</sup> meaning that more and more children are being brought into this world each year without the necessary genetic information that would allow them to fill in the missing pieces of their “*genealogical jigsaw puzzle*.”<sup>14</sup>

Admittedly, this area of law involves a number of extremely contentious issues and has been hotly debated over the past two decades.<sup>15</sup> The debate, to be further

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<sup>7</sup> This paper accepts that, if there is a right to receive information about one’s genetic background, there will be a corresponding right *not* to receive information. It is not assumed that every DI child *will* automatically want to know about their genealogical background, but they should at least have the choice.

<sup>8</sup> “Live births” can include stillbirths and neonatal births – see HFEA website – [www.hfea.gov.uk/Forpatients/PatientsGuidetoDI/HowtoreadtheDIdataables](http://www.hfea.gov.uk/Forpatients/PatientsGuidetoDI/HowtoreadtheDIdataables).

<sup>9</sup> HFEA *Annual Report* 2001 (1 April 2000 – 31 March 2001). During this time there were nearly 3 500 DI treatments and over 800 live DI births.

<sup>10</sup> Estimated at approximately 12 000 donor offspring prior to the 1990 Act – DOH Press Release, *Donor Conceived Children to Get More Information about Donors*, 28 January 2003 – [www.info.doh.gov.uk/doh/intpress.nsf/page/2003-0037?OpenDocument](http://www.info.doh.gov.uk/doh/intpress.nsf/page/2003-0037?OpenDocument).

<sup>11</sup> Added to this figure is the number of children born by so-called “D.I.Y.” AID, not covered by HFEA regulation.

<sup>12</sup> HFEA, ss 31(6) and (7).

<sup>13</sup> *Ibid*, s 35.

<sup>14</sup> Donor offspring are currently the *only* group of children to have genetic origin information legally restricted in such a way.

<sup>15</sup> In 1982, the government appointed a Committee of Inquiry, chaired by Mary Warnock (now Baroness Warnock) to, “*consider[ation of] recent and potential developments in medicine and science related to human fertilisation and embryology*,” p4. The Committee reported in 1984 – Department of Health and Social Security, *Report of the Committee of Inquiry into Human Fertilisation and*

examined in this paper, has centred on the apparent conflict between the medical need to treat those who are infertile by means of AID, and the increasing awareness that the interests of the DI child need to be recognised, following the dawn of a new children's rights era.<sup>16</sup>

Promisingly, there does seem to have been some acknowledgement, on the part of the government, that this issue is ripe for reconsideration. In December 2001, the Department of Health published a Consultation Paper examining a number of issues with regard to the position of DI children.<sup>17</sup>

The Consultation Paper set out to consider:

- some of the arguments for and against making Regulations<sup>18</sup> to specify what information should be given to offspring born using donated gametes or embryos;
- the non-identifying information which might be available in the case of existing donors;
- whether a greater range of information might be collected and provided about future donors;
- and whether, **for future donors only**, identifying information should be collected and provided and, whether this should be a requirement in all cases,

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*Embryology* (The Warnock Report), Cmnd 9414, London: HMSO 1984. In 1986, the DHSS issued a Consultation Paper on this issue, followed by a White Paper and then the Human Fertilisation and Embryology Bill, introduced into the House of Lords in 1989, enacted as the HFEA 1990, almost a decade after the initial Committee of Inquiry was set up.

<sup>16</sup> The provisions of the HFEA 1990, relating to the interests of the DI child, stand in stark contrast to other child-orientated legislation – e.g. the Adoption Act 1976, the Children Act 1989 and the Adoption and Children Act 2001.

<sup>17</sup> Department of Health, *Donor Information Consultation: Providing information about gamete or embryo donors*, London: HMSO, 2001.

<sup>18</sup> This refers to HFEA s 31(3)(a), wherein provision was made for both non-identifying (retrospectively and prospectively disclosed) and identifying (prospectively disclosed) information to be made available to DI children born after the Act's inception. This information was to be specified by Regulations enacted at a later date, but thus far no Regulations have been made.

or donors should be able to specify whether they wished to be identified or not.<sup>19</sup>

The points of inquiry of the Consultation Paper provide a good basis for the issues to be considered within this paper and, in response to the issues raised above, this paper would make the following recommendations:

- **Regulations should be enacted to provide donor offspring with more information about their genetic background than is currently available.**<sup>20</sup>

This suggestion is based firstly, on the fact that provision *was* originally made under the HFEA 1990 for Regulations to be enacted; therefore the possibility of further information being disclosed was considered during the drafting of the 1990 Act. Secondly, some non-identifying information is currently held on the HFEA Register of Information,<sup>21</sup> again evidence for the proposition that the provision of information was originally contemplated. Thirdly, the Authority already advises all donors that, although no information about them may be currently given to any DI children resulting from their donation, this may become possible in the future.<sup>22</sup> Therefore, if such Regulations were enacted, they could not be deemed to be retrospective or contravening the rule of law, as the donors have already been advised that the provision of such information could later be entrenched in law. Finally, the HFEA came into force in the early 1990's; the provisions therein specified that, if any

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<sup>19</sup> The Consultation period ended in July 2002; the summary of responses has since been published and the Department of Health is undertaking further research into the issue.

<sup>20</sup> Under section 31 HFEA, the Authority has a legal duty to tell adults who apply to them whether they were born as a result of donation. Some commentators have suggested that this is akin to the provision of non-identifying information – E. Haines, *Recreating the Family? Policy considerations relating to the "New" Reproductive Technologies*, in *op cit*, McNeil, Varcoe & Yearley (eds), fn 5.

<sup>21</sup> Collected through the *HFEA Donor Information Form (91)* 4.

<sup>22</sup> The HFE Authority advises donors that, "[I]n the future Parliament may decide that some details may be given to [children resulting from your donation] if they apply to the Authority," - HFEA leaflet, *"Sperm and Egg Donors and the Law"* (December 1992).



information *were* to be made available, this would not happen until a DI child reached the age of 16, the first instance of this being 2007. The year is now 2004 and arguably opinions on this subject have altered.<sup>23</sup>

- **The non-identifying information currently held on the HFEA Register should be made available to existing DI children.** This is based on evidence that shows that this type of information is important in terms of the DI child's development of their identity and therefore forms a fundamental part of their actual right to an identity.<sup>24</sup> However, empirical evidence shows that the collection of this information by the licensed treatment centres has often been inconsistent and inadequate.<sup>25</sup> Therefore, this paper also proposes that the provision of non-identifying information (specifically, in the form of a "pen portrait") should be made a *compulsory* part of the donation process – again justifiable on the basis that non-identifying information about the donor can form a crucial part of the child's development of an identity.<sup>26</sup> Evidence shows that the collection of this type of information does not occur in every instance of donation;<sup>27</sup> therefore compulsory provision of this information would avoid an inequitable scenario whereby some DI children could access the information whilst others could not.

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<sup>23</sup> According to a recent MORI poll (commissioned by The Children's Society – June 2002) there is strong public support in favour of granting identity rights to DI offspring, albeit when they reach 18 years of age. 80% of the public would support donor offspring having an automatic right to know about their genealogical history – [www.mori.com/polls/2002/cs.html](http://www.mori.com/polls/2002/cs.html).

<sup>24</sup> *Post*, chapters 2 and 3.

<sup>25</sup> See S. MacLean & M. MacLean, *Keeping secrets in assisted reproduction – the tension between donor anonymity and the need of the child for information* CFLQ 8(3) [1996] 243.

<sup>26</sup> S. Wilson, *Identity, Genealogy and the Social Family: The Case of Donor Insemination* IJLPF 11 (1997) 270.

<sup>27</sup> *Op cit*, MacLean & MacLean, fn 25, p245.

- **Identifying information regarding the donor should be made available to the DI child, both on a retrospective and prospective basis.** It is accepted that this proposition goes beyond the terms of inquiry of the Consultation Paper; however, the provision of identifying information in both of these instances is doubly justified because of the necessity of protecting the DI child's identity rights and also in recognition of their need for a complete and ongoing correct medical history.<sup>28</sup> It is further accepted that the provision of such information may conflict with the rights of the other parties involved, i.e. the social parent(s) and the genetic parent(s),<sup>29</sup> e.g. their rights to respect for their private and family lives.<sup>30</sup> Therefore later chapters will examine how a balance might best be struck between the rights of all parties, whilst recognising that future legal regulation must begin to take greater account of the rights of the DI child, if not place them as the highest priority.

Further to the proposals for reform suggested above, this paper shall examine how these rights of access to information can be attributed to donor offspring whilst they are still children; justifiable firstly, on the grounds that this information forms a significant part of their right to an identity<sup>31</sup> and secondly, that evidence from adoption circles shows that this information should be provided as early in life as possible.<sup>32</sup>

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<sup>28</sup> *Post*, chapters 2 and 3.

<sup>29</sup> In this paper the term "social parent" will be used to describe those who bring the child up; "genetic parent" will be used for those who have a definite genetic link with the child.

<sup>30</sup> Under Article 8, European Convention of Human Rights (ECHR).

<sup>31</sup> See chapter 3 for an explanation of the identity rights of children under the United Nations Convention on the Rights of the Child 1989 (UNCRC), Articles 7 and 8.

<sup>32</sup> *"When knowledge [of adoption] is delayed to adolescence or adult age, the feeling of "rejection" seems to be infinitely greater than when revelation takes place in earlier years. It appears that when knowledge of adoption comes early – possibly before the age of 8 or 10 – there is time for the trauma to heal where accepting and cherishing relationships prevail,"* J. Triseliotis, *In Search of Origins*, London: Routledge & Kegan Paul, 1973, p155.

Another important issue relates to *how* this information could be made effective, given that whilst DI offspring are still children they are under the control of their social parent(s) and that it is they who will be the ones to decide whether or not to inform their child of the true nature of their conception.<sup>33</sup> Whilst it is acknowledged that compulsory disclosure on the part of the social parents may be deemed heavy-handed and difficult to enforce, it must be recognised that, without the cooperation of the social parents, it will be almost impossible to extend the rights of DI children. Therefore, this paper will examine the feasibility of a legal mechanism for enforcing those rights, possibly in the production of an altered birth certificate for all donor offspring, thereby providing evidence of their status as soon as they are born.

Chapters 2 and 3 shall attempt to establish that the DI child's interest in genetic origin information is a fundamental constituent of their right to an identity and consequently the rights of the DI child should be placed much higher on the legal and political agenda. Unfortunately, there is a significant lack of empirical evidence concerning the development of AID children, given the secrecy and anonymity surrounding this subject. However, there is research in this area<sup>34</sup> and also from the field of adoption<sup>35</sup> – often viewed as analogous to the position of DI children – which strongly suggests that DI children have a “*psychological need*”<sup>36</sup> to know about information relating to their genetic background, as well as an inherent interest in

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<sup>33</sup> Research shows that many DI parents choose not to tell their DI child about the circumstances of their birth – S. Cook, R. Golombok, A. Bish & C. Murray, *Keeping Secrets: A study of parental attitudes towards telling about donor insemination*, Clinical and Health Research Centre, City University, London, 1995.

<sup>34</sup> A.J. Turner & A. Coyle, *What does it mean to be a donor offspring? The identity experiences of adults conceived through donor insemination and the implications for counselling and therapy* (2002) 15 HR 2041.

<sup>35</sup> J. Owusu-Bempah & A. Coyle, *Socio-genealogical connectedness, attachment theory and childcare practice* CFSW 1997 (2) 199.

<sup>36</sup> *Op cit*, Triseliotis, fn 32.

knowing about their genetic background for medical purposes, relating to their possible predispositions to hereditary illnesses and genetic conditions.<sup>37</sup>

However, it must be acknowledged that the issue of granting rights to donor offspring is an extremely contentious one: the DI child does not exist in a vacuum and their interests need to be weighed against the rights of the other parties involved – primarily, the social parent(s) and the donor – both of whom are assumed as having a strong interest in the retention of the concepts of secrecy and anonymity respectively – concepts that thus far seem to have heavily influenced this area of law and medicine.

Therefore, chapter 4 will examine the position of the social parents in relation to the question of whether or not the AID child should have *the right to be told about their status*. The argument that there is a need for complete secrecy in AID has consistently been used to protect the social parents' rights to privacy and the protection of the stability of their family life.<sup>38</sup> However, the basis of this justification is becoming increasingly tenuous: firstly, due to a growing awareness of the importance of recognising the rights of children in general;<sup>39</sup> secondly, because of the way in which the concept of openness has been gradually embraced within other similar areas of law, such as adoption;<sup>40</sup> and finally, because of a gradual acceptance of value pluralism within the family sphere,<sup>41</sup> i.e. the acknowledgement that families

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<sup>37</sup> S. Simpson, *Truth and the Child: a genetic perspective* in E. Blyth, M. Crawshaw & J. Speirs (eds), *Truth and the Child 10 Years On: information exchange in donor assisted conception*, Birmingham: British Association of Social Workers, 1998.

<sup>38</sup> Article 8, ECHR.

<sup>39</sup> Demonstrated by the inception of the UNCRC 1989.

<sup>40</sup> C. Bridge, *Changing the Nature of Adoption: law reform in England and New Zealand* (1993) 13 LS 81, p92; N. Lowe, *The changing face of adoption – the gift/donation model versus the contract/services model* [1997] CFLQ 371; also B. Lindley, *Open adoption – is the door ajar?* [1997] CFLQ 115.

<sup>41</sup> *Post*, chapter 3, p38.

can be formed in a variety of ways and need not necessarily conform to any preconceptions regarding a “natural” or “normal” family structure.<sup>42</sup>

By way of a brief introduction, the assisted reproductive technologies (ART's) including AID/DI, were originally developed by the medical profession for the treatment of infertile couples;<sup>43</sup> this is still the primary justification for the retention of AID practices. The supposed advantage of AID over adoption for infertile couples is that the process allows them to have “*a child of their own*.”<sup>44</sup> In the majority of instances of DI the child will be the genetic offspring of at least one of the social parents<sup>45</sup> and, even if this is not the case, then the techniques involved will always allow the child to pass as the child of the couple. However, the medicalisation of this area has led to a focus on the needs of the social parents – as patients – with the DI child being seen as a successful “*cure*.”<sup>46</sup> The apparent prerequisite for a high birth rate is therefore seen to be the necessity to maintain the numbers of those willing to donate; something which the medical community has consistently argued cannot be achieved without donor anonymity.<sup>47</sup> Therefore, following on from these arguments, chapter 5 will attempt to investigate and counter the proposition that anonymity is in the best interests of all of those involved in the DI process.<sup>48</sup>

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<sup>42</sup> For a discussion of the history of families, see B.M. Dickens, *Reproductive technology and the “new” family* in E. Sutherland & A. McCall Smith (eds), *Family Rights*, Edinburgh University Press, 1990.

<sup>43</sup> Although the word “infertile” is commonly used, infertility is actually very rare and means a total absence of reproductive function. Most people seeking fertility treatment have a varying degree of “sub-fertility”. However, within this paper the terms “infertile” and “infertility” shall be used to include “sub-fertile” and “sub-fertility”.

<sup>44</sup> C. Overall, *Ethics and Human Reproduction: A feminist analysis*, London: Allen & Unwin, 1987, p145.

<sup>45</sup> Gamete donation occurs much more frequently than embryo donation; on average donor embryos account for only 1% of successful donations, HFEA *Annual Report*, 1993.

<sup>46</sup> See *op cit*, Overall, fn 44, for a discussion of the way in which current legal regulation seems to focus on the language of disease and cure in relation to AID.

<sup>47</sup> P. Braude et al, *Human Fertilisation and Embryo Bill goes to report stage* (1990) 300 BMJ 1410.

<sup>48</sup> Considered necessary to protect the donor from any legal responsibility towards the child and to, “*minimise the intervention of the third party into the family*,” *op cit*, The Warnock Report, fn 15, p 25.

At present, donor anonymity is the accepted norm in the UK. The maintenance of donor anonymity has long been justified by the medical community on the basis that, without such a provision, the number of willing donors would fall substantially and therefore openness and frankness in relation to AID would not be in the best interests of any of the parties, because fewer donations could take place.<sup>49</sup> However, *prima facie*, there seems to be a body of evidence to suggest that the contrary is true. Recent studies have shown that, if anonymity were to be removed, a number of donors might no longer donate, but many would still do so.<sup>50</sup>

AID can take place using donated sperm, eggs or embryos; however, it is conceptions as a result of sperm donation that occur most frequently.<sup>51</sup> As a result, much of contemporary discussion tends to focus on male sperm donors. Evidence shows that there are differences in the attitudes, motivation and expectations of male and female donors and that, overall, it may be mainly sperm donors who demonstrate the greatest resistance towards more openness. Therefore, this paper will focus on how future Regulations could take account of this fact, in order to encourage more male donors to accept the possibility of their identities being revealed to the children whom they have helped to create, on the basis of that child's fundamental right to an identity. However, it is again recognised that this must be balanced against the fact that the donor/genetic parent also has the right to respect for their confidentiality<sup>52</sup> and privacy<sup>53</sup> and the right to respect for their family life.<sup>54</sup>

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<sup>49</sup> S. Cook, R. Golombok, A. Bish & C. Murray, *Disclosure of donor insemination; parental attitudes* American Journal of Orthopsychiatry 65(4) (1995) 549.

<sup>50</sup> A. Kirkland et al, *Comparison of attitudes of donors and recipients to oocyte donation* (1992) 7 HR 355; J.N. Robinson et al, *Attitudes of donors and recipients to gamete donation* (1991) 6 HR 307; see in general, E. Blyth, *Infertility and Assisted Conception: Practice Issues for Counsellors* (1995) Birmingham: British Association of Social Workers, p67.

<sup>51</sup> Estimated at approximately 93% of all live births.

<sup>52</sup> See HFEA Code of Practice, 4<sup>th</sup> edn, London: HFEA, July 1998.

<sup>53</sup> Article 8, ECHR.

<sup>54</sup> *Ibid.*

In general, it is the assertion of this thesis that the rights of the DI child cannot be relegated merely by alluding to the supposed benefits of the preservation of secrecy and anonymity, for the sake of the social parents and the donor respectively. Future government policy and legal regulation needs to become much more focussed on the needs of the DI child, by acknowledging that the current protection of the DI child's interests, in the shape of the section 13(5) "welfare"<sup>55</sup> clause, is woefully inadequate and requires a substantial re-evaluation. Moreover, the government needs to move away from the traditional view of the oft-referred to "nuclear family" as being the prevalent model. The institution of the family in today's society is extremely diverse<sup>56</sup> and what is needed is a fresh sociological approach to the notion of the family, to allow for different models of family life, including AID-generated families, to gain recognition, respect and legitimacy. Outdated notions of the conceptualisation of the family cannot be allowed to detract from the protection of the rights of the AID child.

In the words of one donor offspring:

*"I feel that [these] genetic connections are very important to me, socially, emotionally, medically and even spiritually. I believe it to be no exaggeration that. . . information will assist me in forming a fuller sense of self or identity and answer questions that I have been asking for a long time. . . . I feel intense grief and loss for the fact that I do not know my genetic father and his family."*<sup>57</sup>

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<sup>55</sup> "account must be taken of the welfare of any child who may be born of the treatment (**including the need of that child for a father**)," HFEA, s 13(5) (emphasis added). For an in-depth discussion, see G. Douglas, *Assisted Reproduction and the Welfare of the Child* (1993) CLP 53.

<sup>56</sup> Evidence of this can be seen in ECHR jurisprudence from the past two decades. For further discussion see C. Warbrick, *The Structure of Article 8* [1998] 1 EHRLR 32, p33.

<sup>57</sup> See the comments of Joanna Rose in *R (Rose & Another) v Secretary of State for Health & Human Fertilisation and Embryology Authority* [2002] EWHC (Admin).

It is imperative that the legislature and the courts use the period following the Consultation exercise as an opportunity to listen to the voices of those donor offspring who are arguing for the right to receive information about their genetic origins. The government cannot continue to ignore the academic evidence and opinion, which conclusively shows that many DI children have a desperate need and desire for this information. Surely it is time to give DI children the right to fill in the missing piece of their very own “*genealogical jigsaw puzzle*”?



## 2. The Rights of the Child

This paper argues in favour of the DI child's right to be informed of their status *and* their right to receive information about their genetic background, justified by reference to their right to an identity.<sup>1</sup> Throughout this research these two rights will be shown to be inextricably linked – the donor offspring's right to receive genealogical information would be wholly ineffective without the corollary right to be told of their status – and vice versa. However, on a theoretical level, it seems sensible to examine these two rights independently of each other, thereby demonstrating that the justifications for these two rights may be formed on separate grounds, given the fact that the rights may take effect at different stages of the donor offspring's "childhood".<sup>2</sup>

By way of introduction, it must first be recognised how important it is to accept that children actually possess rights, or at least fundamental interests that should be recognised in law, even though there remains significant controversy as to what a "right" is.<sup>3</sup> Without rights children can easily become marginalised by the adults who shape their world - this could be said to be particularly true in relation to AID children, given that, within legal and medical discourse they are often viewed as "*property*" or "*objects*" that complete the family, rather than as human beings and legal entities in themselves.<sup>4</sup> Furthermore, as Eekelaar<sup>5</sup> points out, because AID children are created by the means of a deliberate act of social policy, then there is an

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<sup>1</sup> Articles 7 & 8, United Nations Convention on the Rights of the Child (UNCRC).

<sup>2</sup> *Post*, chapter 3, pp46-50.

<sup>3</sup> For a discussion of the problem of children's rights, see W.N.R. Lucy, *Controversy About Children's Rights* in D. Freestone (ed), *Children and the Law*, Hull University Press, 1990, p213.

<sup>4</sup> See further M. Kellmer-Pringle, *The Needs of Children*, London: Hutchinson, 1975, pp69-70 – "*a baby completes a family, rather like a TV set or a fridge. . . a child belongs to his parents like their other possessions over which they may exercise exclusive rights.*"

<sup>5</sup> J. Eekelaar, *The Importance of thinking that Children Have Rights* IJLF 6 (1992) 221, p231.

even greater responsibility on the state to protect the human rights of the donor offspring. Current provisions under the Human Fertilisation and Embryology Act 1990, relating to the “*welfare*” of the AID child are wholly inadequate<sup>6</sup> and nowhere in the Act is there explicit reference to the “rights” of the DI child. The only way to address this untenable situation is to re-evaluate current legislation and grant effective legal identity rights to donor offspring, justified by reference to the theoretical discussion set out below.

Some commentators would counter this suggestion by questioning whether rights really are important for children; in the case of AID children, why should they need further rights when their “*welfare*” is already clearly legislated for under the HFEA 1990? Critics might also argue that the importance of legal rights in this context has been exaggerated and that children’s immediate interests lie in more altruistic, albeit paternalistic, notions of love, nurture and compassion. Those who favour this argument tend to adopt a *laissez-faire* approach to children’s rights. For example, Goldstein, Freud and Solnit argue that the only right a child has is to autonomous parents, thereby requiring minimal intervention by the state into the private family sphere.<sup>7</sup> However, this notion assumes that adults always relate to children in terms of what they consider to be in their “best interests,” and within the AID parent/child relationship, the separate interests of the parent and the child can often be viewed as being in opposition to each other.<sup>8</sup> Therefore this paper supports the proposition that state intervention within the private AID family sphere is justified and warranted: firstly, because of the “public” nature of the AID child’s conception; secondly, because of the state’s role in the way that an AID child’s birth is registered and

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<sup>6</sup> HFEA, s 13(5). For a full discussion of the effects of this section see *post*, chapter 3, pp34-38. See also G. Douglas, *Assisted Reproduction and the Welfare of the Child* CLP (1993) 53.

<sup>7</sup> J. Goldstein, A. Freud & A. Solnit, *Beyond the Best Interests of the Child*, New York: Free Press, 1973.

<sup>8</sup> *Post*, chapters 3-5.

thirdly, because the collection and retention of information regarding the AID child is maintained by a state agency – the HFE Authority. The UK government cannot justifiably continue to refuse to recognise and respect the identity rights of AID children.

Indeed, children's rights *in general* have begun to gain recognition at both domestic and international level. Developments in international law can be traced back to the United Nations Year of the Child 1979, subsequently bolstered by the United Nations Convention on the Rights of the Child 1989. Domestic law has seen the introduction of more child-centric UK legislation, such as the Children Act 1989 and child-orientated jurisprudence such as the *Gillick* decision.<sup>9</sup> However, the theoretical justifications for the ascription of legal rights to children are still hotly debated amongst legal philosophers and jurists.<sup>10</sup>

Prima facie, by reference to the analysis offered by some commentators, it seems mistaken to ascribe rights to children at all.<sup>11</sup> According to the “will” or “power” theory, a right is a normative capacity that the right-bearer may choose to exercise over others, who themselves have a correlative duty to comply with the exercise of the right-holder's will.<sup>12</sup> Many legal philosophers claim that children do not have the relevant capacities of choice to claim these rights and therefore children have no “claim-rights”<sup>13</sup> whatsoever. Some “will” theorists avoid this assertion by suggesting that a proxy, such as a parent, may exercise the right on behalf of the child. However, for the purposes of this paper, it must be acknowledged that this cannot be

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<sup>9</sup> *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112.

<sup>10</sup> See W. G. Paton, pp285-90 in W.G. Paton & D.P. Derham (eds), *A Text-Book of Jurisprudence*, Oxford: Oxford University Press, 1972, cited in N. MacCormick, *Children's Rights: A test-case for theories of right*, in *Legal Reasoning and Legal Theory*, Oxford: Clarendon Press, 1978, p154.

<sup>11</sup> *Op cit*, MacCormick, fn 10, p154.

<sup>12</sup> H.L.A. Hart, *The Concept of Law*, Oxford: Clarendon Press, 1961.

<sup>13</sup> See W.N. Hohfeld, *Fundamental Legal Conceptions*, Yale University Press, 1919, for a full explanation of what is meant by a “claim-right”.

said to be a full right, because it is the proxy who is the right-holder and they who possess the power to exercise or waive the right.<sup>14</sup> The process of the child choosing to exercise their right is missing, i.e. the child lacks the autonomy of a right-holder.

Furthermore, if the proxy was to exercise the right on behalf of the child, then it would be the adult proxy (generally a “natural” parent – in the case of AID, the social parent) who would represent the child’s interest in his/her own welfare. The proxy version of the “will” theory does not address the proposition that there might be a multiple number of conflicting interests at issue; neither does it address the fact that the adult decision-maker might not represent the “best interests” of the child whom they are making the decision for.<sup>15</sup>

There is an extended version of the “will” theory, which suggests that rights are also related to a person’s capacity for choice and rational action, in that all rights must be linked to the exercise of a person’s self-determination, because rights have the function of protecting these capacities. Therefore, it is because human beings have the power of reasoned self-determination that they can have rights.<sup>16</sup> According to this fuller version of the “will” theory, children would only have rights if they could demonstrate their capacities for reasoned decision-making and willed conduct. However, this theory may be criticised on two bases. Firstly, because it seems inherently wrong to deny children’s rights purely on the basis that they do not “fit” with the “will” theory; for example, if we consider something as fundamental as the right to life, it seems unacceptable that this right should be denied to a 6 month old baby for any reason whatsoever, purely on the theoretical basis that they do not have the will and capacity to exercise their right to life. Secondly, if we consider the

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<sup>14</sup> T.D. Campbell, *The Rights of the Minor: as person, as child, as juvenile, as future adult* 6 IJLF (1992) 1.

<sup>15</sup> See further M.D.A. Freeman, *Freedom and the welfare state: child-rearing, parental autonomy and state intervention* (1983) *Journal of Social Welfare Law* 70.

<sup>16</sup> *Op cit*, MacCormick, fn 10.

possibility of a children's rights theory that takes account of "childhood" as consisting of a number of varying stages, e.g. infancy, adolescence etc., then it may be possible to ascribe rights to AID children under the age of majority, given the proposition that children at the adolescent/juvenile stage of their "childhood" could certainly be said to have the capacity for rational thought and autonomous behaviour.

However, it is generally accepted that the "*interest*" theory presents a much more attractive justification for the general assertion that children should be granted full legal rights.<sup>17</sup> According to the "*interest*" theory, children have rights if their interests are the basis for having rules requiring others to behave in certain ways to protect the child's fundamental interests. Therefore children could be said to have "interests" to be protected *before* they have the necessary will to assert those "interests."

It would be sufficient if there were ways and means of pointing to a child's fundamental interests, i.e. there is no assertion that interests have to be connected to a rational decision-making capacity. Some "*will*" theorists counter the "*interest*" theory's application to children's rights as simply reducing rights to assertions of existing duties.<sup>18</sup> Further, they have difficulty with the fact that the "*interest*" theory seems far too broad, in that there seems to be no mechanism for identifying the actual features of rights-creating interests, i.e. which interest would give rise to distinctive rights and which would not.

To a certain extent theorists accept the stalemate between the "*will*" and "*interest*" theories, particularly in terms of children's rights,<sup>19</sup> although the "*interest*" theory is generally supposed to be a better formulation for the justification of

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<sup>17</sup> For further discussion, see N. Simmonds, *Central Issues in Jurisprudence: Justice, Laws and Right*, London: Sweet & Maxwell, 1986.

<sup>18</sup> *Ibid.*

<sup>19</sup> P. Jones, *Rights*, London: Macmillan, 1994, ch 20.

children's rights.<sup>20</sup> What is important is that many commentators believe that children's fundamental rights definitely *should* be protected; the disagreement arises over the most appropriate way of achieving this. This chapter shall go on to demonstrate that, in actual fact, both theories may be employed to fully delineate the rights of the AID child, firstly to be informed of their status and secondly, their right to receive information about their genetic background.

Let us look first at whether DI children could be said to have a *moral* right to either of these interests. There is still a great deal of debate over the exact nature of moral rights - particularly fundamental moral rights, to which overriding importance is attributed within most theories. Doubt could be cast as to the actual existence of moral, non-positive rights, because these moral rights appear to require the prior existence of independent, naturalistic, moral rules dictating what are and are not moral rights.

Turning first to the AID child's right to be informed of their status. With reference to MacCormick's "*interest*" theory, he speaks of a child's fundamental right to be nurtured, cared for and loved and explicitly refers to this as a moral right<sup>21</sup> – one that can be claimed primarily against the "natural" i.e. social parents of the AID child.<sup>22</sup> If we go on to re-phrase the DI child's right to be informed of their status as a right to the truth and/or a right not to be deceived or lied to (by their social parents), then this could be seen to be analogous to MacCormick's concept of a right to be loved, nurtured and cared for, or at least a component of this right. Alternatively, if we examine the right purely in terms of the right to be told the truth, then there is an argument that this could be deemed to be a fundamental moral right in and of itself.

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<sup>20</sup> *Op cit*, MacCormick, fn 10.

<sup>21</sup> *Op cit*, MacCormick, fn 10, p155.

<sup>22</sup> *Ibid*, p156.

Furthermore, if we refer to Eekelaar's categorisation of rights<sup>23</sup> then we could describe this right to the truth as a "*basic*" interest<sup>24</sup> because it directly relates to the physical, emotional and intellectual care of the AID child. Eekelaar considers these "*basic*" interests to be pre-eminent to all other interests, therefore providing justification for acknowledging a fundamental moral right of the AID child to be informed of their status.

Concerning the question as to whether the AID child has a moral right to receive information about their genetic background, this may warrant a different approach. Campbell<sup>25</sup> suggests that moral rights can be viewed in terms of reasons for attributing positive rights to individuals, centring on the identification of certain interests that are important in and of themselves. Therefore, it could be possible to argue that DI children should have the right to information about their genetic background based, not on a moral right as such, but on a moral right *rationale*. In other words, this interest could be considered by society as being *so significant* that it ought to be given priority wherever possible. Allied to this is the notion that this could form the basis of a "*developmental*" interest within Eekelaar's categories of rights,<sup>26</sup> such a right entails the promotion of an individual's potential to be developed so that they are able to enter adulthood as far as possible without disadvantage. It is arguable that withholding information on genetic origins could harm a child's chances of a stable emotional and psychological development of their sense of self.<sup>27</sup> On the basis of these arguments it seems possible to assert the *moral* rights of AID children to receive information about their genealogical background.

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<sup>23</sup> J. Eekelaar, *The Emergence of Children's Rights* (1986) 6 Oxford Journal of Legal Studies 161

<sup>24</sup> *Ibid*, pp171-172.

<sup>25</sup> *Op cit*, Campbell, fn 14.

<sup>26</sup> *Op cit*, Eekelaar, fn 23, p173.

<sup>27</sup> Eekelaar acknowledges that "*developmental*" and "*autonomy*" interests may need to be compromised in relation to the rights of others, such as the social and genetic parents, as opposed to "*basic*" interests, which are regarded as being pre-eminent.

In furtherance of this analysis, we shall now refer closely to Campbell's account of a child's rights as "*person, child, juvenile and future adult.*"<sup>28</sup> His account seems to demonstrate that it is possible to allege a justification for the two rights at issue on the basis of the concept of "childhood" representing a range of different states of being a "child" and that the two rights might be brought into effect at different stages of this "childhood," in order to fully and effectively protect the rights of the AID child.

In this context, it seems to be a natural assumption on the part of many legal theorists that children are human beings and that, if human rights are acknowledged as being universal, then they should be applied equally to both adults and children. A young child's main interests relate to the love, care and affection provided by their primary carers – for AID children this is their social parents.<sup>29</sup> The right to be told the truth about their status is an important part of this stage of "childhood", particularly considering that evidence shows that this should occur as early as possible in a child's life.<sup>30</sup> However, some theorists would dispute that the AID child has such a right, given the fact that at this stage in their lives, they cannot exercise their claim-right to force another person to carry out their correlative duty by telling them the truth; neither can they relieve that person of this duty.<sup>31</sup> The most appropriate way of attributing such a right to DI children would therefore be by reference to the "*interest*" theory, i.e. that donor offspring should have the right to be told about their status because they have a fundamental interest in such a right, as it relates to the protection of their "*basic*" interests.

However, despite the fact that MacCormick's theory incorporates a measure of paternalism, it must be stressed that adopting the "*interest*" theory in relation to this

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<sup>28</sup> *Op cit*, Campbell, fn 14.

<sup>29</sup> *Post*, chapter 3, p48 *et seq.*

<sup>30</sup> J. Triseliotis, *In Search of Origins*, London: Routledge & Kegan Paul, 1973.

<sup>31</sup> *Op cit*, MacCormick, fn 10, p156.



right should not necessarily entail an automatic acceptance of the “best interests” or “welfare” test for determining the way in which the right should be exercised. The reasons for this being, firstly, this test has often been used to actually deny the rights of DI children to information on their origins, as it was considered to be in the best interests of the child *not* to disclose this information;<sup>32</sup> secondly, because it should be recognised that children’s rights need to be analysed in and of themselves, not merely as part of paternalistic, adult-centred concerns.

Eekelaar<sup>33</sup> and Freeman<sup>34</sup> have argued that, in order to ascertain what is in a child’s best interests there needs to be a hypothetical enquiry into what children would want, on the basis of what adults would have wanted for themselves as children. This argument seems far too idealistic, particularly in the AID context, and it is accepted that what probably happens in practice is that adult decision-making of this nature tends to reflect the value judgements of the adults, as has been suggested by Ruth Adler.<sup>35</sup> Possibly the best resolution to this issue may be to reformulate the notion of the “welfare” principle as one that gives, “*priority to children’s rights over those of parents (or others) in cases where they cannot be reconciled,*”<sup>36</sup> although this would not be an automatic assumption, as the balancing of interests would depend on the particular facts of each case.

However, this paper concedes that the most important right for the *younger AID child* is the right to be told of their status – the right to genealogical information is not a necessarily useful part of the *younger child’s* childhood, i.e. this right may be better

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<sup>32</sup> Post, chapters 3-5.

<sup>33</sup> *Op cit*, Eekelaar, fn 23. See also J. Eekelaar, *The Interests of the Child and the Child’s Wishes: The Role of Dynamic Self-Determinism*, in P. Alston (ed), *The Best Interests of the Child*, London: Clarendon Press, 1994.

<sup>34</sup> M. Freeman, *The Moral Status of Children*, Martinus Nijhoff, 1997.

<sup>35</sup> R. Adler, *Taking Juvenile Justice Seriously*, Scottish Academic Press, 1985.

<sup>36</sup> J. Eekelaar, *The Wardship Jurisdiction, Children’s Welfare and Parents’ Rights* (1991) 107 LQR 368, p389.

attributed to them at a later stage. Sociological and psychological evidence shows that both identifying and non-identifying information relating to a child's genetic identity becomes much more important during their adolescent years, when they are developing into their adult selves.

Modern rights discourse has begun to recognise that older children may have certain rights attributed to them on the basis that they have developed sufficient maturity to recognise, understand and assert these rights. Such an analysis allows for the acknowledgement of the significance of a transitional phase from "childhood" to "adulthood." At this juvenile stage, certain distinctive rights of the adolescent begin to emerge; these rights often include important elements relating to both childhood and adulthood. There is therefore scope for recognising a juvenile stage of human life, which could properly be brought within the sphere of children's rights. Indeed, this has already been demonstrated in other jurisdictions with relation to the rights of the AID child. The Swedish Act on Insemination 1985 makes explicit reference to the child's right to identifying information about their donor when they achieve sufficient "maturity" and it shall be argued within this paper that this right could be incorporated into UK law, using the benchmarks of maturity and competence as opposed to age.<sup>37</sup>

Child liberationists such as Farson<sup>38</sup> and Holt<sup>39</sup> would agree with this suggestion: firstly, because they would entirely refute the claim that children lack the same capacity as adults to hold rights; secondly, because they would point to the arbitrariness of any specific age-line that may be drawn between those who do and those who do not possess these rights. This leads to the conclusion that age alone is insufficient to warrant the denial or ascription of a right; in this way the ascription of

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<sup>37</sup> *Post*, chapter 3.

<sup>38</sup> R. Farson, *Birthrights*, Penguin USA, 1978.

<sup>39</sup> J. Holt, *Escape from Childhood*, E.P. Dutton, 1974.

the right on the basis of perceived maturity or competence seems much more sensible and would fit with the justification of the “will” theory.

Indeed in *Gillick*<sup>40</sup> we can already see a firm commitment, on the part of the judiciary, to recognise the child as a developing and potentially rational decision-maker in their own right. According to Lord Scarman:

*“I would hold as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminated if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. It will be a question of fact.”*<sup>41</sup>

It needs to be acknowledged that, at a certain stage in their life, a child begins to develop a number of autonomy interests, i.e. they have the capacity for autonomous behaviour because they are sufficiently mature to select what they wish to have and not to have – this could therefore be true of AID children in relation to their decision to exercise a right to information on genetic origins or not. Therefore, it appears that the right to information would readily fit with the “will” theory, in that, such adolescents may be capable of rational and autonomous decision-making and may be able to exercise rights over others; although this right could equally be justified by reference to the “interest” theory. This would necessarily entail the existence of a correlative duty – in this case on the part of the state, i.e. the HFE Authority, to collect, retain and disseminate information relating to a DI child’s genetic background, in order to give effect to this positive legal right.

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<sup>40</sup> *Op cit*, fn 9.

<sup>41</sup> *Ibid*.

However, autonomy on the part of the AID child need not lead to the dismissal of the proposition that these children are at a vulnerable stage in their lives and therefore may require some *adult support* in the exercise of their right to information. Minow suggests that there is, “*something terribly lacking in rights for children that speak only of autonomy.*”<sup>42</sup> Therefore, although the child may have reached a stage in their lives where they can assert their rights, it is still a transitional phase for them and the practical implications of these rights being granted may entail continued adult support.<sup>43</sup>

In conclusion therefore, it can be said that AID children *are* capable of being right-holders, this assertion being justified in relation to both the “*interest*” and the “*will*” theory. However, this is not to say that their rights are absolute; it must be remembered that DI children do not exist in a vacuum and that their rights need to be balanced against those of the adults involved – the social parent(s) and the genetic parent(s). However, this paper will show that the result of such a balancing act would still be a strong argument in favour of AID children being granted *the right to be told of their status and the right to receive information about their genetic background.*

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<sup>42</sup> Article 5, UNCRC makes explicit reference to the need for, “*appropriate direction and guidance*” from adults, in the exercise of Convention rights.

<sup>43</sup> e.g. counselling and advice.

### **3. The A.I.D. Child**

The question: should AID/DI children be granted the legal right to be told about their status and the right to access both non-identifying and identifying information regarding their genetic background? The answer: yes. The justification: on the grounds that knowledge of their genetic origins constitutes a vital part of their identity and that such a right should be afforded to them on the basis of their fundamental right to an identity.

#### **1 Current UK Regulation**

In the UK, the regulation of AID/DI is founded on the Human Fertilisation and Embryology Act 1990<sup>1</sup> and the HFE Authority Code of Practice.<sup>2</sup> Section 5 HFEA 1990 provides for the establishment of the HFE Authority,<sup>3</sup> which is responsible for the licensing of treatment centres<sup>4</sup> and the overseeing of all ART “*treatment services*”.<sup>5</sup>

However, the HFEA 1990 does not apply when AID conception takes place on a “do-it-yourself” basis,<sup>6</sup> whereby a woman uses the sperm of a friend or acquaintance, by injection or full sexual intercourse, without the need for medical assistance.

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<sup>1</sup> Hereinafter “HFEA”.

<sup>2</sup> Hereinafter “the COP”; 4<sup>th</sup> edn, July 1998, London: HFEA. HFEA, s 25(1) requires the HFE Authority to, “*maintain a code of practice of activities carried out in pursuance of a licence under this Act and the proper discharge of the functions of the person responsible and other persons to whom this licence applies.*” The COP is not legally binding but it is considered a major part of UK ART legal regulation and arguably establishes what a *reasonable* doctor should do (*Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118). Failure to comply with the Code may therefore constitute a breach of duty – see I. Kennedy & A. Grubb, *Medical Law: Text with Materials*, London: Butterworths, 1994, p793.

<sup>3</sup> Hereinafter “the Authority”.

<sup>4</sup> HFEA, ss 9-22.

<sup>5</sup> Defined in HFEA, s 2(1).

<sup>6</sup> Only occurs with sperm, not egg donation.

Situations like this occur most frequently where women have already been refused treatment in a licensed clinic, e.g. lesbian, single women<sup>7</sup> and women refused treatment due to age restrictions.<sup>8</sup> When self-insemination occurs, the social parent(s) of the child will usually know the donor's identity and can decide whether or not to provide the DI child with information about the donation and/or donor. Unfortunately, there is no empirical evidence available on how frequently these DIY inseminations take place, but the case of *Re T (Paternity: Ordering Blood Tests)*<sup>9</sup> demonstrates that infertile couples in the UK may resort to these methods. Such practices raise a whole gamut of difficult legal and ethical issues; for example, where the insemination does not take place in a licensed centre, the donor is deemed to be the legal father of the resulting child with all of the attendant legal, financial and familial responsibilities attributed to such a status.<sup>10</sup> Unfortunately, the legislature chooses not to intervene in these situations,<sup>11</sup> leaving the donor offspring at the mercy of the adults who have engineered their creation, possibly with their own interests, not those of the donor offspring, foremost in mind.<sup>12</sup>

Paradoxically, "D.I.Y. donor offspring" may find in future that their rights to an identity receive significantly greater protection than the rights of DI children legally conceived under HFEA regulation. Judicial dicta in three recent cases involving orders for blood tests to determine paternity has shown that the courts now seem

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<sup>7</sup> HFEA, s 13(5) – this provision has led many clinics to refuse treatment to lesbians and single women on the grounds that any resulting child would be fatherless – see G. Douglas & N.V. Lowe, *Becoming a Parent in English Law* (1992) 108 LQR 414, p419 and G. Douglas, *Assisted Reproduction and the Welfare of the Child* CLP (1993) 53, p 63 – although the COP advises treatment centres not to discriminate against any particular group of women, HFE Authority, *Annual Report*, (1992), p20.

<sup>8</sup> See *R v Sheffield Health Authority ex parte Seale* (1994) 25 BMLR 1 in relation to age restrictions in IVF treatment.

<sup>9</sup> [2001] 2 FLR 1190 (an infertile married couple agreed that the wife would have sexual intercourse with a third party in order to become pregnant).

<sup>10</sup> cf HFEA, s 28(6)(a) – the donor of sperm used in accordance with the HFEA is not the *legal* father.

<sup>11</sup> For instance, by not providing criminal sanctions against the use of AID outside the scope of the HFEA 1990; see further the Infertility Treatment Act 1995 (Vic) s 7.

<sup>12</sup> As the COP states, "*the welfare of [the] children [cannot] always adequately be protected by concern for the interests of the adults involved,*" COP, Ch 1, p1.

willing to uphold the rights of children in general to know the truth about their genetic background. *Re H (Paternity:Blood Tests)*,<sup>13</sup> concerning a direction for blood tests in a paternity dispute that arose following an extra-marital affair, established that, “every child has a right to know the truth unless his welfare clearly justifies the cover-up,”<sup>14</sup> with explicit reference being made to the child’s rights under the United Nations Convention on the Rights of the Child.<sup>15</sup> This maxim was followed in *Re H and A (Paternity:Blood Tests)*,<sup>16</sup> a similar paternity dispute case arising from an extra-marital affair, wherein it was held that, “the interests of justice are best served by the ascertainment of the truth.”<sup>17</sup>

The third case can be said to be even more analogous to the situation of “D.I.Y. donor offspring”, in that it concerned a married couple who were unable to conceive naturally and therefore agreed that the woman would have sexual intercourse with a third party in order to become pregnant. The decision in *Re T (Paternity:Ordering Blood Tests)*<sup>18</sup> found that in general it was in the best interests of the child to know the truth about their paternity, although this needed to be balanced against the rights of the other parties involved, e.g. their right to respect for their private and family lives under Article 8 of the European Convention of Human Rights. The decisions in these cases are to be welcomed, for they demonstrate the courts’ commitment to recognising the identity rights of children, but it is disappointing to note that only “D.I.Y. donor offspring” might benefit from the principles evinced in these cases, *specifically because* their predicaments are *not* covered by the HFEA 1990.

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<sup>13</sup> [1996] 2 FLR 65, per Ward LJ.

<sup>14</sup> *Ibid*, p80.

<sup>15</sup> *Supra*, fn 13, p80 – Article 7 UNCRC – “a child has, as far as possible, the right to know and be cared for by his or her parents.”

<sup>16</sup> [2002] 1 FLR 1145.

<sup>17</sup> *Ibid*, p1153. Following *S v S; W v Official Solicitor* [1972] AC 24.

<sup>18</sup> *Supra*, fn 9.

Where donor gametes and embryos are used in accordance with the HFEA 1990, the rights of the social parent(s)<sup>19</sup> and the anonymity of the donor are almost always guaranteed. There is a statutory obligation upon the HFE Authority to keep a Register of Information relating to the users of their services, including information about the patients/social parents, the donors/genetic parents and any resulting DI children.<sup>20</sup> However, access to the information contained therein is strictly limited to the members and employees of the HFE Authority and staff at the licensed treatment centres.<sup>21</sup> Any unauthorised disclosure of the information contained on the Register is a criminal offence, attracting a fine and a maximum penalty of two years' imprisonment<sup>22</sup> – such is the perceived importance of protecting the confidentiality and anonymity of those involved. Consequently, the donor, the recipients of the treatment and the resulting donor offspring cannot be identified or identify anybody else in the AID process.

Despite this, within the Act there are certain mechanisms for a DI child to find out *some* information about their conception,<sup>23</sup> although there is nothing that allows the disclosure of *identifying* information to the donor offspring.<sup>24</sup> Currently, upon reaching the age of 18, a child can apply to the Authority to discover whether or not his/her name is on the Register.<sup>25</sup> The HFE Authority has:

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<sup>19</sup> See *Re CH (Contact:Parentage)* [1996] 1 FLR 560 and *Re B (Parentage)* [1996] 2 FLR 15, regarding the effects of the HFEA 1990.

<sup>20</sup> HFEA, s 31(1) and (2).

<sup>21</sup> *Ibid*, s 33.

<sup>22</sup> *Ibid*, s 41(1).

<sup>23</sup> See further Human Fertilisation and Embryology (Disclosure of Information) Act 1992.

<sup>24</sup> COP, para 10.7(c).

<sup>25</sup> HFEA, s 31(3)(a).



*“a legal duty to tell adults, who ask, whether they were born as a result of treatment using donated eggs or sperm. They must be given a suitable opportunity to receive proper counselling about the implications of this information.”*<sup>26</sup>

However, this provision is of very limited value, given that its usage depends upon the child having prior knowledge, or at least a suspicion, that their name may be included on the Register. This knowledge, or lack thereof, is of course dependent upon how much information the DI child’s social parents will have already passed on and, as the evidence tends to show, there is a significant degree of reluctance on the part of the child’s social parents to disclose this fact.<sup>27</sup> The Code of Practice, para 3.14, currently advises that prospective parents merely be aware of, *“a child’s potential need to know about his or her origins,”*<sup>28</sup> prior to treatment by AID – a relatively weak statement, demonstrating little recognition of the actual needs of the DI child.

Donor offspring aged 16 and over can approach the HFE Authority to inquire as to whether or not they might be related to someone that they intend to marry.<sup>29</sup> Again, this provision may be under-utilised, given the likelihood that they may not even suspect anything about their true status or have any knowledge of the existence of this provision. This section seems to be of much greater value to the Authority itself, in

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<sup>26</sup> HFEA Leaflet, *“Sperm and Egg Donors and the Law”* (December 1992).

<sup>27</sup> Two studies found that over 70% of couples questioned had not revealed this fact to their children – see G. Kovacs, D. Mushin, H. Kane & H.W.G. Baker, *A controlled study of the psychosocial development of children conceived following insemination with donor semen* (1992) 8 HR 778; see also S.C.Lui, S.C. Weaver, J. Robinson, M. Debano, M. Neiland, S.R. Killick & D.M. Hay, *A survey of semen donor attitudes* (1994) 9 HR 459. Others have estimated that less than 5% of parents actually tell their children the truth – see M. Rayner, *The Child’s Right to an Identity Rights Now*, Dec 1998, p20.

<sup>28</sup> Other issues to be considered include the, *“attitudes of other family members towards the child; implications for the child’s welfare if the donor is known to the family; and any possible dispute over the identity of the child’s legal father”* – COP, paras 3.14 – 3.17.

<sup>29</sup> HFEA, s 31(4)(b) and 6. However, there is no protection from the possible consequences of consanguinity for unmarried couples who conceive together.

attempting to limit its liability for the potential legal, moral and medical dilemmas, should two AID offspring, who are genetically related, attempt to marry and start their own families.<sup>30</sup>

Finally, if a DI child was to be born with an inherited disease or disability and the screening of the donated genetic material had previously failed to detect any genetic defects, which the donor either knew about and had failed to disclose, or something which he/she ought reasonably to have known about, the donor could be sued for damages under the Congenital Disabilities (Civil Liability) Act 1976.<sup>31</sup> Any child suffering physical damage as a result of the donor's failure to disclose would be allowed a copy of their original birth certificate upon reaching the age of 18, in order to bring negligence proceedings against the donor and/or clinic.<sup>32</sup> However, in an attempt not to deter potential donors, the Authority has stated that, *"legal action is extremely unlikely provided a donor is open and honest about his or her medical or family history."*<sup>33</sup>

It has been suggested that this last provision could raise issues of equity for all DI children, given that in these extenuating circumstances some children would be allowed to find out the identity of their genetic parents and others would not. In reality this is unlikely to be the case, firstly, because the provision will be infrequently invoked and secondly, because the donor's name is not currently included on an AID child's birth certificate. Indeed, one wonders about the real reason for the inclusion of this provision in the Act, considering the statute's rigorous preservation of the concept of donor anonymity in all other circumstances. Perhaps, as some

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<sup>30</sup> Counselling is to be offered to people seeking this information: HFEA 1990, ss 31(3) and (6).

<sup>31</sup> HFEA, s 35.

<sup>32</sup> Parental Orders (Human Fertilisation and Embryology) Regulations 1994 (SI 1994/27670, amending the Adoption Act 1976, s 50).

<sup>33</sup> *Op cit*, fn 26.

commentators have astutely pointed out,<sup>34</sup> this exception to the principle of anonymity exists because, if there were no one to pursue for negligence, the state would have to commit considerable resources to support the disabled child. Certainly, this provision represents an isolated example in the HFEA 1990 of the state's explicit acknowledgement of the presence and importance of a genetic link – could this approach not be extended therefore to disclosure of identifying and non-identifying information, justified by reference to a donor offspring's *identity rights*?

## 2 The A.I.D. Child

### 2.1 The rights of the A.I.D. child?

As we have already seen, the rights of the AID child are extremely limited. Currently, the law in this area states that a person who has reached the *age of 18* can apply to the Human Fertilisation and Embryology Authority Register<sup>35</sup> to find out if they were conceived by means of donated gametes or embryos.<sup>36</sup> Furthermore, at the age of 18, the applicant could have the opportunity of receiving certain non-identifying information, such as ethnic background, medical history, physical attributes, etc. about the donor/genetic parent, although no Regulations regarding the provision of this information have as yet been made. Fortunately, such Regulations to provide *non-identifying* information *could* be made to operate retrospectively,<sup>37</sup> and

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<sup>34</sup> M. Roberts, *Children by Donation: Do they have a claim to their genetic parentage?* In J. Bridgeman & D. Monk (eds), *Feminist Perspectives on Child Law*, London: Cavendish, 2000, 47, p53.

<sup>35</sup> See HFEA s 31(1) and (2).

<sup>36</sup> *Ibid*, s 31(3)(a).

<sup>37</sup> HFEA, s 31.

there seem to be significant justifications and little opposition<sup>38</sup> to the proposition of certain Regulations being enacted in any future legislative measures.<sup>39</sup>

However, despite the fact that the HFE Authority is under a statutory duty to keep a Register of information from licensed centres, including identifying information about gamete/embryo donors and their resulting offspring,<sup>40</sup> this information cannot be disclosed, except to certain specified people.<sup>41</sup> Furthermore, the retention of such information is often alleged to be justified on medical grounds, rather than for the purpose of providing genealogical information to DI children; for example, medical supervisors need to have access to the identity of the donor to assess the suitability of the specimen and to know the identity of both donor and donor offspring for the purposes of assessing the risks of any future congenital defects.

Furthermore, the Act provides that any future Regulations to provide identifying information cannot be made to operate retrospectively,<sup>42</sup> a point on which the government appears to be firmly resolute, according to the recent Consultation Paper. Arguably, it *would* be possible for primary legislation to be passed to provide for retrospective disclosure of a donor's identity, as has already happened with adoption legislation,<sup>43</sup> particularly given the fact that this information is already contained on the HFE Authority's database.<sup>44</sup> Despite the government's apparent resistance to retrospective disclosure of identifying information, within the following paper, the

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<sup>38</sup> Although an amendment was made to the HFEA 1990 during the report stage in the House of Commons preventing disclosure of non-identifying information – see further D. Morgan & R. Lee, *Blackstone's Guide to the Human Fertilisation and Embryology Act 1990*, London: Blackstone Press Ltd, 1991, p163.

<sup>39</sup> Even Baroness Warnock, chairman of the 1984 Warnock Committee, has recently acknowledged that donor anonymity should not be allowed to continue because, "[W]e are so much more sensitive now to the idea of genetic inheritance," *The Guardian*, Tuesday 14 May 2002.

<sup>40</sup> Section 31(1) and (2). See HFE Authority, *The Role of the HFEA*, (December 1992).

<sup>41</sup> HFEA, s 33.

<sup>42</sup> *Ibid*, s 31(5).

<sup>43</sup> Children Act 1975.

<sup>44</sup> See M. Roberts, *A right to know for children by donation – any assistance from down under?* CFLQ (2000) 371, p374.

emphasis shall actually be on recognising the importance of providing identifying and non-identifying information to DI children, both prospectively and retrospectively.

Currently, the law in this country does not even provide for a right of access of *adult* donor offspring to information about their genetic parentage. Clearly, there is no such corresponding right for donor offspring as *children*. However, this paper argues that there should be a right of access to this information for donor offspring *before* they reach the age of majority, i.e. whilst they are still *children*. Chapter 2 has already demonstrated that it is theoretically possible to ascribe basic human rights to children *per se*. We shall now go on to consider the arguments for and against granting actual and effective identity rights to DI children, bearing in mind that their rights and interests must be balanced against the rights of the social and genetic parent(s) to privacy, confidentiality and respect for their family lives.<sup>45</sup>

To recapture, at present, in almost all cases of AID the anonymity of the donor is guaranteed and the confidentiality of the social parents is stringently protected at the expense of the donor offspring's right to *any* information regarding their genetic background. In general, the mutually reinforcing concepts of *secrecy* and *anonymity* can be said to have taken tight hold of the existing legal regulation governing donor insemination. What is needed now is an extensive re-evaluation, both at a theoretical and practical level, to allow for the principle of *openness* to be wholeheartedly adopted within the sphere of AID.<sup>46</sup> The government has the opportunity to do this if it uses the Consultation period wisely<sup>47</sup> and accepts that there needs to be a complete overhaul of current legislation – one that recognises the inadequacy of the HFEA

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<sup>45</sup> Article 8, ECHR.

<sup>46</sup> See the HFE Authority's response to the government's Consultation Paper, s 15.

<sup>47</sup> Department of Health, *Donor Information Consultation: Providing information about gamete or embryo donors*, London: HMSO, 2001.

1990 in protecting the DI child and also acknowledges that the “rights” - not the “welfare” - of the child need to be the primary concern.

## 2.2 The welfare of the A.I.D child?

Current legal regulation has been shown to be woefully inadequate in protecting the rights and interests of the DI child, arguably the person in need of the greatest protection.<sup>48</sup> The HFEA 1990 seems to focus more on issues surrounding embryo research, than it does on the needs of the donor offspring. This is surprising given the child-orientated climate in which the HFEA was born, most notably the provisions contained in the Children Act 1989<sup>49</sup> and the implementation of the UNCRC 1989.<sup>50</sup>

Indeed, under the HFEA 1990, the degree of concern that should be placed on the donor offspring’s welfare is extremely ambiguous. Initially there was *no* explicit reference to the child’s welfare in the Human Fertilisation and Embryology Bill. A clause was inserted quite late on during the reading of the Bill, and this only because of pressure from the political, moral right to ensure that access to treatment services would be restricted to prevent lesbian and single women making use of them.<sup>51</sup>

Under section 13(5), HFEA:

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<sup>48</sup> For a fuller discussion of the implications of section 13 (5) HFEA, see *op cit*, Douglas, fn 7.

<sup>49</sup> Described by the then Lord Chancellor as, “*the most comprehensive and far-reaching reform of child law which has come before Parliament in living memory*,” - Hansard (HL) Vol 502, col 488.

<sup>50</sup> Now acknowledged as the most authoritative statement of children’s fundamental (though not necessarily *legal*) rights. The UK ratified the UNCRC 1989 on 16 Dec 1991, but it does not form a substantive part of English domestic law – see G. van Bueren, *The United Nations Convention on the Rights of the Child: The Necessity of Incorporation into United Kingdom Law* [1992] FL 373; although the philosophy and principles of the Convention can be significant in the English courts, *supra*, fn 13, p80.

<sup>51</sup> An early amendment to the Bill would have made it a criminal offence to provide treatment for unmarried women; this was eventually defeated but only by one vote – HL Debs Vol 515, 6<sup>th</sup> Feb 1990, col 787.

*“A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born of the treatment (including the need of that child for a father)<sup>52</sup> and of any other child who may be affected by the birth”* (emphasis added).

Arguably, under the HFEA 1990, the “welfare” of the child is not accorded a particularly high status. This apparent relegation of the child’s welfare stands in stark contrast to the emphasis placed on the welfare concept within other child-orientated legislation. For example, section 1 of the Children Act 1989 provides that the child’s welfare should be the “*paramount consideration*,” as does section 1 of the more recent Adoption and Children Act 2002. It is hereby alleged that the actual welfare of the AID child was not really at issue in the HFEA 1990. The Warnock Committee had already articulated fears about autonomous motherhood in their Report<sup>53</sup> and wanted to ensure that treatment services would only be available to women together with a partner. It stated:

*“To judge by the evidence many people believe that the interests of the child dictate that it should be born into a . . . .loving, stable, heterosexual relationship.”<sup>54</sup>*

Over the past decade, it has become increasingly obvious that section 13(5) and the Code of Practice do not provide sufficient safeguards to protect the interests of the DI child. As long ago as 1993, Gillian Douglas articulated significant concerns that

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<sup>52</sup> An amendment introduced at the Report stage by David Wilshire MP – HL Debs Vol 174, 21<sup>st</sup> June 1990, col 1021.

<sup>53</sup> Department of Health and Social Security, *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (The Warnock Report), Cmnd 9414, London: HMSO, 1984, paras 2.9 – 2.11.

<sup>54</sup> *Ibid*, p11.

section 13(5) was not working as it should and required a substantial overhaul.<sup>55</sup> Douglas' article identified several concerns, which shall be referred to here to demonstrate the inadequacy of the current provisions.

Firstly, it has become clear that the true purpose of section 13(5) is as a smokescreen behind which value judgements can be made about who should be allowed access to treatment services.<sup>56</sup> This allows social judgements to be made by the medical professionals<sup>57</sup> – people who may not necessarily be qualified to judge who is fit to be a parent or assess all of the emotional and psychological needs of the future child, including their desire to know about their genetic background.<sup>58</sup> This situation can be contrasted with the adoption process, whereby prospective adopters must satisfy an adoption panel, which will include non-medical professionals such as social workers, of their suitability. It has been said that there are significant differences between AID and the adoption process, however, it is argued here that they are both concerned with family formation – the fact that one is about finding parents for children and the other deals with creating children for parents should not interfere with welfare considerations.

Admittedly, guidance on the welfare of the child *is* currently provided in the Code of Practice, which includes a list of factors to be taken into account when assessing the welfare of the child. Most importantly, where donated gametes are used, the Code states that clinics and patients should consider, "*a child's potential need to know about their origins and whether or not the prospective parents are prepared for*

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<sup>55</sup> *Op cit*, Douglas, fn 7.

<sup>56</sup> See J. Bridgeman & S. Millns, *Feminist Perspectives in Law*, London: Sweet & Maxwell, 1998, pp131-145, for a discussion of access to treatment.

<sup>57</sup> Douglas draws attention to the fact that the HFEA was the first (and possibly only) statute to consider the fitness of prospective parents to have a child of their own.

<sup>58</sup> Douglas carried out empirical research into the actual experiences of fertility patients in licensed treatment centres – *op cit*, fn 7, p61. Her findings showed that, in practice, few attempts were made to assess the child's welfare being at risk if the patient were treated.



*the questions which may arise when the child is growing up.*"<sup>59</sup> This particular COP provision suggests that the government has already recognised that there *is* an issue here.<sup>60</sup>

Further criticism on a different basis may be levelled at section 13(5); in the words of the Warnock Committee, who:-

*"... believed that as a general rule, it is better for children to be born into a two-parent family, with both a father and a mother. . . ."*<sup>61</sup>

The history and philosophy behind section 13(5) has demonstrated that the medical professionals, the lawyers and the politicians all honed in on the concern that AID creates families that differ from the normal, traditional, heterosexual family. Despite the proposition that AID can be viewed as being supportive of families' interests,<sup>62</sup> in that it is an alternative option for family formation, section 13(5) was adopted in a blatant attempt to prevent the sanctioning of too much societal divergence from the normal family structure.<sup>63</sup> This in turn prevents acceptance of the proposition that the "new family" can be formed in a variety of ways and that it would be quite possible to take account of the presence of both social and genetic parents within the

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<sup>59</sup> *Ibid*, paras 3.14 – the basis for this recommendation however is not discussed.

<sup>60</sup> Despite the arguments of some that the DI child's welfare might best be served by *not* granting them the right to any information, because disclosure of the truth might actually harm their emotional and psychological development. See K. O'Donovan, *What shall we tell the Children?* in R. Lee & D. Morgan, *Birthrights, Law and Ethics at the Beginnings of Life*, London: Routledge & Kegan Paul, 1989, p104, for examples of it being stressful for some adoptees who decide to meet their genetic parents.

<sup>61</sup> *Op cit*, fn 53.

<sup>62</sup> See further S. Millns, *Social Judgements that Go Beyond the Purely Medical: The Reproductive Revolution and Access to Fertility Treatment Services* in J. Bridgeman & S. Millns (eds), *Law and the Body Politics: Legislating the Female Body*, Dartmouth Publishing Company Ltd, 1995, p82.

<sup>63</sup> Admittedly, a concern has been expressed that, "*AID becomes a means of dispensing with marriage and the inconvenience of a husband and, of course, with a father too*" – R. Snowden & G. Mitchell, *The Artificial Family: A consideration of artificial insemination by donor*, London: Unwin, 1981, cited in K. Arnup, *Finding Fathers: Artificial Insemination, Lesbians and the Law* (1994) 7 Canadian Journal of Women and the Law 97, 114.

family structure. Indeed, the provisions of the HFEA seem inherently contradictory: on the one hand, sections 27 and 28 render the genetic link between parent and child almost irrelevant, whilst section 13(5) strives to maintain the apparent validity of the naturally created genetic family. This theoretical conflict does little to clarify the position of any member of the DI family, something that needs to be borne in mind in any future regulation. The government would do well to take time to consider the views espoused by Bainham,<sup>64</sup> regarding Joseph Raz's theory on "*value pluralism*" – that, "*there are many different and incompatible ways of life.*"<sup>65</sup> Specifically, Bainham suggests that in the context of family relationships, this would mean that, "*all those intimate and family relationships which can be considered valuable should be supported by the state in an even-handed way.*"<sup>66</sup> Practically speaking, it should not be difficult for the government to make this leap and actively support the validity of the AID family.

Therefore, the government needs to seize the opportunity provided by this Consultation period, to re-evaluate the proposition that DI child *should* have the right to be informed of their status and the right to receive both non-identifying and identifying information about their genetic parent(s). A swift legislative response to the current situation is necessary and this paper suggests that the government should bear in mind firstly, the importance of identity to the AID child; secondly, the importance of recognising the right to an identity and thirdly, the theoretical and practical ways in which their welfare could be better protected, by following the proposals for change suggested in chapter 1 of this paper.<sup>67</sup>

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<sup>64</sup> See A. Bainham, *Family Rights in the Next Millenium* (2000) CLP 471.

<sup>65</sup> J. Raz, *The Morality of Freedom*, Oxford: Oxford University Press, 1986, ch 14.

<sup>66</sup> *Op cit*, Bainham, fn 64, p 475.

<sup>67</sup> Chapter 1, pp4-6.

### 3 The Importance of Identity

#### 3.1 Social identity

The provision of information relating to a person's genetic background is often justified on two grounds.<sup>68</sup> Firstly, for medical reasons, i.e. in terms of the prevention and cure of hereditary illnesses and genetic conditions, there is a growing recognition that genetic origin information is vital for the health of the DI child. Simpson points out that:

*“...any child born as a result of donor assisted conception who is denied knowledge of their family history could justifiably be said to be at a medical disadvantage compared to any child brought up by their biological parents.”*<sup>69</sup>

This argument is extremely persuasive, particularly if we consider that the information relating to a donor's medical history is important, not just at the point of donation, but on an ongoing basis throughout the lives of both donor and donor offspring, therefore justifying continual reciprocity between the two parties to update the information pertaining to them. This justification for disclosure of information on medical grounds is difficult to argue with. However, some might say that such medical information could be provided, possibly via an intermediary such as the HFE Authority, on the basis of a register linking *only* the medical information relating to the donor and the child. Critics of the concept of disclosure of full identifying information might thereby argue that it need not be provided purely on the medical grounds suggested above.

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<sup>68</sup> HFE Authority Response to the 2001 Consultation, ss 14-15.

<sup>69</sup> S. Simpson, *Truth and the Child: a genetic perspective* in E. Blyth, M. Crawshaw & J. Speirs (eds), *Truth and the Child 10 Years On: Information exchange in donor assisted conception*, Birmingham: British Association of Social Workers, 1998.

We need therefore to conclusively demonstrate that disclosure can be justified by reference to notions of *identity*. Arguably, there is a substantial legal basis for donor offspring *under the age of majority* to be afforded a right of access to information, based on the provisions of the UNCRC 1989, whereby every child has, “*as far as possible, the right to know and be cared for by his or her parents*,”<sup>70</sup> and the right, “*to preserve his or her identity, including nationality, name and family relations as recognised by law without unlawful interference*.”<sup>71</sup> However, as shall be discussed later in this paper, despite the fact that such a right may be granted to the donor offspring whilst they are still children, this may need to be qualified by reference to a benchmark of “*maturity*”<sup>72</sup> and further qualified by reference to Article 5 of the UNCRC which provides for, “*appropriate guidance and direction*” to be provided by a child’s parents in the exercise of their rights.

It is almost impossible to deny that identity is of fundamental importance to the individual. On a theoretical level, evidence shows that the notion of identity is considered a vital part of an individual’s personality and their sense of self.<sup>73</sup> On an emotional level, those DI children who are aware of their situation have spoken out about their feelings of “*shock*” and “*loss*” and “*grief*” at not having a complete sense of their own genealogical identity.<sup>74</sup> Identity helps to define not only how these individuals view themselves, but also how others view them as members of society. An individual’s identity is an acknowledgement of that person’s existence,

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<sup>70</sup> Article 7(1).

<sup>71</sup> Article 8(1).

<sup>72</sup> As included in the Swedish Act on Artificial Insemination 1985. This standard is assessed by the child/adolescent’s general practitioner and counsellors, a practice that could easily be adopted in the UK.

<sup>73</sup> For personal accounts of donor offspring and their desire for genealogical information see C. Whipp, *Offspring’s perspectives on secrecy in contraception* and B. Lauren, *Issues for donor inseminated offspring*, both in *op cit*, Blyth, Crawshaw & Speirs (eds), fn 69.

<sup>74</sup> See A.J. Turner & A. Coyle, *What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications of counselling and therapy* 15(9) (2002) HR 2041.

encompassing all aspects of a human being's personality, their birth, childhood and adult experiences, beliefs and principles. Admittedly, the concept of identity will be viewed differently by every individual,<sup>75</sup> however few would deny that one's relationships with immediate family members are one of the most important ways in which we define ourselves, whether that be at a genetic or a social level.<sup>76</sup>

Because of the secrecy and anonymity that currently pervades this area, the evidence relating to the AID child is limited and often conflicting, therefore needs to be assessed very carefully.<sup>77</sup> However, the research that is available seems to suggest that overall, openness is in the best interests of DI children,<sup>78</sup> to ensure an honest and healthy relationship within the social family.<sup>79</sup> Much of this evidence is based on research carried out into adoption,<sup>80</sup> which many commentators would suggest is analogous to the experiences of those born by AID and therefore lessons could be learnt.<sup>81</sup> Such research has suggested that adopted children have a "psychological need"<sup>82</sup> to find out about their genetic origins and that they should be provided with this information early on in life to be able to place themselves within a social context. A recent study conducted by Howe and Feast found that finding out information relating to their genetic origins was the *primary* reason for adoptees initiating the search to find their birth parent(s), and notably, that they were *not* necessarily

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<sup>75</sup> Even article 8 of the UNCRC does not provide a clear definition of "identity".

<sup>76</sup> What must be stressed is the importance placed on both the "social" and "genetic" parent(s), but in entirely different ways – the "social" parent being responsible for primary care on a daily basis, the "genetic" parent as a component of the donor offspring's identity.

<sup>77</sup> For a summary of a number of relevant studies see E. Blyth, *Infertility and Assisted Conception: Practice Issues for Counsellors*, Birmingham: British Association of Social Workers, 1995, p82.

<sup>78</sup> See further M. Johnson, *Payment to gamete donors: position of the Human Fertilisation and Embryology Authority* HR (1997) 1839.

<sup>79</sup> Recent research conducted within the sphere of adoption suggests that it would be much better for a policy of openness to be embraced in relation to AID. See further D. Casey & A. Gibberd, *Adoption and Contact* [2001] FL 39.

<sup>80</sup> D. Howe & J. Feast, *Adoption, Search and Reunion: The long-term experience of adopted adults*, The Children's Society, 2000.

<sup>81</sup> E. Haimes, *Secrecy: What can artificial reproduction learn from adoption?* IJLF (1988) 46, p47.

<sup>82</sup> J. Triseliotis, *In Search of Origins* London: Routledge & Kegan Paul, 1973.

motivated by a desire to form new relationships with their genetic relative(s).<sup>83</sup> This demonstrates the importance of information relating to genetic origins, as opposed to necessarily having contact with a genetic relative. This point must be stressed here – that in no way does this paper consider that contact should be an automatic right of donor offspring. It is *information* that is vital and, as Haimés argues,<sup>84</sup> information that allows children to get a sense of their past, to achieve continuity in life and to have a complete biography with regard to their own identity and sense of self. Genealogical information is, “*essential to our sense of who we are, what we want to be, where we come from, and where we belong in the order of things.*”<sup>85</sup>

Critics of this proposition might argue that such identity issues are not really important to, if even comprehensible by, young children. Alternative research does indicate that the “*need*” to know the identity of their donor might not be as great for some AID children as for others.<sup>86</sup> However, this apparent disinclination of some DI children should not be used to justify withholding information from those who do wish to know. It has also been suggested that neither secrecy nor anonymity causes any harm to the DI child.<sup>87</sup> Some commentators have gone as far as to say that:

*“The average AID child who has not been told of the AID will be as certain of its origins as any other child. The fact that it is mistaken about half of its genes is [to my mind] of no importance whatsoever.”*<sup>88</sup>

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<sup>83</sup> *Op cit.*, Howe & Feast, fn 80.

<sup>84</sup> E. Haimés, “*Now I know who I really am*” *Identity Change and Redefinitions of the Self in Adoption* in T. Honess & K. Yardley (eds), *Self and Identity*, London: Routledge & Kegan Paul, 1987, p363.

<sup>85</sup> J. Owusu-Bempah & D. Howitt, *Socio-genealogical connectedness, attachment theory and childcare practice* CFSW 1997 (2) 199, p201.

<sup>86</sup> L. Saffron, *Challenging Conceptions: Planning a family by self-insemination*, London: Cassell, 1994.

<sup>87</sup> F. Shenfield & S. Steele, *What are the effects of anonymity and secrecy on the welfare of the child in gamete donation?* (1997) 12 HR 392.

<sup>88</sup> D. N. Joyce, paper in *AID and After*, Birmingham: British Association of Adoption and Fostering, 1984.

However, if a child is deliberately prevented from knowing about their genetic origins early on in life, as seems to be the case in the overwhelming majority of DI conceptions,<sup>89</sup> but later learns the truth, this could almost certainly lead to feelings of confusion, bewilderment and distrust<sup>90</sup> of those who may have withheld this information from him/her, i.e. the social parents. This point was expressly referred to almost twenty years ago in the Warnock Report.<sup>91</sup> The members of the committee of inquiry felt that, “*secrets would undermine the whole network of family relationships,*” and that it was, “*wrong to deceive children about their origins.*”<sup>92</sup> Although, in their wisdom, they still saw fit to propose anonymity for donors, at the time considered necessary to protect them from parental and financial liability, to also maintain an adequate supply of donors and to prevent possible third party intrusion in the newly created DI family.<sup>93</sup>

Triseliotis’ extensive research into adoptees’ experiences has shown it to be the case that deception can cause damage to the adoptee child/adult,<sup>94</sup> and one could certainly draw an analogy here with the position of DI children. Surely there is scope here for the argument that the earlier a child is aware of their situation the easier it is for that child to grow up with such information and learn how to handle their status.<sup>95</sup> Indeed, one of the factors influencing the change in practices within adoption, leading to greater openness and access to birth records,<sup>96</sup> was because of a concern for the

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<sup>89</sup> 70% of AID parents do not tell their children of their genetic origins, M. MacLean & S. MacLean, *Keeping Secrets in Assisted Reproduction – the tension between donor anonymity and the need of the child for information* (1996) CFLQ 243.

<sup>90</sup> With specific reference to the comments of Joanna Rose in ch 1 of this paper.

<sup>91</sup> *Op cit*, fn 53.

<sup>92</sup> *Ibid*, p21.

<sup>93</sup> See the comments of P. Braude et al, *Human Fertilisation and Embryo Bill goes to the report stage* (1990) 300 BMJ 1410.

<sup>94</sup> *Op cit*, Triseliotis, fn 82.

<sup>95</sup> See the comments of Ward LJ in *Re H(Paternity: Blood Tests)*, *supra*, fn 13, p82.

<sup>96</sup> Adoption Act 1976, s 51.

shock caused by discovering the truth later in life, when a person's sense of identity was already firmly established. This led to the implementation of the Adoption Act 1976, allowing adoptees to access their birth records and the Adoption Contact Register.<sup>97</sup> However, they are only granted such a right when they reach 18, despite the strength of Triseliotis' recommendations that they should have received this right as children/adolescents.<sup>98</sup>

Studies of adopted children have led to a wider recognition that a child's awareness – the earlier, the better – about his/her genetic background is essential to the formation of a positive self-identity. Therefore, within the context of adoption, being open about a child's status is generally considered to be in the best interests of the child. Why then is this not the case for DI children?

Disclosure of information to adoptees has often been justified on the basis of a notion of identity that recognises the importance of genetic ties, whereas the provisions of the HFEA 1990 are explicitly aimed at de-legitimising the genetic link.<sup>99</sup> Within Western culture and legal traditions, a great deal of apparent importance is often placed on the blood tie, although it has been frequently argued that this is a purely social construct.<sup>100</sup> O'Donovan states that, "*the literature on the search for origins continually emphasises the blood tie.*"<sup>101</sup> Consequently, she and other feminist commentators have criticised notions of identity based on genetic ties because of the implications this has for the concept of biological determinism, which they consider to be in opposition to the reform of the social status of women.<sup>102</sup> O'Donovan draws out the implications of placing such great importance on the

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<sup>97</sup> *Ibid*, s 51A. [T]o record and make traceable the connection between the entry in the birth register and the entry in the adoption register" – *op cit*, O'Donovan, fn 61.

<sup>98</sup> *Op cit*, Triseliotis, fn 82.

<sup>99</sup> Sections 27 and 28.

<sup>100</sup> *Op cit*, O'Donovan, fn 61, p116.

<sup>101</sup> *Ibid*, p104.

<sup>102</sup> *Ibid*, p104.



genetic link. She argues that granting DI children the right to genealogical information would firstly, reinforce a biologically determined view of gender identity; secondly, would emphasise the importance of “genetic” parenting at the expense of committed “social” parenting<sup>103</sup> and thirdly would reinforce conventional ideas about family structure as consisting of two heterosexual adults, often married, both of whom are genetically related to their children.

It must be conceded that these are harsh criticisms against disclosure of information within the AID context. However, this does not mean that the importance placed on the notion of identity should be wholly rejected, purely on the basis that data should not be provided about the donor because it serves to reinforce the importance of the genetic link. Denying children such information is surely not the way to diminish the importance of the genetic tie. Indeed, it is the concepts of secrecy and anonymity which have served to reinforce the importance of the blood tie. Why go to such lengths to protect this secret if nobody places any importance on it? Furthermore, O’Donovan’s argument that the importance placed on the blood tie is a social construction may be true, but one could certainly argue that such a notion is no more socially constructed than the apparent need of the social parents for secrecy and the parallel need of the donor for anonymity.

Sarah Wilson<sup>104</sup> has suggested a policy of disclosure, informed by the principle that the perceived importance of the blood tie is not because of the genetic link per se, but the impact this has on the continuing development of the donor offspring’s

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<sup>103</sup> See further C. Smart, *There is of course the distinction dictated by nature: Law and the Problem of Paternity* in M. Stanworth (ed), *Reproductive Technologies*, Minneapolis: University of Minnesota Press, 1987, p130.

<sup>104</sup> S. Wilson, *Identity, Genealogy and the Social Family: The Case of Donor Insemination* IJLPF 11 (1997) 270.

identity.<sup>105</sup> She suggests that the way to do this is to understand that the notion of identity could often be seen as being described from two different viewpoints – a “fixed” and a “narrative” identity.

By way of a brief explanation, descriptions about the notion of identity are sometimes made in terms that focus on a fixed, inherent content to a person’s identity. For example, when Triseliotis talks of a “psychological need”<sup>106</sup> for genealogical information, this suggests that such information will *always* be crucial to a person’s identity, even if that person has been brought up by a social family, with no means of being aware of the existence of an alternative genetic parent, let alone who that person may be or what they may be like. O’Donovan might therefore question why an unknown genetic parent would be important to an AID child who had an existing satisfactory relationship with a social parent. Wilson would counter this by suggesting that a more helpful analysis may be to look at identity in terms of a fluid, constantly evolving response to a person’s environment and their social experiences, i.e. a “narrative” identity. Identity therefore becomes an ongoing reflection of one’s life based on new information and new experiences - a “continuously revised biographical narrative.”<sup>107</sup> Furthermore, a person’s identity is greatly influenced by his/her interaction and relationships with others, i.e. “[T]he narrative of any one life is part of an interlocking set of narratives,”<sup>108</sup> and undoubtedly, some of the most important interaction experiences when one is a child are with the immediate family.

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<sup>105</sup> For example, “[O]ur sense of self is bound up with the story that we tell about ourselves. A life where the biological parents are unknown is like a novel with the first chapter missing,” J. Glover, *Ethics of the New Reproductive Technologies: The Glover Report to the European Commission*, Northern Illinois University Press, 1989, p37.

<sup>106</sup> *Op cit*, Triseliotis, fn 82.

<sup>107</sup> A. Giddens, *Modernity and Self-Identity: Self and Society in the Late Modern Age*, London: Polity Press, 1991, p5.

<sup>108</sup> E. Haimes & N. Timms, *Adoptions, Identity and Social Policy: The search for distant relatives*, Aldershot: Gower, 1985, p3.

Young children tend to experience their sense of self in very factual, concrete terms; they class the people who take care of them as their family, i.e. their social parents. However, as children mature, they begin to define themselves in relation not only to their primary carers but also as part of the larger society and taking account of a longer sense of time and history.<sup>109</sup> Therefore, part of the relationship with the people with whom one grows up with often involves asking them questions about one's own or that other person's genealogical heritage.<sup>110</sup> Answering the question, "who am I?" thus entails some reference to background or family history<sup>111</sup> and this could account for the importance often ascribed to the link with one's genetic parent(s).

Wilson's sociological explication of the notion of identity can certainly encompass the rights theories proposed in chapter 2, as can Bennett Woodhouse's theory which is detailed below. Both commentators suggest that "identity" can represent something entirely different to a child during different stages of their childhood and that this should be taken into account when deciding at what age different types of "identity rights" come into play. Bennett Woodhouse further elaborates on Wilson's concept of a "narrative" identity by arguing that a child's identity rights theory has two components and that the law should attempt to recognise and respect both of these.<sup>112</sup>

Firstly, there is a child's *personal identity*, defined as their sense of self in relation to those whom they call family, specifically their daily interactions with their primary caregivers – their social family. At this stage, the social parents are all-important and Goldstein, Freud and Solnit would refer to these people as the child's "*psychological*

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<sup>109</sup> See further the comments of B. Bennett Woodhouse, *Protecting children's rights of identity across frontiers of culture, political community and time* in N. Lowe & G. Douglas, *Families Across Frontiers*, Netherlands: Kluwer Academic Publishers, 1996, p259.

<sup>110</sup> See judicial dicta in the recent case of *Gunn-Russo v Nugent Care Society and Secretary of State for Health* [2001] UKHRR 1320.

<sup>111</sup> *Op cit*, Haines & Timms, fn 108.

<sup>112</sup> *Op cit*, Bennett Woodhouse, fn 109.

parents.”<sup>113</sup> From a practical point of view, children need a safe and secure family environment in order to survive their early years and to begin the process of forming any further explicit notion of identity. The *right of AID children to be informed of their status by their social parents*, as explored in chapter 2, could form a component of this *personal identity*, in terms of the fact that, at this age children need to develop relationships based on honesty and to know that they are not being lied to or deceived.<sup>114</sup>

However, Bennett Woodhouse argues that, as children grow into adolescents and then adults, they begin to develop a second component to their identity, one that begins to have even greater significance as they continue to mature. Bennett Woodhouse terms this as the child’s *identity of origin*, encapsulated within their interest in developing their own autonomy and exploring their identity as a member of the family into which they have been born.<sup>115</sup> At this stage of their development, children also begin to play a pivotal role in constructing their own identities, taking part in a constant dialogue with the world around them.<sup>116</sup> The *right to information about their genetic background* could therefore be crucial at this stage in their lives, at a time when they are considered mature enough to understand the implications of such information, but when they are still young enough to make use of this information to fully develop their own identity.

In the context of a “*narrative*” identity therefore, the significance of the genetic link lies in the alleviation of uncertainty about the past, created by a lack of

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<sup>113</sup> J. Goldstein, A. Freud & A. Solnit, *Beyond the Best Interests of the Child*, London: Burnett Books, 1973.

<sup>114</sup> “[H]onesty is the best policy,” per Ward LJ in *Re H(Paternity:Blood Test)*, *supra*, fn 13.

<sup>115</sup> This “family” could be deemed to include extended family members and even genetic parent(s).

<sup>116</sup> See J. Masson & C. Harrison, *Identity: Mapping the Frontiers* in *op cit*, Lowe & Douglas, fn 109, p277.

information available to the child.<sup>117</sup> This lack of certainty may be very difficult to accept on the part of the child and the need to access information concerning their genetic parent(s) could reflect a desire to end that uncertainty, although this desire does not, by any means, suggest that the genetic link supersedes or de-legitimizes all other relationships that the child has, e.g. with their social parents.<sup>118</sup> For example, Triseliotis found that 37% of adoptees studied, simply wanted to obtain *information* about their sociological and biological origins.<sup>119</sup>

Research carried out by Haimes and Timms within adoption circles led them to conclude that some of the adoptees, “*want[ed] a narrative in order to place themselves in a continuum of their past, present and future, which will account for and explain the possibilities of their lives which underwent a shift, a disjuncture – even a displacement – when they were placed for adoption.*”<sup>120</sup> Haimes and Timms describe this sense of disjuncture in terms of a social difference between them and many other people, in that they do not have any information concerning their genetic background, whereas the majority of other people do.<sup>121</sup>

*Wilson describes people in such a situation as having a desire to reclaim a “memory” in order to help understand one self.*<sup>122</sup> It is certainly true that many people describe themselves with reference to past events; AID children are denied this opportunity and their only recourse is to rely on the accounts of others in constructing

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<sup>117</sup> In the case of adoptees this sense of displacement can generally only be alleviated by access to a birth certificate, i.e. a “*paper identity*” providing an undisputed, accurate record of the past – *op cit*, Haimes & Timms, fn 108, p70.

<sup>118</sup> Studies have shown that adoptees attempting to trace their genetic parent(s) do not themselves perceive their desire to obtain information as undermining their loyalty to their adoptive parents and often try to protect their social parents by not telling them about their attempts to trace their genetic parents. This seems to indicate that adoptees generally perceive their social family as their “real” family. Some adoptees have also displayed concerns about not disrupting the families of their genetic parents – *supra*, Triseliotis, fn 82.

<sup>119</sup> *Op cit*, Triseliotis, fn 82, p15.

<sup>120</sup> *Op cit*, Haimes & Timms, fn 108, p81.

<sup>121</sup> Giddens refers to this being almost a sense of “*shame*” because they feel their inadequacy in these terms. See further *op cit*, Giddens, fn 107, p65.

<sup>122</sup> Memory here does not refer explicitly to what a person actually remembers and recalls about their past, but it is used in a broader, more generalised way to explicate a sense of history and biography.

their own “*narrative*.”<sup>123</sup> Wilson’s analysis of the concept of a “*narrative*” identity recognises the importance of this type of information; the justification therefore for allowing the disclosure of information relating to genetic background is that the denial of access to this information represents the loss of the ability to tap into the memory of others and interpret their genealogical heritage accordingly.

Evidence of the recognition of the importance of information at this level is best demonstrated by the comments made by the European Court of Human Rights and the Commission in relation to the case of *Gaskin*, the root authority regarding disclosure of personal information. In *Gaskin v United Kingdom*<sup>124</sup> the applicant was taken into care when he was six months old, following his mother’s death. Graham Gaskin petitioned to the European Court to seek access to local authority files which related to the period he had spent in care, alleging that the refusal of access to his file was contrary to his right for respect for his private and family life under Article 8(1) and contrary to his right to receive information protected by Article 10(1) of the European Convention on Human Rights.

One of the applicant’s aims was to obtain access to his files to learn more about his past and to obtain more accurate information about events that he only partially remembered. In the opinion of the Court, because Gaskin had been taken into care at such a young age, the files were really the, “*only coherent record of his early childhood and formative years*.”<sup>125</sup> Therefore this information was important because, “*it provided a substitute for the memories and experiences of the parents of the child who is not in care*.”<sup>126</sup>

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<sup>123</sup> According to Haimes & Timms, many adoptees were dissatisfied with this, mainly because they often doubted the accuracy of the information – *op cit*, Haimes & Timms, fn 108.

<sup>124</sup> *Gaskin v United Kingdom* (Access to Personal Files) (1989) Eur Court HR Ser A No. 10454183, 32 YB Eur Conv HR 176, 12 EHRR 36.

<sup>125</sup> *Ibid*, p46.

<sup>126</sup> *Op cit*, fn 124, p45.

Also, according to the European Commission:

*“an individual’s entitlement to such information relating to his or her basic identity and early life is not only of importance because of its formative implications for his or her personality. It is also by virtue of the individual’s age and condition at the relevant time, information which relates to a period when the individual was particularly vulnerable as a young child and in respect of which personal memories cannot prove a reliable or adequate source of information.”*<sup>127</sup>

However, the Commission drew a distinction between Gaskin applying as a child and applying as an adult, for access to his file, implying that he would not have been ascribed such rights if he were still a child. Unfortunately for our purposes, the Court did not believe it was necessary to consider this point, as Gaskin had applied after the end of his childhood. The Court held that Gaskin *did have the right* to obtain information relating to his time in care, effectively creating a right not to be deprived of information regarding one’s personal history, that could be used to make sense of one’s present life. Importantly, their comments relating to the importance of information can be interpreted as reflecting the notion of a “*narrative*” identity with regard to how Gaskin had lost the opportunity of acquiring any genealogical information relating to his past. However, the narrow scope of the *Gaskin* judgement clarifies that there is *no general right* of access to information about family ties or background, regardless of the individual claimant’s circumstances; nor is there a general right under the Convention to know who one’s parents are.

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<sup>127</sup> *Gaskin v United Kingdom* No.10454/85 Comm Rep, 13.11.87, Ser A No. 160, 11 EHRR 402, 89, p90.

Therefore, it is proposed that the notion of identity should be re-evaluated as being something that encompasses *all* spheres of a person's life, one that recognises that all of an individual's interactions, including links with social and genetic parents, have a significant part to play in the development of that person's sense of self. As such, there is no justification for dismissing the notion of an AID identity right merely because it is perceived as a social construction that reinforces notions of biological determinism and undermines the creation of new types of family structure. A concept of "*narrative*" identity is compatible with different notions of parenthood and therefore would allow equal emphasis to be placed on the roles of the genetic parent and the social parent, recognising that each has a very significant part to play in the wellbeing of the donor offspring. Genealogical background *does* form a vital part of who a child is and recognition of this *does not* displace the importance of the social family. A number of different people contribute to the creation and upbringing of a child and all should be viewed as equally important, therefore the AID child should have the right to information about *all* of the people, who have contributed to their creation.<sup>128</sup>

### 3.2 Legal identity

In England and Wales, the birth certificate provides a statement of what is officially recognised as the core of identity and evidence of such for both the individual and for the wider society. No other formal documentation pertaining to

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<sup>128</sup> See *supra*, *Gunn-Russo v Nugent Care Society*, fn 110, for a discussion of confidentiality and the disclosure of information relating to third parties.



identity is currently available in the United Kingdom.<sup>129</sup> The national system of birth registration was established by the Births and Deaths Registration Act 1836, replacing the local parish registers, primarily in order to allow for more accurate proof of succession and knowledge of parentage – the importance of a traceable lineage line having long been perceived as vital in English law.<sup>130</sup> The birth certificate includes the person's name, gender, date and place of birth, the names, occupations and place of birth of each of the parents. Therefore, for people who are brought up without any contact with or knowledge of their origins, the birth certificate may be the only and most important source of their *original identity*.<sup>131</sup>

However, where children are born by means of AID, birth certificates are issued in the names of the legal parents, i.e. the social not the genetic parents,<sup>132</sup> thereby deliberately falsifying the birth register – the only instance where the genetic parent(s) are purposefully not recorded accurately. Even where children are adopted, new birth certificates are issued but the original is always maintained;<sup>133</sup> therefore, donor offspring would appear to be in the anomalous position of being the only group of people whose birth records are genetically inaccurate from the start.<sup>134</sup> It has been argued that the birth register can never actually be considered an accurate record of genetic parentage, because of false information provided by married parents and entries that fail to disclose the father's name for a variety of reasons; for example the

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<sup>129</sup> Although there have been recent moves in the UK to introduce identity cards – see *Identity Cards: The Next Steps*, Cm 6020, London: HMSO, 2003.

<sup>130</sup> *Registration: A Modern Service*, Cm 531 (1988) para 1.11-12.

<sup>131</sup> The historical interest importance of the original birth certificate as a form of one's true identification has always been emphasised in other areas of law – for example, where transsexuals have applied to amend their birth certificate, there has been a consistent refusal on the part of the state to do so, in order to retain the integrity of the birth certificate as a legal document; *Corbett v Corbett (or se Ashley)* [1971] P 83; *Rees v UK* [1987] 2 FLR 111. This insistence on the truth being recorded and maintained in this area of law stands in stark contrast to the way in which birth certificates of AID children are produced, where deception is wholly condoned by the state.

<sup>132</sup> HFEA, ss 27 and 28.

<sup>133</sup> Thereby demonstrating the importance of maintaining the integrity of the original birth certificate, even in areas of law where that birth certificate may legally be altered.

<sup>134</sup> Where children are adopted, new birth certificates are issued, but the originals are always maintained.

mother not knowing whom the father is; not wanting to acknowledge him as the father for fear of adverse consequences or the child may be the product of a rape.<sup>135</sup> However, arguably this is merely a failure of the state to investigate the accuracy of each genetic record, rather than a deliberate attempt to deceive. Within AID, it is the state itself, which, not only allows, but also actually proscribes, the current birth registration system, thus colluding in the falsification of records and allowing for the deception of this group of people. Their interest is in the maintenance of social stability as regards apparent legal lineage and the need for data for government agencies,<sup>136</sup> rather than information for people exploring their family history.<sup>137</sup>

Admittedly, the information provided at birth registration provides a limited basis for the development of an individual's psychological identity, but for most people the recognition and preservation of the family relations contained therein is a huge component of their identity. AID children are denied even this basic information. In this respect, the law as a regulatory institution is heavily implicated in altering an individual's real or potential identity and in impeding and/or assisting the reclaiming of an identity. As such, the government must acknowledge its impact on the development of a person's identity in this way and take responsibility for the implications that deliberate deception as to genetic parentage has on the AID child. Deliberate falsification of the birth certificate could contravene both domestic and international human rights laws, given the importance placed on the accuracy of the birth record within both of these spheres. One suggestion to counter this alleged breach would be to annotate the birth certificates of all donor offspring so that, upon

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<sup>135</sup> M. Freeman, *The unscrambling of egg donation* in S. MacLean (ed), *Law Reform and Human Reproduction*, Aldershot:Dartmouth, 1992, p280. Statistics range from 5% to 50% of conceptions as being recorded inaccurately with regard to the father – see the study of the West Isleworth Area cited in B. Hoggett, D. Pearl, E. Cooke & P. Bates, *The Family, Law and Society*, London: Butterworths, 2002.

<sup>136</sup> *Op cit*, fn 130, para 5.2.

<sup>137</sup> Other statistical data is also recorded on the birth certificate – Population (Statistics) Acts 1938, 1960.

examination, it would be clear to them that they had been born “by donation”. This proposal will be discussed further later on in this paper.

#### **4 The A.I.D. Child’s Identity Rights?**

Having now acknowledged that the concept of identity is both socially and legally fundamental to all children, we must now examine how the right to an identity for AID children could be formulated under existing domestic law. We have already made reference to the case of *Rose* in chapter 1<sup>138</sup> – this case was heard in the High Court in 2002 and was undertaken as a matter of judicial review of the Secretary of State for the Department of Health and the HFEA’s refusals to allow access to significant information for donor offspring. The case was conducted by Liberty on behalf of two specific claimants and on behalf of all DI children who would have an interest in access to this type of information.

The first claimant Joanna Rose was born as a result of AID in 1972, at a time when secrecy prevailed and treatment services were not licensed under the HFEA 1990. The second claimant EM (represented by her mother as litigation friend) was born as a result of AID in 1996 post-HFEA 1990; information about her donor was available but very limited. The proceedings were brought in an attempt to access non-identifying information in relation to the donors (possibly also identifying information); to request that Regulations be made, concerning the provision of information to AID children and the establishment of a voluntary contact register for donor offspring and donors.<sup>139</sup>

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<sup>138</sup> *R (Rose & Another) v Secretary of State for Health & Human Fertilisation and Embryology Authority* [2002] EWHC (Admin).

<sup>139</sup> Para 15.

The claimants sought to rely on Articles 8 and 14, by suggesting that a State Party has a positive duty to ensure that certain vital non-identifying information about donors is collected and made available to AID children. They alleged that the State's consistent failure thus far to take these steps represented a breach of Articles 8 and 14 and that there was no justification for this failure. Following an application from the Department of Health, the High Court only considered whether any of the Articles under the ECHR were actually engaged. Mr Justice Scott Baker therefore devoted the main body of the judgement to deciding whether or not Article 8 was engaged, making specific reference to the root authority – the *Gaskin* case<sup>140</sup> – and found that Article 8 was indeed engaged in this instance:

*“It is to my mind entirely understandable that AID children should wish to know about their origins and in particular to learn what they can about their biological father or, in the case of egg donation, their biological mother. The extent to which this matters will vary from individual to individual. . . . A human being is a human being whatever the circumstances of his conception and an AID child is entitled to establish a picture of his identity as much as anyone else.”*<sup>141</sup>

The case has now proceeded to its second stage, to be decided in the near future, following the Department of Health's application that any decision should only be made in light of the results of the government's Consultation exercise on this issue. The second stage hearing will consider whether there has been a breach of Article 8 by the DOH and the HFE Authority; whether or not AID adults and children have

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<sup>140</sup> *Supra*, fn 124.

<sup>141</sup> Para 47.

been discriminated against and whether the DOH and HFE Authority are under a duty to do more to ensure the protection of the rights of these individuals.

Perhaps one of the most persuasive arguments for the judges in the *Rose* case will be that the positive rights of AID children should be protected by specific reference to their *identity rights* under international law<sup>142</sup> – article 7 of the UNCRC states:-

(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.*"

Article 8 states:-

(1) "*State Parties undertake to respect the right of the child to preserve his or her identity including nationality, name and family relations as recognised by law without unlawful interference.*"<sup>143</sup>

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

Under international law a child is entitled to protection by the State against any unlawful interference with their identity and/or any illegal deprivation of it. When read in conjunction with one another, Articles 7 and 8 of the UNCRC certainly appear to point towards a strong emphasis upon the importance attributed to the preservation

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<sup>142</sup> The UNCRC 1989 has already influenced other domestic family law decisions – *supra*, fn 13.

<sup>143</sup> Under Article 8 a child is identified by reference to their name, nationality and family relations, although the Convention does not contain an explicit definition of "identity".

of a child's identity and one could argue that the preservation of family relations is definitely one component of a person's identity. The issue here is whether or not the United Kingdom's current refusal to allow AID children the right to information about their genetic origins could constitute an unlawful interference or an illegal deprivation of their identity.

The right of children to preserve their identity was first expressly enshrined in the UNCRC as a result of an Argentinian initiative, which had nothing to do with the protection of AID children or children in analogous situations. Briefly, the background to Article 8 comprises of this: during the drafting of the Convention, Argentina's political regime changed from rule by a military Junta to being governed by democratically elected representatives. Article 8(1) was proposed by the post-junta Argentinian delegation specifically as an attempt to prevent a repetition of the events that had occurred during Argentina's "dirty war" between 1975 and 1983. Evidence had emerged that during this time a number of children had been abducted and many others born in secret detention centres and military hospitals, then given to childless military and police couples, who had subsequently raised them as their own.<sup>144</sup> Argentina wished to create a mechanism whereby this situation could be prevented from arising again and also, to place a duty upon states to do their best to re-establish the identities of children who had been forced into similar situations, for example, child refugees and children involved in internal civil wars.

Therefore, Article 8(1) UNCRC places a duty on State Parties to undertake to respect the right of the child to "*preserve his or her identity.*" The specified list of elements, fundamental to the preservation of identity are non-exhaustive and the Convention does not actually define identity. The second paragraph of Article 8

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<sup>144</sup> Amnesty International – "*Missing Children*" 13/7/87.

provides that where children are “*illegally deprived*” of some or all elements of their identity, State Parties will be obliged to provide appropriate assistance and protection with a view to re-establishing their identities as quickly as possible.

Arguably, the Convention’s notion of identity could be said to include *the AID child’s right to an identity* and therefore support their *right to be told of their status and the right to information*. In fact, the United Nations Committee on the Rights of the Child in its Concluding Observations on State Party Reports has recently criticised the UK’s policies and legislation with regard to this very issue. It stated that, “*the Commission is concerned that children born out of wedlock, adopted children or children born in the context of medically assisted fertilization do not have the right to know the identity of their biological parents.*”<sup>145</sup> There could not be a clearer statement that current UK law is not in line with international human rights’ principles.

Article 7 UNCRC allows for the right of children, “*as far as possible to know and be cared for*” by their parents. Arguably the two concepts of knowing and caring are jointly applicable, but they can also be analysed separately. Therefore, the process of allowing an AID child access to information about their genetic background would clearly relate to “*knowing*” one’s parents. In relation to this, “*as far as possible*” should arguably only apply to the practicalities of the situation not to the legalities, i.e. the practical considerations of gathering, recording and retaining the information.

Does Article 7 refer to the genetic or social parents? Some commentators would argue that it could be taken to mean both. The Convention itself does not provide a

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<sup>145</sup> *Concluding Observations of the Committee on the Rights of the Child: United Kingdom*. 09/08/2002. U.N Doc. CRC/C/15/Add.188, para 31. See also the Committee’s observations on the AID genetic information laws of other, supposedly more liberal, European jurisdictions – *Concluding Observations of the Committee on the Rights of the Child: Norway*. 25/04/94. U.N. Doc. CRC/C/15/Add.23, para 10 and *Concluding Observations of the Committee on the Rights of the Child: Denmark*. 15/02/1995. U.N. Doc. CRC/C/15/Add.23, para 11.

definition of parents and the meaning is therefore open to a certain amount of legal and social interpretation. What is clear are the reasons for including Articles 7 and 8 in the Convention at that time.

However, academic analysis from Bainham<sup>146</sup> has picked up on some of the more oblique points regarding Articles 7, which could be used as further support for the protection of the legal status of donor offspring. His arguments suggest that Article 7 could be used as a basis for asserting a fundamental right to information about one's genetic heritage - if we take the word parents to mean genetic parents - and thereby give a strong indication of the importance international law places on the genetic relationship. Article 7 suggests that the international legal community were concerned with a child's status from the moment immediately after their birth, thereby suggesting that there was an emphasis on the child's relationship with the *birth parents*. Secondly, the United Nations Convention on the Rights of the Child is a legal document ratified in 1989, at a time when there was little other domestic legislation in any individual countries, regulating what are now perceived to be the changes to the traditional notion of parents, brought about by the new reproductive technologies. This seems to demonstrate that social and legal attitudes at that time were more concerned with *genetic parenthood*.

Clearly, there are strong legal arguments to support the view that the identity rights of AID children should receive a high degree of protection. However, the Committee on the Rights of the Child is unlikely to reach a judicial conclusion in the near future, as there is currently no mechanism for individual petitions invoking the UNCRC, therefore in order to give practical effect to the arguments concerning the AID child's right to an identity, recourse must be had to domestic legal regulation.

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<sup>146</sup> A. Bainham, *Parentage, Parenthood and Parental Responsibility: Subtle, Elusive yet Important Distinctions* in A. Bainham, S. Day Sclater & M. Richards, *What is a Parent? A Socio-Legal Analysis*, Oxford: Hart Publishing, 1999.



## 5 The Right to be Told

The first step to ensuring an effective right for donor offspring to be told about their status is to make this a *compulsory* part of the DI treatment process – for example, the social parents would not be granted fertility treatment unless they accepted the need to be completely open with their AID child. This policy would reflect the growing trends in adoption practice,<sup>147</sup> although even the law on adoption still does not enforce a positive duty on adopters to inform the child of their status.<sup>148</sup>

A second approach would be for amendments to be made to the current birth registration system, on the basis that it breaches the DI child's right to be told of their status under the ECHR. Arguably, an individual could found a claim under the Human Rights Act 1998, alleging that the current system of birth registration breaches their right to respect for their private and family life, under Article 8 ECHR, given that, "*control over knowledge about oneself*,"<sup>149</sup> is inherent to their right to respect for their private life. Article 8(1) contains a negative obligation on State Parties to ensure that, "[E]veryone has the right to respect for his private and family life, his home and his correspondence," and therefore protects, "*the individual against arbitrary interference by the public authorities in [his] private or family life*."<sup>150</sup>

Difficulties arise when one tries to assess whether it is *private life* or *family life* that is hereby engaged, as the birth registration system relates to both of these aspects

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<sup>147</sup> Many adoption agencies will not select prospective adopters unless they accept the notion of open adoption – see further M. Murch, N. Lowe & M. Burkowski, *Supporting Adoption – Reframing the Approach*, Birmingham: British Association of Adoption & Fostering, 1999, pp80-81.

<sup>148</sup> Although, in 1992 an inter-departmental working group made several suggestions, "*to preclude the likelihood of any adopted child being deprived of this information*." This included placing a duty on the adoption agencies to make adopters aware of the importance of telling their child that they had been adopted (when they were sufficiently mature to understand the nature of this) and also to place a duty on the agencies to make reasonable efforts to contact the adoptive parents (when the child was approaching the age of 16) to remind them that the child needs to be told the truth – *Review of Adoption Law, Report to the Ministers of an Interdepartmental Working Group, A Consultation Document*, Department of Health and Welsh Office (1992) p 52 – a proposition that is supported by this paper.

<sup>149</sup> A. Freud, *Privacy* (1968) 77 Yale LJ 475, p483.

<sup>150</sup> *Belgian Linguistics Case* 1 EHRR 252, p282.

of the individual's life and European case law has shown that it is often difficult and unnecessary to compartmentalise the two rights.<sup>151</sup> *Prima facie*, it might be better to found a claim concerning private life, because the judicial dicta in *Rose*<sup>152</sup> has already shown that private life and identity, not family life, are the issues at stake in the AID context.<sup>153</sup>

The concept of private life is extremely difficult to define precisely, but it has traditionally been recognised as relating to notions of physical integrity and to privacy relating to one's physical environment. There have been suggestions that identity is a part of one's private life, including aspects of one's physical and social identity, psychological integrity<sup>154</sup> and the establishment of the details of one's identity as a human being.<sup>155</sup> Respect for private life should also comprise, to a certain degree, the right to establish relationships with other human beings.<sup>156</sup> In *Gaskin* there was explicit recognition that individuals have, ". . . a vital interest, protected by the Convention, in receiving the information necessary to know and understand their childhood and early development. . . ."<sup>157</sup> Given that the alteration of the original certificate does not occur in any other instance, including adoptees, then the current birth registration system could be viewed as discriminatory<sup>158</sup> and disproportionate to the aim pursued.<sup>159</sup>

At an international legal level a great deal of importance is placed on the registration of a child *immediately* after birth, regardless of their status, and the

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<sup>151</sup> *X, Y & Z v UK* (1997) 24 EHRR 143, para 41.

<sup>152</sup> *Supra*, fn 138.

<sup>153</sup> *Ibid*, para 43.

<sup>154</sup> *Mikulic v Croatia* (2002) App No 53176/99 2002, paras 52-53.

<sup>155</sup> *Johnston v Ireland* (1987) 9 EHRR 303, para 55.

<sup>156</sup> See *mutatis mutandis Niemetz v Germany* 16 EHRR 97 (judgement of 16 December 1992, Series A no. 251-B, p33, para 29).

<sup>157</sup> *Gaskin v United Kingdom* (1989) 12 EHRR 36, para 49. See also *Martin v United Kingdom* App No. 27533/95. Article 8 has also been relied upon in domestic decisions relating to the disclosure of personal information – see further *Re X: Disclosure of Information* [2001] 2 FLR 440, p451.

<sup>158</sup> Article 14, ECHR.

<sup>159</sup> See further *Price v UK* App No. 12402/86 D & R 55, p224 for a discussion of proportionality.

preservation of the accuracy of that birth record.<sup>160</sup> Furthermore, the ECHR does not expressly place a duty on a State Party to register a child immediately after birth, but failure to register could amount to an unlawful interference under Article 8. In *Kalderas' Gypsies v Federal Republic of Germany and Netherlands*,<sup>161</sup> the European Commission on Human Rights considered that a failure to issue a birth certificate could amount to an interference and in *Marckx v Belgium*,<sup>162</sup> the European Court ruled that Article 8 of the Convention included the registration a child's birth without additional procedural requirements, regardless of the marital or non-marital status of the child.

A breach could only be demonstrated if the interference could not be justified under Article 8(2) ECHR. The most pertinent justifications would be, "*for the protection of health or morals, or for the protection of rights and freedoms of others.*" For example, the state could argue that by not currently amending the birth certificate, it is in the best interests of the AID child because it prevents the child from accidentally finding out about the nature of their conception. Given the state's wide margin of appreciation<sup>163</sup> with regard to Article 8, it is difficult to say conclusively whether or not the current system would constitute a breach. The decision in *X, Y and Z v UK*<sup>164</sup> demonstrated that there is still a lack of consensus in legal opinion concerning AID issues amongst ECHR State Parties and therefore accorded a wide margin of appreciation. Certainly, it is assumed that, given the UK government's restrictive stance on this issue, they would want to retain a certain amount of discretion over this sphere of legal regulation, whatever the future may hold.

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<sup>160</sup> Article 7(1), UNCRC.

<sup>161</sup> Application No. 7823 (1977) 11 DR 221.

<sup>162</sup> [1979] 2 EHRR 330.

<sup>163</sup> See *Handyside v UK* 1 EHRR 737.

<sup>164</sup> *Supra*, fn 151.

For example, despite the fact that, in the UK, an adoptee has the right to apply for their birth certificate when they reach the age of 18, the state still retains a discretion as to whether or not the information should be made available. In *R v Registrar General ex parte Smith*<sup>165</sup> the Court of Appeal held that the Registrar General may, in certain circumstances, refuse to supply information to an adopted child applying for their birth certificate as an adult. Indeed, they went so far as to say that it was, “*beyond belief that Parliament contemplated that an adopted child’s right to obtain a birth certificate should be absolute.*”<sup>166</sup>

However, given the arguments evinced above, it seems almost impossible to justify why the present system is still in operation. Annotation of the AID child’s birth certificate to include the words “by donation”, etc. would seem the ideal mechanism for ensuring that donor offspring have the right to be told about their status: firstly because it would have the effect of encouraging the social parents to be open with their child from an early age; secondly, it would encourage openness and acceptance within the whole AID process and thirdly, it would guarantee that the donor offspring would be in a position to take advantage of their right to receive information.

## 6 The Right to Receive Information

Prima facie, the denial of access to AID records could have an impact on a child’s right to respect for their private and family life, under Article 8 ECHR; as demonstrated, Article 8 contains a negative obligation on State Parties not to interfere with an individual’s private and family life. However, the European Court has also

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<sup>165</sup> (1990) 2 QB 253 – concerning an applicant who had been detained in a top security hospital for two murders and who was considered a “*potential menace*” to his biological mother in the future, should he be allowed access to his records.

<sup>166</sup> *Ibid*, p260.

implied that Article 8 may impose positive obligations upon the state to take measures to promote that respect,<sup>167</sup> “to act in a manner calculated to allow those ties to develop normally.”<sup>168</sup> This could imply that the UK government, through the HFE Authority, has a duty to collect, retain and disseminate genetic background information to donor offspring. However, even if one could not point to a positive obligation, there may be a negative obligation on the state to refrain from interfering with the AID child’s right to respect for their family life under Article 8.

Given the nature of the information, it could be said that the right to receive information related to the AID child’s right to respect for their private life, if we accept the above discussion relating to the right to be told. It could also be alleged that this right relates to the child’s family life. The concept of family life is not, however, easy to define and thus far, the European Court and the Commission have not provided a clear statement of what is meant by the family.<sup>169</sup> However, it could be argued that if the definition of family life varies so greatly<sup>170</sup> then the concept of respect for family life should also vary and take on a more dynamic and creative definition.<sup>171</sup> Despite this, an analysis of the relevant treaty provisions and jurisprudence seems to demonstrate that, according to the Council of Europe, the family is rooted in, but not limited by, biological relationships; for example the family could include specific social relationships such as existing adoptive relationships<sup>172</sup> and also foster children.<sup>173</sup> What has also emerged is that when a man donates his

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<sup>167</sup> *Op cit*, fn 162.

<sup>168</sup> *Ibid*, p348, para 45.

<sup>169</sup> G. Douglas, *The Family and the State under the European Convention on Human Rights* IJLF 2 (1988) 101.

<sup>170</sup> Furthermore, “the Convention must be interpreted in the light of present-day conditions,” – *op cit*, fn 162, p346, para 41.

<sup>171</sup> T. Opsahl, *The Convention and the Right to Respect for Family Life* in A.H. Robertson, *Privacy and Human Rights*, Manchester: Manchester University Publishing, 1973, p225.

<sup>172</sup> *Application No. 9993/82, X v France* 31 D & R 1983, 241.

<sup>173</sup> Although, see the submissions of the government and the dissenting opinion of Schermers in *Erikson v Sweden* Series A No. 156 1989 at p56.

sperm specifically to enable a woman to become pregnant through AID, this biological link does not of itself give the donor or the donor offspring a right to respect for their family life with each other. *M v Netherlands*<sup>174</sup> demonstrated that donorship seems to be an unsound basis upon which to formulate the sufficiently close link that is necessary in order to protect family life under the ECHR regime.<sup>175</sup> Further, such an approach seems to be consistent with previous European Commission decisions, that “*close personal ties*”<sup>176</sup> are necessary to bring oneself within the application of Article 8, in addition to parenthood *per se*.<sup>177</sup> Therefore, it would seem that under the European Convention, the genetic link between donor and offspring would be insufficient to give rise to an AID child’s right to protection of their family life.

However, commentators including Geraldine Van Bueren<sup>178</sup> would argue that, at least in relation to adoption, if we restrict the rights of children to information about their genetic background, then we may not know of the existence of living family members including half-siblings. Arguably, to deny access to such information could breach the right to respect for family life in relation to these other family members. Van Bueren<sup>179</sup> has also suggested, again in relation to adoption, but something that could equally be applied by analogy to AID, that, if procedural requirements obstructing registration can amount to a breach of Article 8,<sup>180</sup> it may be arguable, adopting a teleological approach, that procedural obstacles at a later stage, i.e. when the child wishes to access information, are also a violation of their right to respect for

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<sup>174</sup> (1993) 74 DR 120.

<sup>175</sup> *G v Netherlands* Application No. 16944/90.

<sup>176</sup> *R v United Kingdom* App No. 10496/83 D & R 38, 189 at p195.

<sup>177</sup> *Application No. 11468/85* at n12.

<sup>178</sup> G. Van Bueren, *Children’s Access to Adoption Records – State Discretion or an Enforceable International Right?* (1995) 58 MLR 37.

<sup>179</sup> *Op cit*, fn 178.

<sup>180</sup> *Supra*, fn 161, 162.

their private and family life. Despite this there is little evidence to support the suggestion that family life would feature in the argument that the AID child should have the right information on their genetic background, although following *Gaskin* and *Rose*, private life would almost certainly be engaged. Whether or not a breach can be proven on this basis has yet to be demonstrated in the *Rose* case. This again will require an analysis of the provisions under Article 8(2) as to whether the breach can be justified. The provision most likely to be engaged will be, “*for the protection of the rights and freedoms of others*” – in particular the rights of the social parents and the donor, something that we shall now go on to examine in the following chapters.

## 4. The Social Parents

Almost all children can say with certainty that they know who their *mother* is and the majority of children know who their *father* is, but this fundamental human right is denied to AID children under current UK legal regulation. This chapter shall explore if and how the potential rights of the AID child described in chapter 3 might impact upon the rights of the social parents, the possible conflict between these parties and the ways in which future legal regulation could be specifically aimed at resolving any potential conflict to the benefit of all the parties involved.

### **1 The Parents of the A.I.D. Child**

Many people would instinctively point to a child's "natural" mother and father as his/her parents.<sup>1</sup> However, paradoxically, it is this terminology and perception of a "natural" family form that can be partly blamed for many of the current problems within the AID sphere, given that several of the provisions within the HFEA 1990<sup>2</sup> are aimed at perpetuating the myth that there is such a thing as a "normal" family.<sup>3</sup> However, given the nature of AID, donor offspring cannot necessarily point to a "natural" mother and father. Admittedly, there may be some instances other than

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<sup>1</sup> Although, according to Eekelaar, the concept of parenthood can be broken down into three constituents – *biological parenthood*, *legal parenthood* and the concept of *parental responsibility* – all three of which may be vested in the same person or in separate individuals – J. Eekelaar, *Parenthood, Social Engineering and Rights* in D. Morgan & G. Douglas (eds), *Constituting Families: A Study in Governance*, Franz Steiner Verlag: Stuttgart, 1994, pp85-89.

<sup>2</sup> In particular sections 13(5), 27 and 28.

<sup>3</sup> The family in modern society can actually take many different forms. See B. Dickens, *Reproductive Technology and the "New" Family* in E. Sutherland & A. McCall Smith (eds), *Family Rights: Family Law and Medical Advance*, Edinburgh: Edinburgh University Press, 1990, p28.



those involving AID where the identity of a child's genetic parent(s) is in doubt,<sup>4</sup> although this does not on its own justify the retention of the concepts of *secrecy* and *anonymity* within the AID sphere.

Artificial reproduction techniques (ART's) were originally developed in order to treat infertile couples,<sup>5</sup> thereby parent-orientated rather than child-centric in focus. According to the HFE Authority, approximately 16% of all married, heterosexual couples may be infertile<sup>6</sup> and AID is one of the treatments used to remedy infertility. Artificial insemination using a woman's husband's or partner's sperm (AIH/AIP),<sup>7</sup> as opposed to artificial insemination by donation, does not entail any significant consequences for the rights of the donor offspring, as there is no separation of *genetic* and *social* parenthood.

Technological advances now mean that it is possible for the AID child have up to six different "parents" – a genetic mother (egg donation) or mothers (as eggs from two women can now be used to create one egg);<sup>8</sup> a gestational mother (in surrogacy arrangements) and a social mother, a genetic father and a social father.<sup>9</sup> Overall, sections 27 and 28 of the HFEA 1990 have successfully clarified whom we should regard, out of all these possibilities, as the *legal* parents of DI children.<sup>10</sup> However,

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<sup>4</sup> A woman may not know who the father of her child is or may attempt to deceive her husband/male partner into believing that he is the biological father.

<sup>5</sup> ART's are primarily aimed at the alleviation of infertility not childlessness.

<sup>6</sup> [www.hfea.co.uk/ForPatients](http://www.hfea.co.uk/ForPatients).

<sup>7</sup> Some clinicians also advocate the use of AIHD (artificial insemination by husband *and* donor), whereby the infertile couple continue to have sexual intercourse during the course of their treatment, leaving open the possibility that any resulting donor offspring may still be genetically related to both parents. As one commentator says, "*the performance of this medical act is not always conclusive that the child was really born from a donated gamete*" – J. Haderka, *Artificial Reproduction in Czechoslovakia Law with special reference to other European Socialist States* 1 IJLF 72, 85 (1984).

<sup>8</sup> See further "Baby created from two mothers raises hope for childless" The Sunday Times, 14 June 1998; "Fertility doctors create babies with two mothers" The Sunday Times, 16 May 1999.

<sup>9</sup> R. Snowden & G.D. Mitchell, *The Artificial Family: a consideration of artificial insemination by donor*, London: Allen & Unwin, 1981.

<sup>10</sup> HFEA 1990, ss 27 and 28 – the gestational mother is the legal mother, whether or not she is also the genetic mother and whether or not she intends to be the social mother (s 27). Identifying the legal father is more complicated. Section 28(6)(a) ensures that the donor of sperm is not the legal father provided the sperm is used in accordance with the other provisions of the HFEA. If the woman being

conversely, the provisions of the HFEA have also added further complexity to the issue of being a parent under English law – most notably by bringing about a situation where a child born following AID treatment services may be left legally fatherless.<sup>11</sup> However, in general, the *legal* position of the AID child and their social parents seems to be quite clear – the difficulty arises in relation to the balancing of the rights of both of these parties.

Despite the fact that assisted conception techniques were originally envisaged as being *supportive* of the family structure, in that they enabled new relationships to be formed in otherwise impossible situations, the relationships that the AID process throws up can be viewed as being extremely complex; the “genetic link” is severed and a new “social bond” must be established. The members of the newly-created “social” family may find it hard to reconcile their individual interests and the law needs to step in to ensure that, whilst everyone’s needs are met, one party does not suffer at the expense of protecting the rights of others.

With respect to the infertile couple/social parents, their rights and interests might include a right to receive fertility treatment;<sup>12</sup> a right to medical confidentiality in pursuance of that treatment;<sup>13</sup> a right to found a family;<sup>14</sup> the right to respect for their private lives and the right to respect for their family lives.<sup>15</sup> The primary opposing interest of the DI child is in the acknowledgement, by his/her social parents and also

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treated is married, her husband is presumed to be the father (s28(5)(a)). This presumption can be rebutted but if he consented to the treatment, he is the legal father (s28(2)). If a woman is not married but receives treatment services provided for her and a man together then her partner is deemed to be the father (s28(3)).

<sup>11</sup> Where an unmarried woman is treated but not “*treated together*” with her male partner then the partner is not the legal father and the child is left legally fatherless (s28(3) HFEA 1990) – see the recent decisions in *Evans v Amicus Healthcare & Others* [2003] EWHC 2161 (Fam) and *Re R (A Child)* [2003] 2 All ER 131. This may also occur where there is posthumous use of a man’s genetic material (s28(6)(b) HFEA 1990 – see further *R v HFEA ex p Blood* [1997] 2 WLR 806.

<sup>12</sup> See *R v Sheffield Health Authority ex parte Seale* (1994) 25 BMLR 1.

<sup>13</sup> Section 33, HFEA 1990.

<sup>14</sup> According to Articles 8 & 12, European Convention on Human Rights (ECHR).

<sup>15</sup> Article 8, ECHR.

by the state, that they have a *right to be informed about their status*, arguably as early in life as possible, as a constituent of their right to an identity.<sup>16</sup>

The apparent need for *secrecy* within the AID sphere has traditionally been seen to be the barrier to resolving this balancing of rights. However, the evidence is conflicting as to whether or not the prevalence of an aura of secrecy in DI families is real or purported. The Donor Conception Network,<sup>17</sup> a UK voluntary organisation for DI parents and children, firmly states that it actively encourages all of its member to embrace *openness* within the family. Their aims are, “*to provide support to existing parents, to the children themselves and to those contemplating or undergoing treatment,*” and, “*to increase public awareness and acceptance of family creation through gamete donation.*”<sup>18</sup> In their experience, a significant number of those who conceive through AID now actively choose to inform their child of this. However, recent academic research has suggested that the contrary is still true. A Swedish study<sup>19</sup> found that only around half of all DI parents were complying with Swedish law by telling or intending to tell their child about their biological origins, despite domestic legislation enacted as long ago as 1985, which provided for a right to information.<sup>20</sup> This research tends to suggest that *openness* is still not the norm and that an ethos of secrecy continues to pervade many DI families.

This is despite the fact that there is a growing body of very persuasive evidence to show that secrecy and deception can be extremely harmful to the AID child. Another recent study found that keeping secrets can have a very negative effect on the child’s development, leading to feelings of shock and loss on discovery of the truth, often

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<sup>16</sup> Under Articles 7 & 8, United Nations Convention on the Rights of the Child (UNCRC).

<sup>17</sup> See their website at [www.dcnetwork.org.uk](http://www.dcnetwork.org.uk).

<sup>18</sup> *Ibid.*

<sup>19</sup> C. Gottlieb, O. Lalos & F. Lindblad, *Disclosure of donor insemination to the child: the impact of Swedish legislation on couples* (2002) 15 HR 2052.

<sup>20</sup> The Swedish Insemination Act 1985 provides that a DI child has the right to be told about their true identity when they are “*sufficiently mature*”.

occurring in adulthood.<sup>21</sup> Many other commentators have acknowledged the damage that secrets can have on the DI family<sup>22</sup> and espoused the need for openness in these relationships.<sup>23</sup> A Donor Conception Network newsletter makes the point most succinctly:

*"Big secrets are unhealthy in intimate relationships. . . . They are usually caused by feelings of shame, and shame about the methods of family creation will inevitably colour the parent and child relationship."*<sup>24</sup>

Despite some commentators arguing that secrecy does not cause harm to the DI child,<sup>25</sup> there is evidence to suggest that this could indeed be so. Recognition of the impact of secrecy and deception on the lives of the donor offspring and an acknowledgement that these children should have the right to be kept informed of their status outweighs the rights of the social parents and justifies intervention on the part of the government. The difficulty appears to lie in exactly what form such measures should take, given the balancing of interests that must be carried out between both parties, particularly in light of the enactment of the Human Rights Act 1998.

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<sup>21</sup> A.J. Turner & A. Coyle, *What does it mean to be a donor offspring? The identity experiences of adults conceived through donor insemination and the implications for counselling and therapy* (2002) 15 HR 2041.

<sup>22</sup> See E. Haimes, *Secrecy: What can Artificial Reproduction Learn from Adoption?* (1988) 2 IJLPF 46; W. Hewitt, *Why I told our children* in Donor Conception Support Group of Australia Inc., *Let the Offspring Speak: Discussions on Donor Conception*, George's Hall, New South Wales: Donor Conception Support Group of Australia, 1997.

<sup>23</sup> Advocated by the HFE Authority itself, at section 58 of its response to the government Consultation Paper. See further M. Johnson, *Payment to gamete donors: position of the Human Fertilisation and Embryology Authority* HR 12 (1997) 1839; comments of Sir Robert Winston cited in S. Wavell, *The Sunday Times News Review* 6 July 1997, p6.

<sup>24</sup> W. Merricks, *Is it ethical?* DI Network Newsletter, 11 May 1996, p4.

<sup>25</sup> F. Shenfield & S. Steele, *What are the effects of anonymity and secrecy on the welfare of the child in gamete donation?* (1997) 12 HR 392.

## 2 Why the Secrecy?

Traditionally, the process of AID has always been shrouded in secrecy.<sup>26</sup> Modern AID techniques were originally inspired by the desires of infertile couples to become parents and to have a “*child of their own*”.<sup>27</sup> The dynamic growth of the fertility “industry” coincided with a fall in the number of newborn and young babies given up for adoption from the 1960’s onwards, following a change in social attitudes towards single mothers, a lessening in the stigma attached to illegitimacy<sup>28</sup> and an increase in the use of contraception.

AID is primarily a treatment for infertility and, given that almost 1 in 10 couples may have difficulties conceiving,<sup>29</sup> it undoubtedly has an important role to play. Infertility is generally regarded by many clinical professionals as an “illness”<sup>30</sup> – the infertile couple are the patients and the DI child is seen as a successful “cure”.<sup>31</sup> However, not everyone would agree with this approach,<sup>32</sup> given that the birth of a DI child is not really a cure for the condition of childlessness not infertility, and that childlessness may be combated in other ways, for example adoption.<sup>33</sup>

Current legal regulation of this area, in the form of the HFEA 1990, seems to be heavily concerned with protecting the interests of the social parents as patients, not

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<sup>26</sup> AID techniques were also said to have been “*practised discretely*” during the nineteenth century – see S. Novaes, *The medical management of donor insemination* in K.R. Daniels & E. Haimes, *Donor Insemination: International Social Science Perspectives*, Cambridge: Cambridge University Press, 1998.

<sup>27</sup> C. Overall, *Ethics and Human Reproduction: A Feminist Analysis*, Boston: Allen & Unwin, 1987.

<sup>28</sup> Following changes to illegitimacy laws under the Family Law Reform Act 1987. See further M. MacLean & M. Richards, *Parents and Divorce: Changing Patterns of Public Intervention* in A. Bainham, S. Day Sclater & M. Richards (eds), *What is a Parent? A Socio-Legal Analysis*, Oxford: Oxford University Press, 1999.

<sup>29</sup> Donor Conception Network, [www.dcnetwork.org.uk](http://www.dcnetwork.org.uk).

<sup>30</sup> This appears to be the case legally as well, given the decision in *op cit*, *R v Sheffield Health Authority ex parte Seale*, fn 12, concerning age restrictions on access to NHS IVF treatment. S. Elliston & A. Britton, *Is infertility an illness? R v Sheffield Health Authority ex p Seale* NLJ 11 November 1994, p1194.

<sup>31</sup> *Op cit*, Overall, fn 27, for a more detailed discussion of the use of the language of disease and cure in respect of infertility.

<sup>32</sup> A. McWhinnie, *AID and Infertility* (1986) 10(1) A&F 16.

<sup>33</sup> Although the general philosophy of adoption is as a means of providing children with parents, not parents with children.

the donor offspring. The infertile couple appear to be the subject of the Act, with the focus being upon their fertility needs.<sup>34</sup> The medicalisation of this area has led to the resulting donor offspring being regarded as a “cure”, not a newly-created human being, and there still remains little explicit recognition in UK clinical and legal circles, of the *social* significance of gamete and embryo donation within the medical context.

This paper does accept that infertility can be an extremely distressing condition – “a kind of grief, something sent to burden those unable to conceive. . . . a disease just like any other.”<sup>35</sup> This paper also accepts the infertile couple’s right to receive treatment for their condition and, as a corollary to this, their right to found a family, as well as the right to medical confidentiality during that treatment. It seems feasible to speak in terms of a right to fertility treatment by means of AID,<sup>36</sup> although this may not be an absolute right given the limits currently placed on access to treatment.<sup>37</sup> It also seems feasible to speak of the infertile couple’s right to medical confidentiality given the effect of the provisions of the HFEA 1990 relating to the unauthorised disclosure of information.<sup>38</sup>

The right to reproduce or procreate may be viewed as being slightly more contentious. Previous commentators have discussed the issue as to whether there is a

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<sup>34</sup> P. Spallone, *Beyond Conception: The New Politics of Reproduction*, London: Macmillan, 1989 – Spallone argues that the subject of the Act is not children and women, but eggs and sperm.

<sup>35</sup> See further S. MacLean & M. MacLean, *Keeping secrets in assisted reproduction – the tension between donor and anonymity and the need of the child for information* 8 CFLQ [1996] 243; D. Morgan & R. Lee, *Blackstone’s Guide to the Human Fertilisation and Embryology Act 1990*, Blackstone Press 1990.

<sup>36</sup> *Op cit*, fn 12. NHS guidelines issued in August 2003 calling for more free IVF treatment on the NHS also point to greater recognition of the right to receive fertility treatment – [www.doh.gov.uk](http://www.doh.gov.uk).

<sup>37</sup> See the discussion of Gillian Douglas regarding the effects of section 13(5) HFEA 1990 as a barrier to the treatment of certain individuals – G. Douglas, *Assisted Reproduction and the Welfare of the Child* CLP (1993) 53.

<sup>38</sup> HFEA, ss 33 and 41.

basic human right to reproduce<sup>39</sup> and the claim to such a right has often tended to attract much sympathy, particularly in high-profile cases.<sup>40</sup> However, recent judicial dicta has shown that sympathy is not sufficient to claim the right to a baby.<sup>41</sup> Despite this some commentators would argue that there is a general right to reproduce, although it cannot be said to be an absolute right.<sup>42</sup> Within modern legal discourse, one can also point to the combined effects of Articles 8 and 12 of the ECHR, as a substantial legal basis for the right to reproduce and found a family.<sup>43</sup>

However, although we can speak in terms of a basic natural right to reproduce and have a child, can we say that this applies to *medically assisted reproduction*? In this instance, what is essentially a private issue becomes a matter of public concern and hence the object of legal regulation.<sup>44</sup> Also, because AID requires the use of third party genetic material, it has led some commentators to suggest that, within the confines of AID, we cannot speak of a fundamental human right on the part of the infertile couple, to have children using somebody else's genetic material,<sup>45</sup> albeit we can point to a qualified legal right to marry and found a family. However, there is no positive obligation inherent in Article 12 upon a State Party to promote the rights of married couples to procreate, for example by the provision of fertility treatment.<sup>46</sup> Furthermore, it seems difficult to allege that the rights of the social parents – to

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<sup>39</sup> S. MacLean, *The Right to Reproduce* in T. Campbell, D. Goldberg, S. MacLean & T. Mullen (eds), *Human Rights: From Rhetoric to Reality*, Oxford: Basil Blackwell, 1986; E. Kingdom, *Birthrights: Equal or Special?* in R. Lee & D. Morgan (eds), *Birthrights: Law and Ethics at the Beginnings of Life*, London: Routledge, 1989.

<sup>40</sup> *Op cit*, *Evans v Amicus Healthcare Ltd & Others*, fn 17.

<sup>41</sup> *Per Hale LJ, U v Centre for Reproductive Medicine* [2002] EWCA Civ 565, para 24.

<sup>42</sup> C. Hegnauer, *Human Rights and Artificial Procreation by Donor* in J. Eekelaar & P. Sarcevic, *Parenthood in Modern Society*, p207. Historically the process of procreation has been defined and restricted by rules laid down in the criminal law and the rules on marriage.

<sup>43</sup> *X v Belgium and Netherlands* Application 6482/74 D & R 7, p25; *X & Y v United Kingdom* Application 7229/75 D & R 12, p32.

<sup>44</sup> See K. O'Donovan, *Sexual Divisions in Law*, London: Weidenfeld & Nicolson, 1985, cited in J. Bridgeman & S. Millns, *Feminist Perspectives on Law*, London: Sweet & Maxwell, 1998.

<sup>45</sup> *Op cit*, Hegnauer, fn 42.

<sup>46</sup> K. O'Donnell, *Parent-Child Relationships within the European Convention* in N. Lowe & G. Douglas (eds), *Families Across Frontiers*, Netherlands: Kluwer Academic Publishers, 1996.

fertility treatment, to confidentiality in that treatment and to have a child – conflict too greatly with the right of the AID child to be told of their status. Firstly, because these rights have little to do with the provision of information later in the DI child's life and secondly, because at the time that the balancing exercise would be carried out, the child would not have been born and it would be impossible to discuss their human rights as embryos.<sup>47</sup>

However, it often seems that the rights and interests of the future child are overlooked in favour of the more immediate and pressing concerns of the infertile couple.<sup>48</sup> Whilst it is accepted that the law needs to be sympathetic to the needs of the infertile couple, the welfare and the rights of the donor offspring should not suffer as a consequence. To quote from the Human Genetics Advisory Committee/Human Fertilisation and Embryology Authority on Cloning:

*"The relief of the pain of infertility is, in general, a good end, but it is not an absolute end. . . . The wish for genetic offspring is a natural human aspiration, but this is to be held in balance with other desirable aspects of human well being and it cannot be given overriding priority above all other considerations."*<sup>49</sup>

The enactment of the HFEA 1990 arguably placed the infertile couple on a very firm legal footing;<sup>50</sup> legal regulation of the treatment of infertility is now widely accepted and the protection of the interests of the patients as prospective social parents is, on the whole, well protected by the HFEA, the HFE Authority and the

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<sup>47</sup> *In Re F (in utero)* [1988] Fam 122; *Re MB (medical treatment)* [1997] 2 FLR 426.

<sup>48</sup> G.J. Annas & A. Milunsky, *Genetics and the Law*, London: Plenum Press, 1976.

<sup>49</sup> HGA/HFEA, *Cloning Issues in Reproduction, Science and Medicine*, London: Human Genetics Advisory Committee (December 1998), para 4.6.

<sup>50</sup> Prior to 1990, regulation of ART's was through the Interim Licensing Authority for Human In Vitro Fertilisation and Embryology, a self-regulatory body established by the Medical Research Council and the Royal College of Obstetricians and Gynaecologists in 1985 (previously the Voluntary Licensing Authority).



Code of Practice, whilst the rights and interests of the donor offspring seem to have been subjugated, despite recognition within the Code of Practice that:

*“...while infertile people deserve and can expect proper consideration of their medical and social needs, licensed treatments may result in children who would not otherwise have been born, and whose needs must also be taken into account.”<sup>51</sup>*

Therefore, any enactment of future Regulations, as suggested in the government Consultation Paper, needs to take into account the social impact of infertility and secrecy within the DI family – primarily because, as acknowledged earlier in this paper, it is the DI social parents who hold the key to the future of the DI child. They are the ones who can choose to tell their child the truth or not and current statistics consistently seem to show that they are still choosing secrecy over openness.<sup>52</sup>

The perceived importance on the maintenance of secrecy in the DI family has contributed to the current lack of recognition of the rights of the donor offspring. The exact reasons for the importance placed on such secrecy have never been fully and explicitly articulated, but it has been assumed to be due in turn partly to the traditional legitimacy laws; also because of religious and moral concerns over the sanctity of the marital bond between the recipients, which could be disturbed by third party intervention; partly, because of the charge that these processes are interfering with nature and also, when considering donor insemination, the stigma that is attached

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<sup>51</sup> Code of Practice (revised June 1993), ch 4, p2.

<sup>52</sup> *Op cit*, Gottlieb *et al*, fn 19. See also R. Cook, S. Golombok, A. Bish & C. Murray, *Keeping Secrets: A study of parental attitudes towards telling about donor insemination*, Clinical Health and Research Centre, City University, London, 1995.

to male infertility.<sup>53</sup> All of these factors seem to have contributed to enormous pressure on the social parents to keep the means of the conception a secret.

For example, not informing donor offspring of their true genetic heritage allows the DI family to present itself as a traditional nuclear family and therefore assume a mantle of “normality” both for its own sake and for the sake of appearances to the outside world.<sup>54</sup> The issue of “normality” appears to be of great importance to the social parents; one recent study showed that not one of them had told their child of the method of their conception and that most had decided never to do so.<sup>55</sup> An even more recent study assessing the actual reasoning behind parental (non) disclosure of the truth of the child’s conception found that out of 70 men and 86 women who had had children by means of donated gametes and/or embryos, 54% said that they would not disclose this to their children, for reasons of “confidentiality”. However, promisingly, 30% said that they would disclose the truth to their children, with the motivating factor being “honesty”.<sup>56</sup> The government therefore needs to consider how it can act to provide legislative support for the social parents to further embrace the concept of openness.

### 3 The Infertile Couple

The following are the main arguments oft-quoted in support of the maintenance of secrecy.

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<sup>53</sup> E. Blyth, *Secrets and Lies: Barriers to the exchange of genetic origins information following donor assisted conception* A&F 23 (1999) 49.

<sup>54</sup> E. Haines, *Recreating the Family? Policy considerations relating to the “new” reproductive technologies* in M MacNeil, I. Varcoe & S. Yearley, *The New Reproductive Technologies*, London: London, 1990.

<sup>55</sup> *Op cit*, Cook *et al*, fn 52.

<sup>56</sup> R. D. Nachingall, G. Becker, S.S. Quiroga & J.M. Tschann, *The Disclosure Decision: concerns and issues of parents of children conceived through donor insemination* (1998) 199 American Journal of Obstetrics and Gynaecology 1165.

- Fear of societal stigmatisation of the DI parents
- Fear of social stigmatisation of the DI child
- Allows the DI parents to avoid the emotional difficulties of publicly acknowledging their infertility
- Supposedly to protect the DI child from the emotional and psychological impact of disclosure of the truth
- Fear of rejection of the DI parents in favour of the genetic parents
- Allows the DI parents to have a “*child of their own*”<sup>57</sup>

Promisingly, all of these arguments stem from attitudes which are susceptible to change and which *could* be changed if the issues surrounding these apparent justifications were addressed in any future legal regulation. How then can we get rid of secrecy as the status quo?

The first point is that, within the field of AID, the use of donated sperm far outweighs the use of donated ova and embryos<sup>58</sup> and consequently, it is the infertile man who is most protected by this policy of secrecy, therefore it is attitudes towards *male infertility* that need to be highlighted and addressed.<sup>59</sup> Empirical evidence shows a significant difference in attitudes between men and women in DI families towards secrecy and donor anonymity. For example, a study in Holland found that

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<sup>57</sup> *Op cit*, Overall, fn 27.

<sup>58</sup> See the HFE Authority’s website – [www.hfea.gov.uk](http://www.hfea.gov.uk).

<sup>59</sup> For example, women facing fertility problems are still more likely to consider adoption than men, suggesting that they are less preoccupied with genetic links. See M. Stanworth, *Reproductive Technologies: Gender, Motherhood and Medicine*, Cambridge: Polity Press, 1987, p22 and C. Crowe, *Women want it: in vitro fertilisation and women’s motivations for participation* in P. Spallone & D.L. Sternberg (eds), *Made to Order*, Oxford: Pergamon, 1987, p87.

men, more often than women, are very secretive about the use of a donor and men more often than women are in favour of donor anonymity.<sup>60</sup>

One possible reason for this is that, within Western societies, there has always traditionally been a preoccupation with paternity and the protection of the purity of the patriarchal line within a family. Both legally and socially, much significance has been placed on male fertility and its connotations of virility and power.<sup>61</sup> Consequently, male infertility has always been considered a source of shame and embarrassment and the discovery of such within a couple can lead to feelings of male pride and masculinity being greatly damaged,<sup>62</sup> with enormous repercussions for the emotional and psychological well being of both male and female partners.

If we were to ask most men, they would probably be inclined to say that parenthood means *genetic parenthood*, therefore it is unsurprising that an inability to parent can lead to the feelings of loss and failure described by some infertile men. Unsurprising also that, because of this attitude, the first thought of many of the men who take part in the fertility process is that they may want to keep the means of their child's conception a secret. The use of donated sperm is seen as shameful and breaking a taboo, because it also requires acknowledging the fact that third party male masturbation has played a fundamental part in the DI child's conception, ergo it is something that must remain a secret.<sup>63</sup> Interestingly, research shows that when donor sperm is used to achieve conception, the infertile male places much greater emphasis on using a donor from a similar background and with similar characteristics, than

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<sup>60</sup> A. Brewaeys, S. Golombok, N. Naaktgeboren, J.K. de Bruyn & E.V. van Hall, *Donor Insemination: Dutch parents' opinions about confidentiality and donor anonymity and the emotional adjustment of their children* (1997) 12 HR 1591.

<sup>61</sup> J. Dewar, *Fathers in Law? The Case of AID* in *op cit*, Lee & Morgan, fn 39.

<sup>62</sup> R. Snowden & E. Snowden, *The Gift of a Child*, London: Allen & Unwin, 1984. The Warnock Committee also felt that a change in attitude towards male fertility was needed – Department of Health & Social Security, *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, Cmnd 9414 London: HMSO, 1984, para 4.28.

<sup>63</sup> J. Thevoz, *The rights of children to information* in D. Evans (ed), *Creating the Child*, The Hague: Kluwer Academic Publishing, 1996, p198.

women who use donor ova, again highlighting their apparent concern in covering up the truth.<sup>64</sup>

There is also a heavy preoccupation with legal paternity in the UK. Within legal discourse, conclusive evidence of genetic paternity has always been considered important for reasons of legitimacy and for ownership and succession issues.<sup>65</sup> However, the HFEA 1990 has already successfully addressed the issue of any donor offspring's legitimacy. The legislation clearly states that the legal father of the child is the husband of the woman seeking fertility treatment, not the sperm donor.<sup>66</sup> As such, there can be no need to hide the true nature of the conception on legitimacy grounds. Furthermore, implicit within the HFEA 1990, is the recognition that an *intention to parent* can displace the blood tie<sup>67</sup> as the test of *parentage*, demonstrating that there is an acceptance that the social parent's role is equally important to the genetic parent's role within the "new" family.<sup>68</sup>

An added difficulty is the influence of the clinical professionals over the social parents. For instance, some practitioners have been documented as saying that if the social parents were to keep quiet then there would be, "*no reason for him or her ever to know that he or she was conceived by donor insemination.*"<sup>69</sup> Furthermore, in the past some clinicians seem to have viewed a prospective parent's intention to be open with their child as so averse that it would be an indication of their unsuitability for treatment – surely an illogical viewpoint in this far more enlightened age? Institutionalised ideas about the doctor/patient relationship could be said to influence

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<sup>64</sup> V.A. Adair & A. Purdie, *Donor insemination programmes with personal donor: issues of secrecy* (1996) 11 HR 2558.

<sup>65</sup> See *Russell v Russell* [1924] AC 687.

<sup>66</sup> *Op cit*, fn 10.

<sup>67</sup> See C. Barton & G. Douglas, *Law and Parenthood*, London: Butterworths, 1995, p51 – "*the extent to which legal recognition is given to a person's intention or desire to be regarded as a parent. . . . has increased over time, so that it is now the **primary** test of legal parentage*" (emphasis added).

<sup>68</sup> *Op cit*, Overall, fn 27, p206.

<sup>69</sup> Royal College of Obstetricians and Gynaecologists, *Donor Insemination*, RCOG London, 1987, p3.

a patient's response to the doctor's opinion, because often it is taken for granted that what they say goes without question.<sup>70</sup> Even the legislators seem to have bowed to the opinion of the medical professionals in this field.<sup>71</sup> It needs to be remembered that these medical professionals are primarily concerned with the process of procreation and not the social process of forming a family. This focus on providing a cure, and also the lack of follow-up services for the newly-formed family, due in part to confidentiality issues, means that the promotion of services in terms of a successful conception rate often takes precedence over the consideration of the longer-term effects on the individuals involved.

With these considerations in mind, what practical legal measures can be put in place to move away from secrecy? This would depend on whether the state decides to take a *private ordering* or a *state regulation* approach to the issue. This refers to Barton and Douglas' theory of a state regulation continuum, with minimal intervention at one end and interventionist measures at the other.<sup>72</sup> It is hereby argued that the nature of the rights at issue within the AID sphere, would warrant some interventionist measures on the part of the government, to protect the rights of the AID child, despite concerns expressed by some commentators that this type of approach may not be feasible or equitable.<sup>73</sup> Therefore, it is recommended that the first step for the government would be to examine the prospect of a change in the current birth registration system, to allow for them to be annotated "by donation", thereby providing an effective legal mechanism for enforcing the rights of the AID child to be told of their status. Secondly, to allow for follow-up visits to the AID

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<sup>70</sup> See the comments of Frances Price in *Beyond clinical expertise: social and legal concerns in assisted conception* (1994) JCL 68.

<sup>71</sup> See the comments of Erica Haines about the response of the Warnock Committee and those implementing the HFE Bill in the 1980's – *Gamete Donation and the social management of genetic origins* in M. Stacey (ed), *Changing Human Reproduction*, Sage Publications, 1992.

<sup>72</sup> *Op cit*, Barton & Douglas, fn 67, pp50 *et seq*.

<sup>73</sup> See further P. Glazebrook, *Human Beginnings* [1984] CLJ 209, p211.

family by an experienced professional, such as a social worker or psychologist, at certain stages during the donor offspring's childhood, to persistently encourage the AID parents to inform their child of their status at as early an age as possible. Finally, to respect and support the rights of the social parents by providing increased, improving, ongoing counselling, following a model postulated on encouragement as well as enforcement.

Current legislation already provides for some limited counselling within the AID family. The HFEA *Code of Practice*<sup>74</sup> provides for three types of counselling for the prospective parents: implicative, support and therapeutic counselling, and such counselling must be offered to everyone before they consent to the fertility treatment.<sup>75</sup> However, although the evidence seems to show that much of this counselling *is* geared towards increased openness in the family relationships, some commentators have suggested that this measure has been unsuccessful because of its superficiality and, more importantly, the fact that it does little to actively discourage the prevailing ethos of secrecy.<sup>76</sup>

#### **4 The Rights of the A.I.D. Parents?**

Even if convinced of the arguments cited in favour of secrecy, this paper does not accept that they warrant a *right* to secrecy for AID parents. Furthermore, any alleged rights of the AID parents should not be allowed to override the rights of the AID child on the basis of secrecy alone. The main rights at issue here are those of the social parents to respect for their private and family lives under Article 8 ECHR – these

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<sup>74</sup> 2<sup>nd</sup> Revision, 1995, Part 6.

<sup>75</sup> *Ibid*, section 1.3(6), para 3(1)(a).

<sup>76</sup> E. Blyth, *Infertility and Assisted Conception: Practice Issues for Counsellors*, Birmingham: British Association of Social Workers, 1995, p67.

would appear to be at odds with the proposition that donor offspring should have the right to be told about their status.

Arguably, both private and family life issues are engaged in this instance.<sup>77</sup> Any proposed alteration of the birth certificate could interfere with the social parents' private lives because it pertains to information regarding their identification as legal parents, thereby relating to their own identity issues.<sup>78</sup> Compulsory counselling and follow-up visits to ensure that the donor becomes aware of their status could also be seen to impinge on their private lives because of the perceived interventionist nature of these approaches. Furthermore, family life, which could easily be established within the social family given the close personal ties and *de facto* family relationships therein,<sup>79</sup> could also be affected if the social parents were to argue that granting the DI child the right to be told might cause distress for any/all of the family members. Therefore it seems that the social parents would be able to found an argument in relation to Article 8 ECHR on either of these grounds.<sup>80</sup>

Further, given the strength of evidence presented in chapter 3 regarding the AID child's needs and rights relating to their personal identity, it would seem unjustified to allow the rights of the social parents to prevail. One could therefore point to a justification for the alleged breaches described above, in Article 8(2), that the suggested measures are for the, "*rights and protections of others*," i.e. the DI child. In this instance there would have to be a balancing exercise of the rights of both parties and it is this balancing act that has proved to be the crux of the matter.

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<sup>77</sup> No definition of either of these concepts is actually contained within the ECHR.

<sup>78</sup> Protected under Article 8, ECHR, as being a component of an individual's private life – *Mikulic v Croatia* (2002) App. No. 53176/99 2002, paras 52-53.

<sup>79</sup> *Marckx v Belgium* [1979] 2 EHRR 330.

<sup>80</sup> *X, Y & Z v UK* (1997) 24 EHRR 143.



The case of *X, Y and Z v UK*<sup>81</sup> provides a good example of how such an exercise might be carried out. X was a post-operative female-to-male transsexual, who together with his partner Y, received licensed fertility treatment and conceived Z following AID. However, the Registrar General refused to allow X to be registered as the legal father, taking the view that only a biological male could be so registered. X, Y and Z *together* alleged a breach of Articles 8 and 14 ECHR. The majority of the court found no violation on the basis of the wide margin of appreciation afforded to State Parties concerning the sphere of AID, but it is not the main decision that is of interest here. A disagreement arose between Judges Pettiti and Foighel regarding the apparent conflict between the *rights of the parents and the rights of the child*. Judge Pettiti advanced concerns over the *independent* interests of the child Z, suggesting that more weight should have been given to those interests and that possibly Z should have been separately represented because it was not obvious to the court that it was in the child's *best interests* for X to be recognised as the father. In other words, the registration of X as the legal father might impede Z's identity rights, should she wish to gain more information about her genetic father in the future. This discussion is itself interesting because it demonstrates a tacit recognition of the AID child's identity rights, but, underlying this, it also highlights the inherent difficulties of resolving the conflict of rights that can sometimes occur between family members.

In such a conflict a State's usual concern is to protect the rights of the weaker party, i.e. the child, but it will often seek to justify its policies on the basis that they protect the rights of the family.<sup>82</sup> Recognition of the interests of the child is enshrined within domestic law in the Children Act 1989<sup>83</sup> – the interests of the child

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<sup>81</sup> *Ibid.*

<sup>82</sup> For example, *B, R & J v Federal Republic of Germany* App 9639/82 D & R 36, p130; *Jolie & Lebrun v Belgium* Application 11418/85 D & R 47, p243; *Rasmussen v Denmark* 7 EHRR 371.

<sup>83</sup> Section 1.

being *paramount*. This approach is further reinforced by Article 3 of the UNCRC – in general, “*the interests of the child shall be a primary consideration.*” However, the rights relating to family life as expressed in the European Convention appear not to be weighted in favour of either the child or the parent, making the conflict between AID child and AID parent even more difficult to resolve. Jurisprudence from the European Court suggests that, where the rights and interests of the family members pull in opposite directions, then the best interests of the child become of crucial importance. Over twenty years ago *Hendriks v Netherlands*<sup>84</sup> established that where there was a serious conflict between the child and one of its parents, that could only be resolved to the disadvantage of one of them, the interests of the child had to prevail under Article 8(2). This principle has also been taken into account in the UK courts post-implementation of the Human Rights Act 1998, in relation to domestic violence issues in *Re L (Contact:Domestic Violence)*; *Re V (Contact:Domestic Violence)*; *Re M (Contact:Domestic Violence)*; *Re H (Contact:Domestic Violence)*<sup>85</sup> and explicitly referred to in *Re T (Paternity:Ordering Blood Tests)*<sup>86</sup> – a case that has already been shown to have a number of parallels to the position of DI families and could be alluded to in future AID identity disputes.

It is difficult to say how these decisions will be interpreted in the future; even the decision anticipated in *Rose*<sup>87</sup> may have little to say on the subject, given the fact that the social parents of both parties in that case are not objecting to the application to receive more non-identifying information. Regardless of the outcome in *Rose*, this paper maintains that the rights of the AID child should supersede the rights of the social parents. Evidence has shown that they have a fundamental right to an identity

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<sup>84</sup> (1983) EHRR 223. See also *Johansen v Norway* (1996) EHRR 72.

<sup>85</sup> [2000] 2 FLR 334.

<sup>86</sup> [2001] 2 FLR 1190.

<sup>87</sup> *R(Rose & Another) v Secretary of State for Health & Human Fertilisation and Embryology Authority* [2002] EWHC (Admin).

and the only effective way of doing this would be to provide a legal mechanism for encouraging and enforcing the social parents to embrace the concept of openness and tell the child of their status, thereby giving them the opportunity to access information relating to their genetic background.

## 5. The Donor

Under the HFEA 1990 the *anonymity* of the donor is almost always guaranteed.<sup>1</sup> Therefore, if the donor offspring were to be granted the right to receive information about their donor(s), how would this impact on the donor's rights – to confidentiality,<sup>2</sup> respect for their private life<sup>3</sup> and respect for their family life?<sup>4</sup>

### 1 The UK Donor

Earlier chapters have demonstrated that there are strong arguments for allowing AID children to access information relating to their genetic origins, justifiable on two grounds: firstly, their fundamental need<sup>5</sup> and right to an identity<sup>6</sup> and secondly, the importance of having ongoing access to information relating to their medical history.<sup>7</sup> What kinds of information regarding the donor should be made available on these bases considering that information about gamete donors can be divided into two types – identifying and non-identifying – and that both can have an equally important role in the DI child's life?

Identifying information would include the name, date of birth and address of the donor, from which a donor could possibly be traced and contacted.<sup>8</sup> However, this

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<sup>1</sup> HFEA, s 35.

<sup>2</sup> HFEA, ss 33 and 41.

<sup>3</sup> Article 8, European Convention on Human Rights (ECHR).

<sup>4</sup> *Ibid.*

<sup>5</sup> See J. Triseliotis, *In Search of Origins*, London: Routledge & Kegan Paul, 1973.

<sup>6</sup> Under Articles 7 and 8 of the United Nations Convention on the Rights of the Child (UNCRC).

<sup>7</sup> See further S. Simpson, *Truth and the Child: a genetic perspective* in E Blyth, M. Crawshaw & J. Speirs (eds), *Truth and the Child 10 Years On: Information exchange in donor assisted conception*, Birmingham: British Association of Social Workers, 1998.

<sup>8</sup> Future Regulations may need to take into account that the address of the donor may have changed since the time of the donation, although if we are discussing the right to information, not contact, the HFE Authority may be under a duty to ensure the accuracy of the address, if it were to disclose any identifying information.

paper does not propose that contact should be an automatic right of the donor offspring. Being identified as a child's genetic parent does not mean that a social relationship should necessarily follow, as the existence of a genetic tie does not of itself merit the creation of a social relationship.<sup>9</sup> Non-identifying information could include such things as eye and hair colour and other physical characteristics, as well as occupation, religious and ethnic background and personal interests.

All sperm and egg donors accepted by a treatment centre are currently required to fill out a donor information form. This form is completed and returned to the HFEA, so that information about a donor can be entered and stored on the HFEA's register, established on 1 August 1991, and containing data concerning patients, donors and children conceived by means of AID only as of that date.<sup>10</sup> On the form, the donor must fill in his/her name, address and age, thereby enabling the HFE Authority to identify the specific donor from each treatment cycle. Therefore, the Authority *does already* have the identifying information available. Some might argue that the very fact that this data has already been collected and is waiting to be accessed is reason enough to allow the information to be made available; at the very least the HFE Authority could not argue that collecting and retaining this data would be an unreasonable demand upon their resources, when this is already a part of the donation process. Indeed, it seems paradoxical that the HFE Authority should have gone to the time, effort and expense of collection and retention of this data, in circumstances dictating the need for stringent security measures, if the possibility of disclosure of this information was never considered.

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<sup>9</sup> See the discussion of the European Court of Human Rights in *M v Netherlands* (1993) 74 DR 120.

<sup>10</sup> The Department of Health has set up a pilot scheme allowing for the establishment of a voluntary contact register for those involved in AID pre-1990 – [www.UKDonorLink.org.uk](http://www.UKDonorLink.org.uk).

The non-identifying information currently obtained by the HFE Authority from donors is very limited.<sup>11</sup> There is a section where donors can write something about themselves and a description of their lives and interests,<sup>12</sup> with the intention that it could<sup>13</sup> be passed on to any child born as a result of their donation.<sup>14</sup> Donors are encouraged to provide:

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

Therefore the HFEA collects:

*“ . . . additional, non-identifying information [about the donor] because it may be helpful to children born following treatment with your eggs or sperm who want to gain some insight into their genetic origins. With this in mind the Authority collects general information about what you look like. It also offers the opportunity to describe yourself and your interests more fully in your own words if you think that could be helpful to a child born as a result of your donation. If Parliament in the future makes this decision, such a child after reaching the age of 18, could contact the HFEA for information. ”<sup>15</sup>*

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<sup>11</sup> Some centres do collect more information; see E. Blyth, *Infertility and Assisted Conception: Practice Issues for Counsellors*, Birmingham: British Association of Social Workers, 1995, p67.

<sup>12</sup> This includes ethnic group, eye colour, hair colour, skin colour, height, weight, occupation and interests (notably, only one line is provided for listing interests – perhaps an indication of how little value is currently attributed to this type of information – *HFEA Donor Information Form 91(4)*).

<sup>13</sup> Should Regulations be enacted.

<sup>14</sup> The HFEA *Code of Practice*, 4<sup>th</sup> edition, July 1998, London: HFEA, para 3.43, states that donors should be encouraged to provide non-identifying information about themselves.

<sup>15</sup> HFEA Leaflet, *Sperm and Egg Donors and the Law*, December 1992.

Guidance from the HFE Authority suggests that this information could include further details about the donor's interests, family background, childhood and region of origin etc. However, the amount of space on the form for this type of information is very limited<sup>16</sup> and, as the form makes clear, this self-description by the donor is completely optional.

Recent studies have shown that only a small number of donors complete this section of the form. MacLean and MacLean<sup>17</sup> found that less than 20% of donors were completing this descriptive section. However, some of the larger centres offering reproductive treatment using donated gametes had a higher completion rate, suggesting that the culture at these centres might be more geared towards information provision. MacLean and MacLean suggest that it could be an institutional factor affecting completion rate, with low completion rates from centres with lower numbers of successful donations, perhaps reflecting their size and experience.<sup>18</sup> In a separate study Blyth and Hunt found that treatment centres reported that donors cited several reasons for not providing extra information: for example, donors not being interested in, or not attaching any significance to, providing further information; donors being ambivalent about providing information about themselves; and donors fearing that non-identifying information could compromise their anonymity.<sup>19</sup>

Undoubtedly however, if Regulations were to be enacted, so as to allow for retrospective disclosure of non-identifying information, this optional self-description

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<sup>16</sup> Little more than 150 square centimetres, although additional sheets of paper may be attached to the original form.

<sup>17</sup> S. MacLean & M. MacLean, *Keeping secrets in assisted reproduction – the tension between donor anonymity and the need of the child for information* [1996] CFLQ 243.

<sup>18</sup> Also, note the low response rate in a study conducted by the Lister In-Vitro Fertilisation Unit, London, where 94% of egg donors did not respond to the last question on the form asking for a brief description of themselves – see H. Abdalla, F. Shelfield & E. Latache, *Statutory Information for the children born of oocyte donation in the UK: what will they be told in 2008?* (1998) 13 HR 1106.

<sup>19</sup> E. Blyth & J. Hunt, *Sharing genetic origins information: views from licensed centres on HFEA Donor Information Form 91(4)* 13 HR 3274.

would form part of the information to be disclosed.<sup>20</sup> Consequently, due to the optional nature of this section, some AID children may receive descriptions of their genetic background whilst others would not – raising questions of equity. Such a scenario would be unfair not only to the donor offspring but would also have important implications for the other parties involved, i.e. the social parents, who might want to tell their child of their origins – *“DI parents [are] often conscious of the difficulty of providing an explanation [to their children] in the absence of information about the donor.”*<sup>21</sup>

The HFEA 1990 currently provides that the HFE Authority may give out information as is required by Regulations.<sup>22</sup> Regulations could easily be enacted to allow for the prospective provision of non-identifying information; further there seems a strong argument to allow for prospective provision of identifying information, although in this instance, there would need to be a greater consideration of the competing rights of the donor. There is much greater resistance however to the proposition that identifying information could be retrospectively disclosed,<sup>23</sup> on the grounds that it would breach the donors’ rights to respect for their private and family life. Some have argued that it is unlikely that children in this situation will ever be able to gain access to any such information. Lee and Morgan have gone so far as to call these donor offspring, *“hostages to the reproductive revolution,”*<sup>24</sup> since full parliamentary debate and alternative primary legislation would be required for such a change.

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<sup>20</sup> *Op cit*, MacLean & MacLean, fn 17, pp245-6.

<sup>21</sup> R. Cook, S. Golombok, A. Bish & C. Murray, *Disclosure of Donor Insemination: parental attitudes* American Journal of Orthopsychiatry 65 (1995) 549.

<sup>22</sup> HFEA 1990, s 31(4)(a).

<sup>23</sup> *Ibid*, s 31(5).

<sup>24</sup> D. Morgan & R. Lee, *Blackstone’s Guide to the Human Fertilisation and Embryology Act 1990*, London: Blackstone Press Ltd, 1991.



The issues surrounding disclosure of information, particularly identifying information are extremely contentious. Looking back to 1984, the Warnock Committee found it difficult to decide what type of information should be made available to donor offspring about their genetic background.<sup>25</sup> They recognised that, “*it was wrong to deceive children about their origins,*”<sup>26</sup> and that secrets could, “*undermine the whole network of family relationships,*” but they were not prepared to take the next logical step and recognise that AID children should have the right to information about their genetic parent(s). It concluded that *no* identifying information about the donor should be made available to a child born by donation.<sup>27</sup> Therefore, whilst implicitly supporting the principle that donor offspring should be told the truth about their conception, it is obvious, both from the recommendations of the Warnock Committee and subsequent legislation, that the donor’s identity is, and always has been, protected much more stringently than that of the patient parent or of any child born.<sup>28</sup>

Several things emerge from the current rules relating to the collection and retention of donor information. Firstly, there is a strong argument for encouraging, or even enforcing, standardised practices within the licensed clinics; at present the importance of the completion of the donor information form is undervalued and the HFE Authority needs to do more to ensure that the treatment centres and the donors understand the relevance of the information contained therein.

Secondly, the government needs to strongly consider making the completion of this “pen portrait” section of the donor information form *compulsory*. Some might

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<sup>25</sup> Department of Health and Social Security, *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, Cmnd 9414, London: HMSO, 1984.

<sup>26</sup> *Ibid*, p21.

<sup>27</sup> *Ibid*, para 4.26.

<sup>28</sup> For further discussion of this point see I. Kennedy & A. Grubb, *Medical Law: Text with Materials*, London: Butterworths, 1994, p793.

argue against this, given the impact that this may have on the donor's right to respect for their private lives.<sup>29</sup> However, it must be acknowledged that all donors have a choice whether or not to donate; if they object to the compulsory nature of the provision of this information, they can choose *not* to donate. It therefore seems difficult to argue that there would be a breach of their rights under Article 8 of the European Convention on Human Rights. Admittedly, there is a concern that, if too many donors objected and chose not to donate, this could lead to a fall in the overall number of those donating. However, this leads us to the final point that the government needs to consider in the enactment of future Regulations – that there needs to be much greater focus on the counselling and advice given to donors at the time of donation, as already occurs in other legal jurisdictions.<sup>30</sup> This would help them to understand the *legal* position surrounding donation, i.e. that they will not be viewed as the legal father of the donor offspring, and the *social* consequences that may follow from donation, i.e. the fact that they will actually become a “parent”.

The current lack of consistency within AID clinical practices and the reluctance of the legislature to make a strong commitment to move away from *anonymity* and embrace the concept of *openness* means that the rights and interests of the donor offspring are often relegated to take greater account of the rights of the donor. A conflict of interests is bound to arise in these circumstances and it is the resolution of this conflict that will be discussed in the following sections.

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<sup>29</sup> Article 7, ECHR.

<sup>30</sup> Infertility Treatment Act 1995 (Vic), ss 12, 13, 16 and 17.

## 2 Why the Anonymity?

At the time of the inception of the HFEA 1990, anonymity was considered necessary, firstly to prevent the donor from believing that they would have any financial or parental responsibility for the donor offspring;<sup>31</sup> secondly, because, without the protection of anonymity, insufficient donors (men in particular) would be prepared to donate their gametes.<sup>32</sup> This last ground for anonymity has long been strenuously justified, mainly by the medical professionals, on the basis that anonymity is necessary to recruit donors. Also, the policy of anonymity is generally thought to reflect an apparent societal concern with the maintenance of the image of a “natural” family as the norm. Anonymity, alongside secrecy, allows the social family to appear normal and minimise the intervention of any third party donor into the family<sup>33</sup> – something that could be perceived as a threat to the newly-formed family. Anonymity protects all the individuals from the apparent threat that providing detailed information about the donor might, “*introduce the donor as a person in his own right*,”<sup>34</sup> allowing for an unwanted, unnecessary breach of the apparent “normality” of the social family. Thirdly, there is still a stigma attached to the reality of this type of formation of a family – the process is not 100% natural or ideal and, in the case of male sperm donors, it involves masturbation – an unsavoury, unmentionable taboo subject.<sup>35</sup> Donor anonymity allows these difficult issues to be overlooked by all of those involved.

However, by far the most oft-cited reason for the retention of donor anonymity is the justification that anonymity is necessary to maintain a steady supply of donors – in

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<sup>31</sup> This is no longer a concern; HFEA, s 28(6)(a) ensures that the donor of sperm is not the legal father provided the sperm is used in accordance with the other provisions of the HFEA.

<sup>32</sup> P. Braude, M.H. Johnson & R.J. Aitken *Human Fertilisation and Embryology Bill goes to report stage* (1990) 300 BMJ 1410.

<sup>33</sup> *Op cit*, fn 25, p25.

<sup>34</sup> *Op cit*, fn 25.

<sup>35</sup> Sperm donation accounts for approximately 93% of all live DI births – [www.hfea.gov.uk](http://www.hfea.gov.uk).

particular male sperm donors, without which the whole process would be unable to take place and the medical professionals would be unable to provide assistance and care for all of the infertile couples so desperately in need of treatment. *Prima facie* this sounds a very appealing argument – it strikes at the very heart of the proposition that we should not prevent the infertile couple from receiving treatment if it would deny them their right to found a family.<sup>36</sup> However, is this really a credible argument and is there any evidence to support it? Or is the policy of anonymity merely a shield to allow the medical professionals to pursue their own research in the way that they see fit?

Whilst there is a great deal of research on this subject, the majority of evidence shows that many of the AID clinical professionals are united in their arguments for the retention of donor anonymity. It should be mentioned here that donation is not always anonymous, since the HFEA 1990 does allow for the use of donor sperm where the donor is known to the recipients. However, when deciding whether or not to use a known donor, the clinics are directed towards, “*the implications for the welfare of the child if the donor is personally known within the child's family and social circle,*”<sup>37</sup> suggesting that many clinicians try to avoid open procedures as much as possible.<sup>38</sup>

Therefore, is the need for donor anonymity real or artificially constructed? Given the academic research and empirical evidence, it would seem that the latter is the case. However, to be able to understand the true basis of the policy of anonymity we need to examine the studies of donor attitudes that have already been undertaken. These studies may not provide a comprehensive insight into the attitudes of *all* donors, but at

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<sup>36</sup> Articles 7 and 12, ECHR.

<sup>37</sup> *Op cit*, HFEA Code of Practice, fn 14, para 3.18(c).

<sup>38</sup> See further M. Warnock, *A Question of Life: The Warnock Report on Human Fertilisation and Embryology*, Oxford: Basil Blackwell, 1985, p82.

present they are the only source for determining whether donor anonymity is necessary to protect the supply of gametes and they throw up some interesting and contradictory findings.

Some studies have shown that, if anonymity were removed, a number of donors would no longer donate, but that the majority would still do so.<sup>39</sup> However, Robinson *et al* looked at the level of personal involvement of the donors towards their act of donation and concluded that, by removing the guarantee of anonymity contained within the HFEA 1990 this would damage the numbers of those who were willing to donate.<sup>40</sup> Another study highlighted the complex nature of the emotions felt by donors towards their acts of donation<sup>41</sup> and again confidentiality and anonymity were found to be of great importance to the donors. However, interestingly donors do not seem to regard the fact of their donation as a secret. A study conducted in one clinic found that 80% of gamete donors had told their friends, relatives and doctors,<sup>42</sup> others had even told their stories in the public sphere.<sup>43</sup>

Notably, and perhaps a factor which further complicates matters, studies have shown that there are marked differences between the attitudes and motivations of sperm and egg donors. There are however, a number of possible reasons for this. It has been suggested that men and women regard their gametes in different ways: firstly, for biological reasons, i.e. women produce one egg a month, whilst men will release millions of sperm each time they ejaculate, therefore possibly women view their gametes as a much more valuable “commodity” than men. Furthermore, the

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<sup>39</sup> A. Kirkland *et al*, *Comparison of attitudes of donors and recipients to oocyte donation* (1992) 7 HR 355; J.N. Robinson *et al*, *Attitudes of donors and recipients to gamete donation* (1991) 6 HR 307.

<sup>40</sup> J.N. Robinson, R.G. Forman, A.M. Clarke, D.M. Egan, M.G. Chapman & D.H. Barlow, *Anonymity of gamete donors: a survey of attitudes* (1990) JRF 67, abstract 5.

<sup>41</sup> L. R. Schover, S.A. Rothmann & R.L. Collins, *The personality and motivation of sperm donors: a comparison with oocyte donors* (1992) 7 HR 575.

<sup>42</sup> M. Power *et al*, *A comparison of the attitudes of volunteer donors and infertile patient donors on an ovum donation programme* (1990) 5 HR 352.

<sup>43</sup> See J. Blizard, *Blizzard and the Holy Ghost*, Peter Owen, 1977.

way that the donation of sperm and eggs takes place is hugely different. To extract eggs from a woman, she has to undergo drug treatments to stimulate her ovaries into extra egg production and then undergo an invasive surgical procedure,<sup>44</sup> thereby facing medical risks that male sperm donors are not exposed to.<sup>45</sup> Sperm donation involves the simple, painless, indeed pleasurable, act of masturbation – although there is a certain amount of stigma attached to sperm donation. This fact generally means that men who donate tend to be regarded with greater suspicion,<sup>46</sup> possibly generating negative emotions on the part of these men towards the act of their donation – something that might be avoided if there was a greater degree of openness and acceptance in this whole area.

There also seem to be gender differences in a man and woman's motivation to donate. As we have seen men tend to donate anonymously, whilst many women tend to donate for family and friends.<sup>47</sup> Plus, in general, men may feel more detached from the recipients of their gametes and any resulting children; in fact, Lui *et al* suggest that some donors are, "*naïve towards their donation.*"<sup>48</sup> Legally, it is possible for donors to specify some characteristics of the recipients of their donation, for example requesting a specific age group. However, the study conducted by Lui *et al* showed that only 7% of male sperm donors were interested in having a say in the selection of the recipients if this was possible. Furthermore, 87% had no desire in meeting the resulting children and only 2% said that they would welcome any regular contact with the donor offspring. However, in another study conducted by Price and

<sup>44</sup> B.H. Smith & I.D. Cooke, *Ovarian Hyperstimulation: actual and theoretical risks* (1991) BMJ 127.

<sup>45</sup> S.C. Lui, & S.M. Weaver, *Attitudes and motives of semen donors and non-donors* (1996) 11 HR 2061.

<sup>46</sup> E. Haines, *Recreating the Family? Policy considerations relating to the new reproductive technologies* in M. McNeil, I. Varcoe & S. Yearley (eds), *The New Reproductive Technologies*, Basingstoke: Macmillan, 1990.

<sup>47</sup> See further L. Nelson, *Truth and the Surrogate Child*, in *op cit*, Blyth *et al*, fn 7.

<sup>48</sup> *Op cit*, Lui *et al*, fn 45.



Cook,<sup>49</sup> it was found that almost 66% of the women questioned who had donated anonymously, would have liked to have known something about the outcome of their donation. In comparison to the sperm donor's apparent lack of consideration for the consequences of their actions, these women were able to envisage a future child born of their donation and had concerns about the child itself and the family it would be born into.<sup>50</sup> These differences may be attributed to inherent biological and psychological reasons or socially constructed stereotypes of the roles that men and women play as parents; this is not the main issue. What needs to be focussed upon is how future legal regulation can encourage both of these groups to consider the repercussions of their actions to an even greater extent?

One method would be to provide much more extensive counselling for the donor prior to donation. Currently, under the HFEA 1990, prospective donors must be offered counselling before they donate, although there is no obligation for them to take up this offer. However, in practice, some licensed treatment centres may not accept individuals as donors unless they do undertake some counselling. During counselling, prospective donors (and recipients) are, "*invite[d]. . .to consider. . .the advantages and disadvantages of openness about the procedures envisaged,*"<sup>51</sup> and, "*to consider in particular. . .their perception of the needs of any children born as a result of their donation.*"<sup>52</sup> One consideration is how counselling could be improved to import the message that the welfare of the future offspring must be a *paramount* consideration in the whole process.<sup>53</sup>

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<sup>49</sup> F. Price & R. Cook, *The donor, the recipient and the child – human egg donation in UK licensed centres* [1995] CFLQ 145.

<sup>50</sup> *Ibid.* p149.

<sup>51</sup> *Op cit*, fn 14, p39.

<sup>52</sup> *Ibid.* p40, 6.16d.

<sup>53</sup> Unfortunately, in practice, treatment centres are often left to interpret these provisions in the way that they see fit and research has shown that the emphasis on the provision of non-directive counselling means that counselling about openness is unlikely to be provided by the centres.

Another complicating issue is the factor that financial incentives seem to be important for sperm donors, as evidenced in the study conducted by Lui *et al*, although admittedly the payment that donors receive is not a great amount.<sup>54</sup> Section 12(e) of the HFEA 1990 states that no money or other benefit may be derived from gametes and embryos, except in accordance with HFEA provisions.<sup>55</sup> There have been moves by the HFEA to recruit more altruistic donors, however, it was agreed in 1999 that the withdrawal of payments might impact negatively on the supply of donors.<sup>56</sup> Indeed, one UK study did try to recruit altruistic donors, through newspaper and radio advertising campaigns and leaflet distribution, but the number of donors recruited was very low.<sup>57</sup> It seems that the stereotypical image of the majority of sperm donors consisting of impoverished, but easily accessible, medical students may be true. The second question therefore is how we can create a situation whereby they would be less inclined to concentrate on the financial incentives and more inclined to consider the future well-being of their genetic offspring?

As we can see the results of these various studies are contradictory but they do demonstrate a certain reluctance on the part of the donors to relinquish their anonymity, possibly due to the influence of the medical professionals involved and a lack of consistent advice from the licensed clinics regarding the implications of their donation. For example, there is likely to be an uncertainty on the part of the donors about the social role and relationship they might have with the child/children<sup>58</sup> should

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<sup>54</sup> After a recent Consultation exercise, the HFEA decided to retain the figure of £15 per donation, plus reasonable expenses - HFEA Annual Report, 1999.

<sup>55</sup> A Direction issued by the Authority in August 1991 regularised payments for both men and women – up to £15 for men and for women, “benefits in kind”, such as free sterilisation or IVF treatment.

<sup>56</sup> See also S. Ramsay, *Experts advise on payment for gametes in the UK* (1995) 345 *The Lancet* 1498.

<sup>57</sup> E.A. MacLaughlin, J. Day, A. Harrison, J. Mitchell, C. Prosser & M. Hull, *Recruitment of gamete donors and payment of expenses* (1997) HR 12 1842.

<sup>58</sup> Donor sperm may be used in multiple attempts at conception, leading to the possibility that they may be faced with several genetic offspring – another issue that needs to be tackled in future regulation, given that one way to discourage donors from accepting anonymity would be for them to face the prospect of multiple donor offspring contacting them in later life.



their identity be revealed. Changes in attitudes on these matters are likely to be slow and the individuals involved need to be given all the assistance and encouragement that they can by the state, in the form of increased information, advice and counselling about the implications of the donation, to recognise that anonymity is not the only option.

A second argument in favour of a move away from anonymity pertains to the lessons learned in other jurisdictions. The Swedish Act on Artificial Insemination 1985 gave children born by means of AID the right to know the identity of the sperm donor, when they were *sufficiently mature* (no age being specified), justified by reference to the fact that the rights of the AID child should override the rights of the other individuals involved, including the donor's right to anonymity.<sup>59</sup> Plus, contrary to practices in UK treatment centres, the prospective recipients of the gametes must be evaluated by clinicians regarding their ability to foresee the consequences for their child. They must also be willing to tell the child of its origins, although they are not legally required to do so. Unfortunately, the Swedish legislation has proved to be fallible in this respect, given that in a recent study of 148 Swedish couples who had given birth to an AID child, 90% had said that they had not told their children.<sup>60</sup>

Notably, however, for the purposes of this chapter, the prospect of disclosure did not harm the numbers of individuals willing to donate, something that is oft-cited by the clinicians as the main reason for retaining anonymity. In Sweden there was opposition to the legislation because of a concern that donation would be discouraged; although numbers did initially fall, they have gradually increased again since 1985 and, interestingly, the demographic of the majority of those who now donate appears to have changed from young students to mature men who seem to be more

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<sup>59</sup> D. Bradley, *Family Law and Political Culture*, London: Sweet & Maxwell, 1996, p112.

<sup>60</sup> C. Gottlieb *et al*, *Disclosure of donor insemination to the child: the impact of Swedish legislation on couples* (2002) 15 HR 2052.

altruistically motivated.<sup>61</sup> From this perspective it is worth giving further thought to the consequences of the removal of anonymity and not automatically assuming that it would be detrimental to the process of AID.

Other research has shown that donors' attitudes to the disclosure of information about them may not be so wholly entrenched in their minds as the clinicians and lawmakers would have us believe. In the study by Lui *et al*, in response to the statement, "*I would not mind if donor offspring were given details of my physical characteristics, attitudes and personal interests,*" 82% said that they would be willing to provide non-identifying information. Even more encouragingly, in another New Zealand study, 78% of known sperm donors agreed to being identified to their donor offspring, provided that there were restrictions on the age at which this information would be made available to the child.<sup>62</sup>

However, practical measures are still needed to move away from donor anonymity. It is hereby proposed that the government should consider a two-pronged approach. Firstly, to force donors to accept the concept of openness, Regulations must be enacted to allow for disclosure of genetic information to donor offspring. Secondly, to acknowledge the donor's contribution to society, the government should examine ways in which principles could be enshrined in future legal regulation to allow for increased donor counselling and to re-define the concept of being a parent, thereby accepting that, "*the issue of biological parentage should be divorced from psychological parentage.*"<sup>63</sup>

Bainham's academic analysis of the issues of *parentage, parenthood and parental responsibility* provides a sound basis for the way in which society could begin to

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<sup>61</sup> A. McWhinnie, *Who am I? Genealogical disadvantage for children from donated gametes* in *op cit*, Blyth *et al*, fn 7, p72.

<sup>62</sup> V.A. Adair & A. Purdie, *Donor insemination programmes with personal donor: issues of secrecy*, (1996) 11 HR 2558.

<sup>63</sup> Per Ward LJ, *Re H: (Paternity: Ordering Blood Tests)* [1996] 2 FLR 65.

evaluate the way that it views the notion of “*being a parent*.”<sup>64</sup> He proposes an inclusive approach that would incorporate different but complimentary notions of genetic and social parenthood and he also stresses the role of the state in establishing and protecting the genetic connection between donor and donor offspring. He suggests the reformulation of the existing legal concept of *parentage*, which would be reserved for the genetic parent(s). Moreover, this would not interfere with the fact of the social parents’ *legal parenthood* or with the notion of *parental responsibility* under the Children Act 1989,<sup>65</sup> but would serve to reinforce the proposition that the donor does indeed have an important role as one kind of parent, which may in turn lead to a gradual recognition among donors that anonymity cannot continue to prevail.

### 3 The Rights of the Donor?

Despite the fact that there are some persuasive arguments in favour of donor anonymity, the apparent need and desire for such does not warrant its elevation to the status of a right and, even if one could point to such a right, e.g. under Article 8 ECHR, it should not automatically override the rights of the donor offspring to genetic background information.

If information were to be made available to donor offspring, this may raise issues regarding the donor’s right to respect for their “private life”<sup>66</sup> – the disclosure of non-identifying and identifying information relates directly to their identity and privacy interests.<sup>67</sup> Notions of “family life” may not be at stake here; even though it is

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<sup>64</sup> A. Bainham, *Parentage, Parenthood and Parental Responsibility: subtle, elusive yet important distinctions* in A. Bainham, S. Day Sclater & M. Richards (eds), *What is a Parent? A socio-legal analysis*, Oxford: Hart Publishing, 1999.

<sup>65</sup> Section 3(1).

<sup>66</sup> Article 8 ECHR.

<sup>67</sup> *Mikulic v Croatia* (2002) App No 53176/99 2002, paras 52-53.

accepted that a blood tie would create a strong presumption of family life<sup>68</sup> and that cohabitation of the family members is not essential for family life to be established,<sup>69</sup> there must also be evidence of sufficient constancy in a relationship to point to *de facto* family ties.<sup>70</sup> The decision in *M v Netherlands*,<sup>71</sup> relating to a sperm donor's application for contact established that sperm donation, even when coupled with occasional visits to an AID child, did not create a sufficiently close personal tie to be regarded as family life.

As regards the argument that disclosure of information breaches the donor's right to respect for their private life, this needs to be explored further in relation to the different types of information that might need to be available. Given that the possibility of the provision of non-identifying information on a prospective and retrospective basis was included in the HFEA 1990, provision of this type of information should not constitute a breach, as all donors are fully aware of the possibility of Regulations being enacted and have impliedly consented to this proposition.

The main difficulty lies in relation to the provision of identifying information, as this has not been adequately provided for in legislation. Certainly, retrospective disclosure would cause problems relating to principles of foreseeability and this may make it impossible to incorporate enforced disclosure into future legislation, although one may be able to point to a positive duty on the state to provide a voluntary information/contact register for past donors and donor offspring. Prospective disclosure could be more easily contemplated but would still entail a balancing of the rights of the donor and donor offspring. Recent domestic and European court

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<sup>68</sup> *Keegan v Ireland* (1994) 18 EHRR 342.

<sup>69</sup> *Kroon v Netherlands* (1994) 17 EHRR 263.

<sup>70</sup> *MB v UK* Application No 22920/93 (Dec) 6 April 1994. See also *Re H:Re G (Adoption Consultation of Unmarried Fathers)* [2001] 1 FLR 646.

<sup>71</sup> *Op cit*, fn 9.

jurisprudence provides an indication of how this balancing exercise may be carried out.

The most pertinent domestic authority is *Gunn-Russo v Nugent Care Society and Secretary of State for Health*.<sup>72</sup> The claimant was adopted as a child and sought judicial review proceedings to obtain disclosure of records held by the adoption agency that handled her adoption. She succeeded because the disclosure policy of the first defendants was applied without taking account of the individual facts of her case. A parallel can be drawn between this case and the position of AID children, although *Gunn-Russo* dealt with the provision of information from third parties and did not engage Article 8 ECHR. The confidentiality interests of these third parties were relegated in favour of the adoptee and dicta implied that the case for disclosure to AID children could be even stronger given that information about genetic parent(s) is, “something that goes to the very heart of their identity, and to their make up as people.”<sup>73</sup>

However, recent European jurisprudence has upheld notions of a genetic parent’s general right to confidentiality. *Odievre v France*<sup>74</sup> concerned an adoptee applying for genetic background information, who had been legally abandoned under French law, which allows for “birth by an unidentified person” – “*accouchement sous X*”. Traditionally, French law allows for the provision of non-identifying information to such an applicant but upholds the mother’s right to confidentiality. Despite the fact that only two other State Parties, Italy and Luxembourg, do not make provision for the compulsory registration of the identity of the legal parents, the European Court accorded a wide margin of appreciation to the French government and found no

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<sup>72</sup> [2001] 1 UKHRR 1320.

<sup>73</sup> Cited with reference to *Gunn-Russo* in *R(Rose & Another) v Secretary of State for Health and Human Fertilisation and Embryology Authority* [2002] EWHC (Admin).

<sup>74</sup> Application No 42326/98 13.2.2003.

violation of the applicant's right to respect for their private and family life under Article 8 ECHR.

*Prima facie* the decision in *Odievre* seems to be a step in the wrong direction, particularly in light of the promising judgements in past cases such as *Gaskin*<sup>75</sup> and *Mikulic*.<sup>76</sup> However, the applicant was an adult, not a child, and the European Court examined the matter on the basis of a conflict of competing adult rights. Had the decision concerned a child the outcome may have been different, because the Court would have given more weight to a consideration of the child's "best interests". Furthermore, there would be nothing to prevent domestic courts from taking a dynamic approach in the future and utilising the wide margin of appreciation accorded to them in decisions of this nature to advance the rights of donor offspring beyond the decision of *Odievre* to enable them to better protect the rights of the AID child to receive information about their genetic background.

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<sup>75</sup> *Gaskin v United Kingdom* (Access to Personal Files) (1989) Eur Court HR Ser A No. 10454183, 32 YB Eur Conv HR 176, 12 EHRR 36.

<sup>76</sup> *Op cit*, fn 66.

## 6. The Way Forward?

### 1 The Consultation Paper

The relevant governmental Consultation period ended in July 2002<sup>1</sup> and the Department of Health has since published a summary of the responses received.<sup>2</sup> 237 responses were received and the key message to emerge was that the rights of the donor offspring *should receive much greater recognition and protection*.

- 211 responses supported the enactment of Regulations in the future to allow for the provision of **non-identifying information**; 17 were against this (although some gave their reasons as being that non-identifying information was not enough and that identifying information alone would suffice).
- A majority of respondents agreed that the **types of non-identifying information** to be collected and made available should definitely include personal characteristics (e.g. eye, hair and skin colour, ethnic group, height and weight) and medical history. Other respondents suggested additional non-identifying information such as interests, likes, dislikes, education, marital status and possibly a personal message to their offspring. The possibility of updating this information at regular intervals was also proposed.
- 132 respondents said that **identifying information** should be made available; 70 said that it should not and 23 were undecided.

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<sup>1</sup> Department of Health, *Donor Information Consultation: Providing information about gamete or embryo donors*, London: HMSO, 2001.

<sup>2</sup> See the DOH website at [www.doh.gov.uk/consultations/](http://www.doh.gov.uk/consultations/).

Following the publication of these responses, in January 2003, the former Health Minister Hazel Blears announced that a pilot voluntary contact register would be established for all those who had been involved in AID prior to the enactment of the HFEA 1990. This pilot scheme – known as UKDonorLink<sup>3</sup> – will run from early 2004 and will report back to the Department of Health on whether such a scheme could be extended to the other individuals in the AID sphere.

Whilst these measures are welcomed, they represent a very tentative approach to the issues raised in this paper and demonstrate that the government has yet to make a genuine commitment to practical change. Speaking at the annual HFEA conference, Hazel Blears said:

*“We agree that there is a strong argument in principle for children conceived using donated sperm, eggs or embryos being able to find out the identity of their donor. . .we also understand that at some point in their lives they may decide they want to know more about their genetic origins. However, we believe that this sensitive area needs further consideration and debate. . .”*

The arguments evinced in this paper have demonstrated that the time is ripe for the complete reconsideration of current legal regulation in this area. The evidence presented herein has pointed to a strong legal basis for the protection of the identity rights of donor offspring and this paper now calls for the enactment of Regulations, if not new legislation, to allow donor offspring to be able to exercise their fundamental rights *to be told about their status and to receive further information about their genetic background*. It is unjustifiable that *secrecy* and *anonymity* are still the norm

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<sup>3</sup> [www.UKDonorLink.org.uk](http://www.UKDonorLink.org.uk).



in AID and yet *openness* now pervades so many other analogous areas of law, both in the UK and in other jurisdictions.

## 2 The Rights of the Adopted Child – a comparison

Evidence from adoption circles shows that secrecy and anonymity were prevalent in adoption practice in Britain, at least up until 1975,<sup>4</sup> if not even after this time.<sup>5</sup> However, adoption legislation has now recognised that *adoptees have a right to information about their genetic background*, in sharp contrast to the current position of donor offspring.<sup>6</sup>

An adoption is now registered in the Adopted Child Register,<sup>7</sup> in a similar way to the registration of AID children in the HFE Authority Register of donations resulting in a live birth. There is however one fundamental difference: on reaching the age of 18, an adoptee has the right to obtain a copy of his or her original birth certificate.<sup>8</sup> This will show the name and place of birth of the biological parents, the mother's maiden name and the father's occupation and will often be sufficient to give the adoptee a good chance of tracing their parents, or at least their mother. Furthermore, the Adoption and Children Act 2002 now allows for the provision of further non-identifying information in relation to a person's adoption, from either the adoption agency or the courts,<sup>9</sup> but this will only occur when the child reaches the age of

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<sup>4</sup> Children Act 1975, s 26.

<sup>5</sup> Section 39 of the Adoption Act 1976 still provided for the adopted child to be treated in law as the legitimate child of the adopting couple, perpetuating the "*veil of secrecy*" surrounding the adoption. See C. Bridge, *Changing the Nature of Adoption: Law Reform in England and New Zealand* (1993) LS 81, p82.

<sup>6</sup> *Op cit*, fn 4.

<sup>7</sup> Adoption and Children Act 2002, s 60.

<sup>8</sup> *Ibid*, s 77.

<sup>9</sup> Section 60. As with AID, the exact nature of this information is to be prescribed by regulations.

majority. The question is why the adoptee's right to an identity now receives such legal protection whilst the AID offspring is still overlooked?

Secrecy in adoption was originally maintained in order to protect the adopting couples from the shame and stigma of infertility and childlessness,<sup>10</sup> similar to the present approach in AID. An adopted child would be "matched"<sup>11</sup> with adopters in, for example, physical appearance, intelligence and character, in an attempt to keep up the appearance of a "normal" family unit, reminiscent of the reasons for the retention of secrecy in AID.<sup>12</sup> The concealment of a child's identity at birth was also designed to protect the single birth mother from the shame of an illegitimate birth and to prevent her from interfering in the child's life at a later stage, in much the same way that donor anonymity today protects all those involved from the embarrassment of admitting that the act of masturbation played a part in the process and avoids the donor interfering in the AID child's life. However, the changing nature of society dictated certain changes in adoption practice.<sup>13</sup> In recent years, there has been a significant decline in the number of babies available for adoption,<sup>14</sup> due to an increase in the use of contraception, changes to the abortion laws and the erosion of the stigma attached to single parenthood. This situation has led to a corresponding increase in

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<sup>10</sup> The Adoption Act 1976 was aimed at providing new homes for unwanted babies, generally with married couples who were unable to have children of their own, although, "*the role played by adoption has changed radically over the last three decades*" – The Prime Minister's Review of Adoption, Cabinet Office: Performance and Innovation Unit, 2000, p10.

<sup>11</sup> This process of "matching" has been practised by adoption societies in England and Wales since the inception of adoption services.

<sup>12</sup> K. O'Donovan, *What shall we tell the Children?* in R. Lee & D. Morgan, *Birthrights, Law and Ethics at the Beginnings of Life*, London: Routledge & Kegan Paul, 1989.

<sup>13</sup> *Op cit*, Bridge, fn 5; also, N. Lowe, *The changing face of adoption – the gift/donation model versus the contract/services model* [1997] CFLQ 371.

<sup>14</sup> *Adoption: The Future* (1993) Cmnd 2288, London: HMSO suggests that the number has fallen dramatically over the past thirty years. The total number of adoptions fell from approximately 25 000 in 1968 to just over 7 000 in 1991, of which only 12% were under twelve months old.

the number of couples making use of AID techniques – demonstrating that although adoption and AID may not be exactly analogous, they are inextricably linked.<sup>15</sup>

Compared to AID, it has generally been considered good practice for a number of years that adopted children should know of their adoption from the earliest possible time.<sup>16</sup> It is national policy for all adoption agencies to obtain a commitment from prospective adopters to tell their children that they are adopted, delivering the message that openness is the preferred model – not the case within AID families. Also, adoptive parents are given fairly detailed information about their child's background for them to pass onto the child. Again, this is miles away from the current policies in AID circles; further, this lack of information is apparently one of the reasons given by AID parents for not telling their child about the means of their conception, given the frustration that may ensue from not being able to access additional information.<sup>17</sup>

Today, adoption legislation, policy and practice<sup>18</sup> is based upon the belief that there is a “*psychological need*” to know about one's genetic background for the, “*formation of a positive concept of self.*”<sup>19</sup> There are no official figures showing how many adopted children make enquiries about their birth relatives or make contact with them.<sup>20</sup> It has been estimated that around 40-50% of adopted people have

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<sup>15</sup> A. McWhinnie, *AID and Adoption: Some Comparisons* A&F 10(1) (1986) 16. McWhinnie suggests that the professionals involved in both of these areas would undoubtedly benefit from sharing their experiences in order to improve their methods of dealing with the individuals involved, particularly in relation to counselling services.

<sup>16</sup> J. Triseliotis, *In Search of Origins*, London: Routledge & Kegan Paul, 1973, p155.

<sup>17</sup> See further J. Lasker & S. Borg, *In search of parenthood: coping with infertility and high-tech conception*, London: Pandora Press, 1989.

<sup>18</sup> Adoption and Children Act 2002.

<sup>19</sup> J. Triseliotis, *Obtaining Birth Certificates* in P. Bean (ed), *Adoption: Essays in Social Policy*, London: Tavistock, 1984, pp38-41.

<sup>20</sup> If an adopted person already knows their original name and the agency that placed them, they can bypass the official route for access to their original birth certificate, therefore it is impossible to have accurate figures in relation to those who do and do not search for their genetic parents.

sought background information or contact with a birth relative.<sup>21</sup> However, there are few studies regarding the numbers and characteristics of the people who search for information relating to their background. Although Triseliotis did find that the need for information and/or contact was often felt by adoptees who had not been given sufficient information about their origins, or those who had gone through a major crisis or life-changing event<sup>22</sup> - characteristics that could almost certainly apply to some AID children.

There are however differences between adoption and AID. Adoption involves finding parents for children who already exist – it is primarily seen as being child-orientated and as having a childcare function; assisted reproduction is generally viewed as creating children for prospective parents. Also, within adoption there will be no genetic link with either social parent; often within AID, there is a genetic link with at least one parent, except in cases of embryo donation. With adoption there may be some early bonding with the genetic father; in AID there can never be any such bonding process. In adoption, social motherhood and genetic motherhood are always separate; in AID, except in cases of full surrogacy, the social mother will generally carry the donor offspring throughout pregnancy, providing the opportunity for early bonding. Another important difference is that the adoptee must often come to terms with the fact that they were relinquished by their biological mother. This may be a complicating factor in the adoptee's motivation to find out their genetic origins, because they want to find the answer to the question – “why was I given up?” In AID, the opposite is true – an AID child is always very much wanted long before they are born. Being told the truth about their conception at an early age ensures that they will know this and they will never have to come to terms with the knowledge of

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<sup>21</sup> J. Feast & D. Howe, *Adopted adults who search for background information and contact with birth relatives* (1997) 12 A&F 8.

<sup>22</sup> *Op cit*, Triseliotis, fn 16.

apparent rejection, unlike adoptees. However, this does not mean that the “*psychological need*” to know about their genetic origins may not be as great as that of adoptees. Their genetic background is still a missing piece of their “*genealogical jigsaw puzzle*” and it seems logical to suppose that, if information about genetic background forms an important part of one child’s identity, i.e. the adoptee, this could very well be the case for AID children.

To conclude, it seems wholly inconsistent to draw an analogy between adoptees and AID children and then go on to argue *for* the rights of adopted children but *against* the rights of children born by AID. Indeed, as Haimes acknowledges, “[A]rtificial reproduction could learn from the omissions and mistakes of adoption rather than simply accepting that the problems of secrecy in adoption have been resolved.”<sup>23</sup> However, it has been accepted that the sensitivity of the issues involved in AID may present problems not encountered within adoption circles. Therefore, whilst adoption may provide some useful guidelines for the future regulation of the AID child’s right to an identity, it may not provide a complete solution.

### **3 The Rights of the Australian A.I.D Child – a model for the UK?**

It is therefore proposed that the UK government might benefit from looking to other, perhaps more liberal, jurisdictions on the way forward for British donor offspring – in particular Australian legislation. Three of the eight Australian states and territories now have legislation relating to assisted reproduction, but all states are covered by guidelines issued by the National Health and Medical Research Council

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<sup>23</sup> E. Haimes, *Secrecy: What can artificial reproduction learn from adoption?* IJLF (1988) 48.

(NHMRC),<sup>24</sup> which contain an explicit commitment to supporting the right of AID children, “*to knowledge of their biological parents.*”<sup>25</sup> However, it is the state of Victoria that seems to have taken the most dynamic approach to these issues. It was the first in the world to regulate the assisted reproductive technologies (ART’s) by enacting the Infertility (Medical Procedures) Act 1984, following the recommendations of the Waller Committee report in 1982.<sup>26</sup> The Waller Committee concluded that, “*it should be possible for everyone to discover their origins,*”<sup>27</sup> although it acknowledged that the DI child’s social parents could not be *forced* either to tell their child about the nature of their conception or to provide information about the donor.<sup>28</sup> However, considering that the Waller Committee was compiling its report at approximately the same time as the Warnock Committee in the UK,<sup>29</sup> the differences in tone are quite astounding. The 1984 Act went on to provide that AID children should be allowed to receive non-identifying information about the donor, again in stark contrast to the HFEA 1990 that ensued from the Warnock Report.

Following a review of the 1984 Act,<sup>30</sup> the Infertility Treatment Act 1995 was passed<sup>31</sup> and it is proposed that this progressive piece of legislation could be used as a model for the UK. The Act contains several explicit guiding principles – highlighting many of the concerns touched upon in this paper. The most important is that, “*the **welfare** and interest of any person born or to be born as a result of a treatment procedure are **paramount***” (emphasis added).<sup>32</sup> The other being, in

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<sup>24</sup> Established by the National Health and Medical Research Council Act 1996.

<sup>25</sup> *Ethical Guidelines on Assisted Reproductive Technology (AGPS)* NHMRC 1996, para 8.5.

<sup>26</sup> Chaired by Professor Louis Waller.

<sup>27</sup> Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilisation, *Report on Donor Gametes in IVF (CCSELIAIVF)* 1982, para 3.29.

<sup>28</sup> *Ibid.*

<sup>29</sup> Department of Health and Social Security, *Report of the Committee of Inquiry into Human Fertilisation and Embryology* Cmnd 9414, London: HMSO, 1984.

<sup>30</sup> Conducted by the Standing Review and Advisory Committee on Infertility (SRACI).

<sup>31</sup> Becoming effective on 1 January 1998.

<sup>32</sup> Section 5(1)(a) Infertility Treatment Act (Vic).

descending order of importance: the preservation of human life, consideration of the interests of the family as a whole and the proposition that infertile couples should be respected and aided in their attempts to conceive.

Most important of all within the Infertility Treatment Act 1995 are its provisions relating to the DI child's right of access to information. A central register of information of *all* AID births is maintained by the Infertility Treatment Authority; a voluntary register is also maintained to provide an intermediary link between children by donation and their donors and donor families. Following the 1984 Act's provision allowing access to non-identifying information, the 1995 Act now allows for the DI child's access to identifying information once they reach the age of 18,<sup>33</sup> although they must first be offered counselling.<sup>34</sup> This provision, however, is not retrospective, therefore only applies to DI children born since the 1995 Act came into effect in 1998.<sup>35</sup> Despite this, the Victoria legislation appears much more liberal and child-orientated than anything we have so far experienced in the UK in relation to AID.

The Infertility Treatment Act 1995 also attempts to consider the position of all of the parties involved in the AID process. Provisions in the Act ensure that donors are encouraged to consider the implications of their donations and the possibility of future contact with the donor offspring, by requiring both donors and their possible spouses to consent to the donation;<sup>36</sup> to receive counselling before they do consent<sup>37</sup> and to

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<sup>33</sup> *Op cit*, fn 32, s 79(1)(b).

<sup>34</sup> *Ibid*, s 80. Once the donor offspring applies for such information, the Infertility Treatment Authority must make attempts to contact the donor to make them aware of this and also suggest counselling for them regarding the implications of this type of situation.

<sup>35</sup> Identifying information can be provided on a retrospective basis where the donor consented to being identified before the enactment of the new legislation. See further H. Szoke, *Regulation of Assisted Reproductive Technology* in I. Freckelton & K. Petersen (eds), *Controversies in Health Law* The Federation Press, 1999, p254.

<sup>36</sup> Sections 12 and 13 Infertility Treatment Act 1995 (Vic).

<sup>37</sup> *Ibid*, s 16.

receive advice about their rights of the AID children with regard to information concerning their donation.<sup>38</sup>

However, disappointingly, the right of the DI child to be told about their status is *not* enshrined within the Victoria legislation, further demonstrating the difficult and sensitive nature of the proposition of state intervention into what is essentially regarded by many as the private family sphere. The Victoria legislation does make some effort to redress the balance between the social parent and the donor offspring. Within the Act, there is provision to allow donors and recipients the right to obtain non-identifying information about each other from the Infertility Treatment Authority's central register and identifying information can also be made available if either party consents. Therefore, there is at least the possibility that children by donation may receive both types of information before they reach the age of 18 but only if: a) the donor has consented; b) their social parents requested the information before their infertility treatment and c) their social parents *choose* to pass on this information to their child. There is still no legislative mechanism to *compel* social parents to inform their AID child about the nature of their conception and, as demonstrated in chapters 2 and 3, this right to be told of their status is a wholly necessary concomitant of the AID child's right to receive information. Therefore, despite the apparently liberal and progressive nature and focus of the Victoria legislation, perhaps it still does not go far enough.

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<sup>38</sup> *Ibid*, s 17.



## 4 The Way Forward?

Therefore, in conclusion, this paper would make the following recommendations, all of which can be justified by reference to the arguments that have been put forward in the preceding chapters.

- The UK government **should** enact Regulations to provide more genealogical information to donor offspring than is currently available.<sup>39</sup>
- The non-identifying information currently held in the HFE Authority's Register **should** be made available to donor offspring applying to the Authority, **as soon as possible** in the near future (given that the first AID babies born since 1991 will now be aged 12 and approaching a critical stage in their psychological development). However, this information should only be made available when they are considered to be sufficiently mature to assimilate the implications of disclosure. This decision could be undertaken, with the input of the social parents, by at least two people with professional expertise in these matters, for example the donor offspring's GP, a social worker, health visitor and/or someone with experience in child psychology.
- The non-identifying information to be collected from future donors should be made available to donor offspring **during childhood**, again when they are considered to be sufficiently mature.
- The range of donor non-identifying information currently collected by the HFE Authority should be extended to cover more personal background information. The Authority should encourage licensed clinics to inform

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<sup>39</sup> HFEA s 31(3)(a).

donors that this information can be updated whenever they so choose and should facilitate their attempts to do so.

- Completion of **all** parts of the donor information form should be made a **compulsory** part of donation and the donor should not be allowed to veto disclosure of any aspect of this information. The importance of the completion of the form should be stressed to the donor before they consent to the donation, through advice and counselling. The possibility of this counselling also being a compulsory part of the donation process should be considered before Regulations are enacted.
- The payment of donors should be prohibited (payment for reasonable expenses should still be available). The HFE Authority should continue to examine ways in which more altruistic donors could be recruited.
- The number of times that one donor's gametes can be used in fertility treatments should be limited; possibly this number could be agreed between each individual donor and the clinic but it is suggested that usage should certainly not exceed 5 occasions.
- **Identifying** information should also be made to **prospective** donor offspring in the future, before they reach the age of majority, again once they are considered to be sufficiently mature. This should not be dependent upon the donor consenting to such information being made available and this should be explained to the donor at the time of their donation.
- A voluntary information exchange/contact register should be made available for all social parents, donors, donor families and donor offspring born both before and after the inception of the HFEA 1990. This could be established in new legislation and could be overseen by the HFE Authority on the basis that

they have the relevant expertise in collecting such data. Counselling of those who would like their details to be placed on this register should feature heavily in this process.

- All of the counselling services provided under the HFEA 1990 and the Code of Practice should be extensively reviewed and, where deemed necessary, improved for the benefit of all of the individuals involved in the AID process.
- Despite the government's current refusal to countenance the possibility of **identifying** information being made available on a retrospective basis, it is strongly advised that this decision should be seriously reconsidered, on the basis that the current legislation breaches the identity rights of the donor offspring.
- Further, although the right of donor offspring to be told of their status did not feature in the government's Consultation Paper, it is also proposed that this decision be reviewed to allow for changes in legislation and current practice. To give practical effect to the DI child's right to genetic background information, it is suggested that the government consider measures to protect the DI child's right to be told of their status by:
  - a) changing the current law on birth certificates to allow for an annotation to be made on the certificate drawing attention to the AID child's status.
  - b) examining the possibility of follow-up visits, for example by social workers, health visitors, etc., to the DI family to make the social parents aware of the importance of the DI child's identity rights and to encourage them to tell their child of the

nature of their conception when it is agreed by all that they are sufficiently mature.

- c) Improving and increasing the counselling available to the social parents, including counselling after the birth of their child; possible aspects of this advice and counselling could be made a compulsory part of their infertility treatment.

This paper has therefore sought to examine a number of areas concerning the rights of donor offspring that it considers to be ripe for reform – some that the government has already chosen to examine, others that it seems to have considered potentially too explosive to delve into. However, it is expected that the current inequities in the AID sphere will not continue for much longer. At the time of the publication of this paper, it has been reported in the national press that a written parliamentary statement on identity issues in AID is expected in the very near future.<sup>40</sup> It is anticipated that Melanie Johnson, the Public Health Minister will unveil plans to allow children born from donated gametes the right to be able to trace their genetic parents. Whether or not this report is correct and whether the content of such rights will go as far as has been proposed in this paper is as yet uncertain. What is clear is that any moves in this area will be welcomed and certainly seen as a step in the right direction for all those AID children who feel that they are still searching for the missing piece of their “*genealogical jigsaw puzzle*”.

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<sup>40</sup> *Sperm donor children win right to trace their fathers*, The Times, Sat 17 Jan 2004, p1.



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## **Appendix 1**

### **Article references**

- AF - Adoption and Fostering
- CFLQ - Child and Family Law Quarterly
- CFSW - Child and Family Social Work
- CLJ - Cambridge Law Journal
- CLP - Current Legal Problems
- FL - Family Law
- FLQ - Family Law Quarterly
- HR - Human Reproduction
- ICLQ - International and Comparative Law Quarterly
- IJLF - International Journal of Law and the Family
- IJLPF - International Journal of Law, Policy and the Family
- JCL - Journal of Child Law
- JRF - Journal of Reproduction and Fertility
- LS - Legal Studies
- MLR - Modern Law Review
- NLJ - New Law Journal

N.B. All other journals are referred to in full within the text

