

# *Donor Anonymity and The Right to Know – Ethics and Jewish Perspectives*

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## **1. The Halachic Obligation to Preserve the Parent's Identity**

The right to information regarding the identity of one's biological parents is a regularly recurring problem. This touches on a person's right, after growing up, to trace his genetic roots, in effect preventing incest and the possibility of birth defects which might result from the union of close relatives.<sup>1</sup>

Jewish law absolutely prohibits producing children when it is clear that their legal father's identity will remain secret.<sup>2</sup> Thus, for example, a widow or divorcee is prohibited from remarrying within three months of the end of her previous marriage.<sup>3</sup>

This is intended to prevent any uncertainty regarding the biological father of any child which the woman might bear at the beginning of the second marriage.

There are also convincing ethical reasons in support of preserving the identity of the genetic father. Among them are:

- (a) A fundamental human right to trace one's origins.
- (b) The prevention of incest and genetic birth defects which might result from the union of close relatives.

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## **2. The Fundamental Human Right to Trace One's Origins**

In 1984 Swedish legislation established the right of a child born as a result of artificial insemination to learn, on reaching maturity, the identity of his biological father. Swedish law, considered among the most advanced in the Western world, recognizes the unreasonableness of irreversible separation between a person and his biological roots.<sup>4</sup> So this fundamental human right is preserved in Sweden so that any adult person, whether naturally conceived or born of donated sperm, can know his genetic father.

This clear position underlying the Swedish law declares that "neither of these interests [of the adoptive parents and the natural parents] seems strong to deny a person essential knowledge about his own identity should he wish to have it. There can be few personal rights more fundamental than the right to know one's parentage."<sup>5</sup>

4. See *Act (1984:1140) on Insemination; Regulation and General Recommendation* - of 27 March 1987 - of the National Board of Health and Welfare on Insemination.

This legislation was based on the recommendations of a governmental commission which evaluated the rights of newborn children who were conceived by medical intervention. The commission determined in 1983 that there is a clear parallel between the fundamental rights of adopted children and those born of donated sperm.

5. Eekelaar John, *Family Law and Social Policy* (London, F. B. Rothman & Co., 1978), 272-273. (first ed.: 1978; second ed.: June, 1984. Quoted by Pinchas Shifman, *Dinei ha-Mishpacha be-Yisrael* (Jerusalem, Heb. U. Law Fac., Sacher Inst. for Legislation and Comparative Law, 1989; vol. 2, p. 62, note 9; p. 114, note 50.)

1. See Mordechai Halperin, "Preserving Parental Data," *Assia* 65-66 (vol. 17:1-2), Elul 5759, pp. 83-93.

2. *Iggerot Moshe, Even ha-Ezer* I:71 and II:18.

3. *Yevamot* 4:10.

There are negative psycho-social ramifications to not knowing the identity of one's parents. More and more adopted children are expending efforts to trace their biological parents in order to complete their sense of personal identity.<sup>6</sup> One clinical study points to emotional tension observed in adopted children, resulting from the absence of clinical genetic data regarding their biological parents.<sup>7</sup> Other studies also point to medical damage resulting from not knowing one's biological parents.

It seems that even without these studies we would conclude that the essential human need to build an individual identity includes the right to know one's genetic parents even in the absence of any potential medical damage, for in the absence of information identifying one's parents, no one can complete his self identity. So a fundamental human right in enlightened society would be abrogated.

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Thus, new regulations were instituted in England regarding provision of information on donors of sperm, eggs and fetuses, which became valid on 1 July 2004. These regulations differentiate between information received from a donor before April 2005 and that received afterward. Regarding information received from a donor

before April 2005 that is held by the Human Fertilization and Embryology Authority (HFEA): HFEA must provide information on the donor following a request presented by a person born through donation of sperm/egg/fetus, who has reached 18, without providing information that

6. P. Turnpenny, "Introduction", in P. Turnpenny (ed.), *Secrets in the Genes: Adoption, Inheritance and Genetic Disease* (London: British Agencies for Adoption and Fostering, 1995), 1-8.
7. See S. Michie & T. Martteau, "Knowing Too Much or Knowing Too Little: Psychological Questions Raised for the Adoption Process by Genetic Testing", in P. Turnpenny (ed.), *Secrets in the Genes: Adoption, Inheritance and Genetic Disease*, 166-175.

might reveal the identity of the donor. Regarding information received after April 2005, the Authority will also provide, on request, details on the identity of the donor, such as surname and first name of donor; donor's date and place of birth, a physical description of the donor and his last known address.<sup>8</sup>

Claims to the contrary, supporting sperm donor's anonymity despite the damage done to their offspring, generally rely on the donor's right to privacy. The donor's right to privacy may indeed be weighed against the more fundamental right of the offspring to preserve his identity.<sup>9</sup> The offspring's right is, of course, more fundamental.<sup>10</sup> Indeed, the Swedish experience demonstrates that it is possible to establish a set of normative laws which prevents conflict between these two rights: Prior to the donation, the donor is made aware of the offspring's legal rights. His agreement to donate under the framework of the law thus constitutes his willingness to have his identity revealed in the future. The Swedish experiment demonstrates that a set of normative laws can preserve the right of the offspring to identify biological parents without reducing the willingness of the donor to donate, although the donors' socioeconomic profile might indeed be affected.

In the State of Israel, the Aloni Commission at first proposed in its interim report that this universal right should be preserved in Israel as well. Accordingly, any child conceived of donated sperm would have the right, upon attaining maturity, and after receiving appropriate guidance, to learn basic details concerning his biological origins. Further, this right to knowledge would not

8. Human Fertilization and Embryology Authority (Disclosure of Donor Information) Regulations 2004, on the official British legislation site: <http://www.hmso.Government.uk/acts.htm>, date of entry: 16 February 2005, quoted by N. Mei-Ami, "Sperm Donation in Israel", *Jewish Medical Ethics* Vol. V, No. 2 June 2006, pp. 14-25.
9. For a relevant discussion of personal identity and bibliography, see Barbara B. Woodhouse, "Are You My Mother: Conceptualizing Children's Identity Rights in Transracial Adoptions", *Duke J. Gender L. & Policy*. (1995), 107. (<http://www.law.duke.edu/journals/djglp/djgv2a7.htm>)
10. M. Shamgar, The Chief Justice of the Israeli Supreme Court, Case 5942/92, *John Doe vs. Jane Doe et al.* Court Reporter, vol. 84, pt. 3, 1994, pp. 839-846, sect. 7c and the summary in sect. 8.

impose any legal obligations on the donor. This suggestion was indeed more limited than the liberal Swedish approach and called for establishing the right of the offspring to receive unconditionally non-identifying information regarding his biological parents. Receipt of identifying information was to be dependent on the consent of the biological parent.

Acknowledging this right of the offspring requires a registration system encompassing both the identity of genetic parents and the identity of the legal parents who raised the child. The Aloni Commission even indicated that such arrangements are already mandated by legislation in England and in Australia.<sup>11</sup>

After publication of the Aloni Commission's interim report, two gynecologists appeared before the Commission and informed it that the Swedish law led to a significant decrease in sperm donation. They did not provide the Commission with any details regarding the degree of this decrease. Nor did they provide any data regarding changes in the characteristics of the donors or the ramifications of financial compensation paid to the donors. The common claim that granting a future right to receive information regarding the donor's identity would lead to a drastic decrease in the number of potential donors remained unsupported by any documentary evidence.<sup>12</sup>

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In order to clarify the matter in a more definitive manner, I met with Prof. Lars (Lasse) Dencik<sup>13</sup> in Copenhagen in January 1996. Prof. Dencik was involved in the debate and the recommendations prior to the Swedish legislation. According to him, reports disseminated around the world regarding the situation in Sweden were simply incorrect. In fact, there was no decrease in available donors. The one change which did occur involved the donors' socioeconomic profile. Instead of young, poor donors who donated sperm for financial compensation, donors after the passing of the new law the donors were older, financially better off and more responsible because they were not concerned with producing another

offspring who might, upon attaining maturity, track them down. In effect, there was no decrease in the number of donors and there were no new difficulties in finding donors after the passing of the new law.

We are left with the impression that the uncalled for conclusion that Sweden suffered a decrease in sperm donation was disseminated by certain parties wishing to block liberal tendencies which would protect the right of offspring to track down their roots and to maintain the *status quo ante* according to which finding one's genetic father was purposely rendered impossible.

In fact, the strongest reason to maintain the status quo is the operational convenience of the fertility clinics. Strict adherence to the law regarding the preservation of adoption information and the maintenance of an orderly, regulated adoption register would be highly inconvenient for

(mistaken, as the Swedish experience has proven) that the absence of anonymity "will in the majority of cases put an end to sperm donation thereby preventing fertilization in many cases," p. 39 in *Ha-Praqlit*.

11. The Aloni Commission Report, sect. 4.4, p. 25, reprinted in *Asufat Maamarim liqrat ha-Kinnus ha-Beinleumi ha-sheini le-Refuah Etika, ve-Halacha* (Schlesinger Inst., Jerusalem, 1996), p. 152. For the Aloni Commission interim report see *Assia* 65-66 (Elul, 5759), pp. 94-111. For background regarding the Aloni Commission, see *ibid.*, pp. 83-84.

For an international comparison of legislation on Donor Anonymity, see *Third Party Assisted Conception Across Cultures*, E. Blyth and R. Landau eds., Jessica Kingsley Publishers, London, 2004; N. Mei-Ami, Sperm Donation in Israel, *Jewish Medical Ethics* Vol. V, No. 2 June 2006, pp. 14-25.

12. Schiffman, *ibid.* (n. 5), p. 152, note 52; the Chief Justice, Meir Shamgar, "Sugiyot be-Noseh Hafrayya ve-Leidah," *Ha-Praqlit* 39, 21-43, barely agreeing to anonymity only on the basis of an estimation

13. Director of the Program for Comparative Research at the "Centre for Childhood and Family Research" at the Roskilde Universitetscenter, Denmark.

the clinics which, without legislation mandating such a register, operate without the need to keep such records.<sup>14</sup>

Those who wish to deny the offspring's right to knowledge regarding his biological parents claim that adoption cannot be used as a model because in cases of adoption there is greater risk of the offspring's discovering the fact of adoption from his peers even if his parents try to maintain the secret. In such a case the offspring will perceive the fact of adoption as a double betrayal encompassing both his birth parents who appear not to have wanted him and his adoptive parents who hid the facts from him. In medically assisted fertility cases, on the other hand, the chances of maintaining secrecy are much greater and revealing the facts would entail no element of rejection or abandonment.

14. "In recent years social workers and others in the field of mental health have been encouraging openness within non-biological families, unlike the conspiracy of silence and secrecy which was the rule in the past. In the light of experience, primarily in the area of adoption, it has become clear that suppressing information regarding the circumstances of a birth entails a certain denial of the uniqueness of familiar relationships and is liable to adversely effect the child's emotional development. Further, the right of adopted children, upon reaching maturity, to find their biological origins is today recognized. Among other reasons this is because of the fundamental need to complete an independent identity" (from the Interim Report [*Assia* 65-66, pp. 94-111], ch. 2:3). Indeed, "on this matter the interests of the adoptive parents and the natural parents seem to coincide in opposition to those of the adopted person... But neither of these interests seems strong to deny a person essential knowledge about his own identity should he wish to have it. There can be few personal rights more fundamental than the right to know one's parentage." as has already been made clear in Eekelaar John, *Family Law and Social Policy*, London, F. B. Rothman & Co., 1978, 272-273, (2<sup>nd</sup> ed. 1984). A proper register is required in order to guarantee this right. The Israeli Law of Adoption (originating in the year 1960) was among the first in the world to establish the government's obligation to maintain an adoption register, granting the adopted child the right of access to the register upon reaching the age of eighteen. According to Israeli Marriage and Divorce Law, which prohibits sibling incest, the registrar of marriages is also entitled to examine the adoption register in order to verify that the proposed marriage suffers no impediment of incest. This liberal approach of Israeli law, recognizing the right to trace one's biological roots, is accepted today in many enlightened states. The right of the adopted child to trace his roots upon attaining majority was almost unique in Israeli law when first legislated in 1960, as only Scotland and Finland had similar laws at that time (Shifman, *ibid.* note 5). In the course of the years, more western nations have recognized the human right to trace one's roots.

In my opinion, these claims are baseless. These are my reasons:

1. The fundamental human right to know one's biological parents is in no way dependent on the possibility or impossibility of maintaining secrecy. We are speaking about a fundamental human right, which is unconditional, as understood by the Swedish legislature.

2. In modern times it is impossible to hide from a child the fact that he is the product of medically assisted fertilization with donated sperm even if the procedure were conducted in the utmost secrecy. The reason for this is simple: HLA and DNA testing is quite common and shows definitively that the offspring is the product of donated sperm.<sup>15</sup> Discovery of this fact after it had been hidden for many years would certainly not contribute to a person's mental health.

It is similarly claimed that after more than forty years of experience in sperm donation there is no verifiable evidence that offspring have any emotional need to know who their biological parents are despite clear indications that adopted children do have such a need.

This claim too, which is based on the absence of evidence, cannot subvert the fundamental human right to know who one's biological parents are. Remember too that forty years ago similar claims were heard in opposing granting adopted children this right. Then too "there was no verifiable evidence that children have a need to know." Only in the course of time has this need become apparent, as is codified in Israeli law, one

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15. Such testing is becoming more and more common for various medical purposes. With the completion of the Human Genome Project, genome mapping will almost surely become routine. See M. Halperin, Human Genome Mapping: a Jewish Perspective, *Jewish Medical Ethics III*, 2:30-33 (1998).

of the most advanced in the Western world, and as has recently been legislated in other liberal countries.

The fundamental human right to know who one's biological parents are was acknowledged in 1989 in the official United Nations "Convention on the Rights of the Child."<sup>16</sup> This Convention recognized the child's rights to maintain its identity and familial lineage. It follows that the change accepted by the majority of the Aloni Commission<sup>17</sup> does not accord with the International Convention of 1989.

The will of a human minor to know his/her origin "in order to maintain its human, familial and property rights" was recognized as a fundamental right by the Supreme Court as well in 1994. The Chief Justice of the Supreme Court of Israel, M. Shamgar, expressed the majority view of the Court:

"Minor enjoys the right to human dignity. Among other things, he is privileged, for the sake of maintaining personal human dignity and for the sake of guaranteeing his legal rights according to his personal law and the laws of property rights, to reject categorization as children-without-known-fathers. Rather, he may demand to know who his father is... Further, proper regard to the benefit of the child is one expression of human dignity....

The minor's objection to anonymity is reasonable and accepted. There are those who claim that man's superiority over animals consists, among other things, in man's knowledge of his origin. This means that the right to know one's immediate origins is part of our charge in guaranteeing human dignity.

...In balancing these rights, the minor's right prevails as he is liable to remain entirely devoid of the right to dignity and benefit and to be seriously damaged in his human personal and property

16. See *United Nation Convention on the Rights of the Child*, art. 8, Nov. 20, 1989, I.L.M. 1448, 1456.

17. Report of the Aloni Commission, ch. 4, Registration.

rights if someone else's right "not to be known" is allowed to prevent or even prohibit a reasonable decision by the court of jurisdiction which is responsible for balancing between the benefit of the plaintiff and that of the minor."<sup>18</sup>

### 3. Preventing Incest and Congenital Defects resulting from the Union of Close Relatives

The Aloni Commission also considered the possibility of using a register in order to prevent incest. From a biological point of view there is no doubt that the offspring's genetic characteristics are inherited from its biological parents. Similarly, it is known that the union of biological siblings greatly increases the incidence of serious birth defects in their offspring. Such offspring are "highly exposed to illness and death".<sup>19</sup> Although our concern here is with marriage of paternal siblings with no maternal relationship and although the risk of severe birth defects is smaller in such cases than in full siblings, genetic calculations show that the risk is still rather high. This fact as well supports keeping a record of the genetic father in order to avoid incest and the union of genetic siblings.

Some people feared that allowing the civil registry office full access to a person's data, as is the case with adopted children seeking a marriage license, might adversely and unnecessarily effect the fundamental right to privacy. Therefore, as a compromise, the Aloni Commission agreed in its interim report to limit the right to access so as not to adversely effect the principle of privacy, while simultaneously preventing incest. The solution agreed upon in the Commission's report included the right of access to computerized information which would cross match the data of couples

18. Case 5942/92, *John Doe vs. Jane Doe et al.* Court Reporter, vol. 84, pt. 3, 1994, pp. 839-846, sect. 7c and the summary in sect. 8.

19. 17-38% mental retardation, 37-69% congenital defects, 10-23% neonatal death. See A. Pinhas-Hamiel and B. Richman, "Incest -- The Sin of the Fathers upon the Children," *Ha-Refuah* 121 (Oct., 1991), pp. 252-253.

seeking a marriage license and either verify or reject any genetic relationship. The computerized report would not provide any additional information in cases where there is no genetic impediment to marriage.

In order to avoid stigmatizing children born as a result of medical fertilization, the interim report agreed to include children not born through medical fertilization in the register as well. The central register, according to this proposal, would be intended to identify any and all cases of inappropriate genetic correlation between candidates for marriage.

After publication of the interim report, the Aloni Commission heard further opposition to maintaining the child's right of determining, upon attaining majority, his biological origin. Some claimed that the probability of incestuous marriage as a result of artificial insemination is no greater than the existing risk of incestuous marriage in the general population, where adulterous unions could have the same result. No factual support could be brought to support this claim.<sup>20</sup> Indeed, even according to this claim, the risk of incestuous marriage must increase. Further, this increase is

20. Analysis of Israeli data indicates a significant likelihood of random mating between genetic siblings. Assuming 100 decedents from a single sperm donor (the number is higher in some fertility clinics), the chance that siblings will meet is very high. This takes into account the fact that every young person in his or her 20s meets thousands of other youths from the same age group. Therefore, in a small country like Israel the chance of meeting a genetic sibling is real. It is however difficult to estimate the probability that a romantic union will result from such meetings because we have no established data regarding the influence of genetic relationship upon romantic attraction between siblings who did not grow up in the same family. In all likelihood, the chances of incest are not small. Therefore, we should reject statistical calculations which do not take these data into account as well as calculations of the likelihood of sibling meeting in other, larger countries.

A simple calculation demonstrates the high probability of random meeting of genetic siblings in Israel: A sperm donor can produce 100 offspring in a situation where there is no overall control, as in Israel. Assuming that the population of young people between the ages of 16 and 26 is around 500,000 (among whom the 100 offspring of the single donor are distributed), it follows that the in average one such offspring will be found in each group of 100/500,000. This means that one offspring of the donor is to be found in each random group of 5,000 young people. If we assume that an average young person meets in this period of his life around 5,000 young people of the opposite sex, the probability of random meeting with a biological sibling is almost 100%.

not due to personal, uncontrollable factors but rather to medical technology which can be easily monitored to prevent any breach. It seems that this claim must be rejected in the face of the offspring's right to seek its roots and society's obligation to prevent, as far as possible, incestuous marriage and preventable birth defects.

Some respondents claimed that even in the face of risk of genetic disease resulting from the relatedness of the candidates for marriage, given expected technological advances the couple can choose to undergo genetic screening,<sup>21</sup> thereby eliminating the risk of incest and genetic disease. In fact, it is clear that as long as such screening is not obligatory, most of the population will choose not to be tested. Thus the possibility of screening cannot be relied upon to prevent incest. It follows that this claim too does not justify a rejection of the register which is intended to prevent medical problems arising from the union of relatives.

Others claimed that we can significantly reduce the risk of incest by limiting the number of pregnancies which a single sperm donor can effectuate. Such a limitation would act to eliminate "professional" sperm donors.<sup>22</sup> This claim also must be rejected because, among other reasons, such limitation cannot be enforced without a complete central register such as exists in Great Britain. Today there already exist guidelines which limit the number of donations a single sperm donor may make. But professional conventions in Israel have shown that such guidelines are not followed and cannot be enforced.

Still others were concerned about the "inevitable" possibility of error in the register or in the computerized routing of the data. They were further concerned about the possibility of illicit hacking of the computerized data base.<sup>23</sup>

In my opinion, these claims cannot alter the Commission's recommendation to preserve parental data because there already exist today

21. The Report of the Aloni Commission, *ibid.* sect. 4.7.

22. The Report of the Aloni Commission, *ibid.*

23. The Report of the Aloni Commission, *ibid.* sect. 4.8.

extremely sensitive data bases where any leaking would constitute a danger to national security or national economy. Nonetheless, none of these data bases has experienced any leakage. Today we have very effective technological solutions to prevent the loss of sensitive data. There is every reason to assume that similar solutions will be effective for the parental data base.

We can also overcome, without causing irreversible damage, the claim that errors might be made.

It is therefore clear that there is no real basis for the opinion that the damage which might result from operating a central register would exceed the benefit which would accrue in protecting the offspring's right to knowledge. Such an opinion is not based on facts or real data, but rather on subjective speculation and irrational fears.

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The natural conclusion is that both on the basis of the fundamental human right to trace one's genetic origins and on the basis of public health policy intended to prevent congenital birth defects resulting from the union of family members:

a. The right of the offspring produced as a result of sperm donation must, upon attaining maturity, have the right to know his genetic parents. This right is to be preserved through the registry system described above.

b. The data relating to the genetic identity of the sperm donor must be held in a secure system in order to enable the offspring to realize his right to know who his father is and to identify his genetic roots. This will prevent incest as well.

#### 4. Summary

It would not be wrong to say that a uniform registry system for sperm donors and their offspring can in effect solve the two problems and enable realization of the offspring's right to find his biological roots<sup>24</sup> regardless of which parent donated the reproductive cell.

It follows that the absence of a supervised registry system recording genetic parents conflicts with the values of an enlightened society, the rights of the individual and the benefit of the offspring.

It would seem that within a few years we will look back in amazement to this period when the fundamental rights of offspring are infringed.<sup>25</sup> Modern legislatures and legal systems must guard the fundamental human rights including those elements which touch on the individual's identity. This surely includes the right of every person to know his parents and to fully grasp his identity.

24. Discussion of the a parent's right to trace his or her children (especially an only child) is beyond the scope of this article. The parent's rights ought to be addressed separately.

25 See: Eric Blyth, Donor anonymity and secrecy versus openness concerning the genetic origins of the offspring: international perspectives, *Jewish Medical Ethics* Vol. V, No. 2 June 2006, pp. 4-13.