The choice of the system of disclosure of the identity of reproductive material donors in Sweden – Application in practice

I. Introduction

Heterologous fertilization happens to be one of the most widely applied techniques in the domain of medically assisted reproduction, applicable as it is both in association with insemination and within the context of in-vitro fertilization. The choice eventually made by national legislators as to the system to be instituted with respect to the disclosure of the identity of reproductive material donors – essentially opting between the anonymity or the disclosure of the donors’ identity - is understandably an aspect intrinsically related to such techniques. In that sense, there are legal orders likes those of Sweden, the United Kingdom, Austria and Switzerland where the principle of anonymity has already been abrogated just as there are countries like Greece\(^1\) and France\(^2\) where such principle remains legislatively valid.

The complexity of this particular issue becomes all the more evident through a series of arguments, some of which seem to corroborate the appropriateness of the donor remaining anonymous whereas others aim at justifying an offspring’s possibility to become informed of the donor’s identity. It is worth noting that in either case, the arguments put forward invoke in justification the offspring’s true interest – as perceived and identified by each side.

II. The Swedish legislative framework

a) In Sweden, the legislator attempted to balance all such arguments put forward by either side before eventually deciding to prime the offspring’s interest of becoming informed of one’s origins. This made Sweden the first state worldwide to opt, already in 1985, for granting offspring born by way of heterologous insemination and later on, since 2005, those born through in-vitro fertilization, the right to become informed of the identity of the donor, once sufficiently matured. Up until 1985, donors in Sweden used to be and remained anonymous both to the couple of


recipients and to the child born to such couple. Medical files featuring information relevant to the identity of the donors used to be destroyed so that it was impossible for a sperm donor to be identified at a later time. Registered as they were as the offspring’s true parents, the mother and the non-biological father were further also advised to refrain from informing their child or any other party whatsoever as to the fact of the offspring’s having been born by way of heterologous insemination.

Under the new system, when it comes to births happening by way of insemination, access to information is regulated under Article (5) of Chapter (6) of the Genetic Integrity Act (2006:351) whereas in the case of births obtained by way of in-vitro fertilization, Article (7) of Chapter (7) of said Act applies. Further provisions relevant to this issue may be found in SOSFS 2009:30, with respect to donation and supply of organs, tissue and cells. More specifically, in Articles (4) and (5) of Chapter (4), there is reference as to the offspring’s right to become informed of the donor’s identity as well as to the obligation of making the donor aware of the potential of an offspring born of his/her genetic material trying to identify such donor. In the light of such considerations, it is obvious that Sweden currently disposes of a comprehensive legislative framework with respect to access to genetic material donor’s identification data.

Thus, according to the Swedish legislation, both in the case of insemination and in that of in-vitro fertilization, the offspring alone is entitled, if so desired, to become informed of one’s origins as well as of the donor’s features. This is the purpose of establishment of a Donors’ Record featuring codified donor identification data.

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9 Interestingly, as of a survey conducted in Sweden in this matter, most sperm donors have been shown to have a positive stance vis-à-vis the prospect of being potentially contacted in the future by offspring born through their genetic material. There have been some, however, who stressed that there pays to be drawn a clear distinction between an offspring legitimate interest to become informed of the donor’s identity and the eventuality of actual contacts between offspring and donors. See E. Ekerhovd/A. Faurskov/Ch. Werner, “Swedish sperm doors are driven by altruism, but shortage of sperm donors leads to reproductive traveling”, Uppsala Journal of Medical Sciences, 2008; 113 (3), p. 310-311.
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data along with the possibility of also including a photograph, the whole meant to be preserved for a period of seventy (70) years.

b) It is just as important to stress, however, that this particular right, also embedded under the GIA, applies for all descendants of genetic material donors, provided they have been conceived whether at a hospital funded by the Swedish State or at a clinic authorized by the National Board of Health and Welfare to carry out medically assisted reproduction sessions. On the contrary, offspring born by use of genetic material outside Swedish territory or by way of insemination performed in private establishments, may not invoke GIA provisions.

c) Under the Swedish legislation, the right to information is unconditional, since it has been instituted exclusively to the interest of the offspring. The parents of such offspring have no right of access to any information likely to identify the former. Nor have donors the right to identify those offspring born by use of their reproductive material, just as they may not be informed of the identity of the social parents of such offspring.

Offspring may have access to such records when “sufficiently mature”. The upper teens, i.e. sometime between the 17th and the 18th year of age, have eventually come to be considered as the point in age where they are “sufficiently mature. In any case, specialists in the field at the various social welfare services and/or at hospitals are expected to evaluate an offspring’s maturity, this being the way whereby it may be

10 See: in the case of insemination, Article (2) of Chapter (6) whereas in the case of in-vitro fertilization, Article (4) of Chapter (7).
14 See: in the case of insemination, Articles (4) and (5) of Chapter (6) GIA (2006:351) whereas in the case of in-vitro fertilization, Articles (6) and (7) of Chapter (7) GIA (2006:351).
ensured that a person is actually mature enough to be informed of the donor’s identity.\footnote{16 J. Stoll, Swedish donor offspring and their right to information, p. 46.}

Social services are indeed under the obligation of assisting the offspring in whichever way possible, in the offspring’s quest for the donor. As a matter of fact, the entire administration of the State is required to operate towards helping offspring to find out who the donor is, by use of the genetic material of which they came to this world.

Meanwhile, there is no reference in the law as to who shall be competent to actually inform the offspring. Still, an offspring is more likely to be informed about its conception by way of heterologous insemination through one’s social parents.\footnote{17 C. Gottlieb/O. Lalos/F. Lindblad, “Disclosure of donor insemination to the child: the impact of Swedish legislation on couples’ attitudes”, Human Reproduction, 2000, vol. 15 No 9, p. 2052 – See also A. Lalos/C. Gottlieb/O. Lalos, “Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking”, Human Reproduction, 2007, vol. 22 No 6, p. 1759. According to such scholars, further to the parents, a third party may also, albeit involuntarily, reveal such fact to the offspring. Equally likely is for the offspring to become informed through a genetic test or within the context of a biology course attended, at school. – Quoting the Swedish National Council on Medical Ethics, Assisted reproduction-ethical aspects (Summary of a report), p. 4-5, parents should already at an early stage make the children aware of their origins.}{18 J. Stoll, Swedish donor offspring and their right to information, p. 72.}

III. Conforming to the legislative framework

Much against expectations of the drafters of this particular legislative framework in Sweden, a considerable number of offspring born by use of the reproductive material donated by a third party shall ultimately find out about the way whereby they were conceived through persons other than their parents. Unless informed about the involvement of a donor in one’s conception, an offspring is not in a position to exercise one’s right to information. Still there is no-one competent to coerce parents into revealing such fact to the child. Thus, despite the legislative provisions, the reason of adoption of which has mostly been to best serve the interests of the offspring, for most of such offspring the system is practically of no real use.\footnote{18 J. Stoll, Swedish donor offspring and their right to information, p. 72.}

IV. Research data

a) Within said context, a series of surveys have been conducted in Sweden, to the purpose of establishing whether and to what extent parents reveal to their offspring the fact that they were conceived by use of third-party reproductive material. A survey conducted in 2000 in the Department of Obstetrics and
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Gynecology at Umea University Hospital as well as in the Reproductive Medical Centre at the Karolinska Hospital\(^{19}\) showed that 89% of the couples had not revealed to their offspring the fact that their birth had been due to the use of donor sperm whereas 59% of said couples admitted they had made some third party privy to such information. Out of the 105 parents inquired, 61 said they intended to inform their offspring at a later time, 16 said they were not sure whereas 28 had already made their mind up not to inform their offspring. A justification commonly invoked by all for refraining from disclosure was a fear that may hurt the child” as well as that such disclosure was “unnecessary”. Some concern was also expressed as to the risk of offspring becoming informed through a third party, privy to that particular information.

b) In 2007, as of a follow-up survey\(^{20}\) to the previous one, there came to be demonstrated that more than half (61%) of the parents inquired had informed their offspring of the fact that they had been born by use of third-party genetic material whilst almost all of them had already revealed so to a third party. The mean age of disclosure for the first offspring was 5 years. Those having reported that they informed their offspring justified their decision to do so mostly by their concern to prevent any accidental discovery, the desire for honesty as well as by a commitment to what is seen as a fundamental right of a human being to know of one’s genetic origins. On the other hand, those parents having declared themselves to be reluctant to let their offspring know, affirmed that, to their opinion, the use of donated sperm is a private matter. What is more, they expressed concern about the potential reaction/attitude of others. In any case, 61% of all parents are as yet to reveal to their children that they have the possibility to find out the donor.

According to another survey, conducted in 2007\(^{21}\), 90% of the participants declared themselves to be in favor of disclosure and an attitude of honesty towards offspring, concerning their genetic origins. Only 6% of those questioned declared not to have shared with other persons the donation treatment whereas 40% of the


participants affirmed they wished to be further informed and supported in their parenting occurring in the wake of the donation treatment.

IV. Conclusions

In the light of outcomes of practically all surveys conducted in this field, the conclusion to be drawn is that in the course of time, more and more people are prepared to disclose the fact of conception by use of third-party donor reproductive material. Such fact in turn seems to herald that more parents might in the future feel prepared to make their offspring privy to such information\(^{22}\).

Whatever the reasons for one to be only moderately optimistic as to the developments in this field in Sweden, surveys under way consistently demonstrate that a number of offspring conceived by use of third-party genetic material will ultimately never have the opportunity to learn about their origins\(^{23}\). This however is a weakness understood to be inherent to GIA and to those structures instituted to ensure management of access to information\(^{24}\).

Moreover, there may expressed some quite serious reserves as to whether and to what extent such information system put in place to the interest of offspring, although theoretically quite sufficient, could ultimately be considered to function in practice or whether offspring are still and despite all facing practical problems, as of their quest of the donors of the genetic material having led to their conception.

What is nevertheless determinant of the success of either system adopted – i.e. that of anonymity of the donor of the reproductive material or of the disclosure of the latter’s identity – is the degree of conformity of the citizens to the provisions in the law. In Sweden, despite the shift having as of recent years been observed, parents still tend to conceal from their offspring the fact that they were conceived through a third-party donor. As long as sterility – especially male– even in countries like Sweden remains a taboo\(^{25}\), things may not be expected to change easily; the Swedes shall therefore continue to cross the border with Denmark, if anything to ensure that donors shall remain anonymous.

\(^{22}\) J. Stoll, Swedish donor offspring and their right to information, p. 80.
\(^{23}\) Stoll, Swedish donor offspring and their right to information, p. 81.
\(^{24}\) Stoll, Swedish donor offspring and their right to information, Uppsala, p. 81.
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