

## Disclosure of donor insemination to the child: the impact of Swedish legislation on couples' attitudes

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**The question whether or not parents of children conceived after donor insemination (DI) tell their offspring about its biological background was addressed. Swedish legislation from 1985 gives the child born after DI the right, when grown up, to receive identifying information about the sperm donor. Until now no information about compliance with the law has been available. All parents who gave birth to a child by DI after the new legislation in two major Swedish fertility centres (Stockholm and Umeå) received a questionnaire containing questions about the issue of informing the child. The response rate was 80%. The majority of parents (89%) had not informed their children, whereas 59% had told someone else. As a response to an open question, 105/132 parents chose to comment on their answer about not having informed their child. Of these families, 61 intended to tell their child later, 16 were not sure and 28 were not going to inform the child. Compliance with the law must be regarded as low since only 52% of the parents had told or intended to tell their child. In addition, concern is raised about the children who run the risk of being informed by someone other than their parents. Key words:** donor insemination/donor insemination children/donor insemination parents/infertility/openness

### Introduction

Donor insemination (DI), or insemination of a woman with spermatozoa from a man other than her husband, has been performed with infertile couples for centuries (Hummel and Talbert, 1989) and is one of the oldest techniques in reproductive medicine. DI has been officially performed in hospitals in Sweden since the early 1960s (Lalos *et al.*, 1998) and in the UK since 1940 (Brewaeyns, 1996).

Before in-vitro fertilization (IVF) with micro-injection of spermatozoa (ICSI: intracytoplasmic sperm injection) became a routine procedure, DI was the only possibility for conception for a couple with severe male factor infertility. Even now, a

couple's desire not to go through an ICSI programme, due to economic reasons or if no spermatozoa at all are available, means that DI is still the only option.

Until 1985 DI was performed world-wide without any legal restrictions. The donor was anonymous to the recipient couple as well as to the resulting child. In Sweden, medical files containing information about donors were routinely destroyed and the sperm donor could never be identified later. The mother and non-biological father registered themselves as the child's parents, and were encouraged not to tell the child or anyone else about the insemination (Sverne, 1990).

Based on knowledge from studies of the welfare of adopted children and of their wishes to learn about their biological roots, a law was established in Sweden in 1985 (SFS, 1984). This gave a child born as a result of DI the right, 'when sufficiently mature', to receive identifying information about the man who donated spermatozoa to his or her mother. According to the preparatory work of the law, this would include not only the identity of the donor but also information about hair colour, physique or profession. 'Sufficiently mature' is not defined in the law text. In the formal instructions from The National Board of Health and Welfare from 1987, where it was clarified how the law should be applied (SOSFS, 1987), the age is specified as 'the upper teens' with reference to the government bill. It should be mentioned that in Sweden 'maturity' is attained at the age of 18 years. According to the law, the social welfare agency has the responsibility for helping the child to get the information. In the instructions mentioned above it is stated that some kind of evaluation of the child's maturity should be performed by an expert either at the social welfare agency or at the hospital.

The law is indirect and does not indicate who is to inform the child. In the preparatory work for drafting the law, the importance of parental openness was emphasized and it was taken for granted that the parents would tell their children about their origin. As a result of this same legislation, the donor remains anonymous to the recipient couple and vice versa, and all records of the insemination are separated from official medical records. Therefore, the child's only possibility of finding out that he/she was conceived as a result of DI is by the parents revealing this to him/her.

Sweden was the first country in the world to regulate DI by law in 1985. Austria adopted a similar legislation in 1992 and later, in 1995, the Victoria State in Australia did the same. The year after the Swedish law was settled, Norway adopted a law which makes donors totally anonymous. In the UK, regulations in the Human Fertilisation and Embryology Act of 1990 declare that identifying information about donors must be stored by a central government organization, the Human

Fertilisation and Embryology Authority (HFEA), but that only non-identifying information about the donor may be disclosed to the child. In the USA and Spain, this anonymity can be abolished if the vital interests of the child are at stake (as decided by the court).

Apart from legislation, views vary as to whether or not children born as a result of DI should be informed. Some authors have argued that secrecy within a DI family undermines the trust between parents and child (Warnock, 1986; Clamar, 1989), and some have claimed it is a child's right to know his/her origin (Daniels and Taylor, 1993; Snowden, 1993). It has also been suggested by some authors that a child may develop identity problems if detailed information of the donor is not available (Haimes, 1993; Snowden, 1993), whereas Nachtigall *et al.* (1997) claimed that not disclosing information about DI protects both the couple and their child from negative reactions of society. The relationship between father and child, as well as the psychological health of the child, has been thought to be jeopardized if information about the DI treatment is revealed to the child (Cook *et al.*, 1995; Shenfield, 1997; Shenfield and Steele, 1997). Several studies have shown that the majority of couples entering a DI programme do not believe that the child should be told (Snowden, 1993; Bolton *et al.*, 1991; Owens *et al.*, 1993; Klock *et al.*, 1994).

At present, the issue of anonymity can be reduced to a conflict of interest between the right of the child to know its genetic origin, and the right of the donor family and the couple receiving donor spermatozoa to maintain anonymity. The United Nations (UN) convention, however, states that we must 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' (The UN convention on the right of the child, 1989). The implementation of this convention varies, and obviously great cultural differences exist.

Until now, no information has been available on the effects of the Swedish legislation or on compliance with the intentions of the law. Since Sweden has developed a special approach to the question of DI disclosure, such an evaluation is important from an international perspective.

One aim of the present investigation was to collect data about whether or not parents treated with DI after the passing of the new law in 1985 have informed their children about the children's biological backgrounds. An additional aim was to find out how and when the children were informed, and if the parents are satisfied with their decisions.

## Materials and methods

Two major centres for DI in Sweden, the Department of Obstetrics and Gynecology at Umeå University Hospital, and the Reproductive Medical Centre at Karolinska Hospital, were chosen for the study. The patients in these units represented a wide variety of Swedish urban and rural areas. In both centres the medical staff was stable over time, and couples were informed about the procedures in a uniform manner throughout the study period. All the couples uniformly discussed the Swedish legislation with the physician and the social worker.

All of the 194 couples who conceived a DI child after the Swedish

**Table I.** Children reported by parents; year of birth

Year of birth	<i>n</i>	%
–1985	8	5
1986–1987	21	14
1988–1989	22	15
1990–1991	8	5
1992–1993	15	10
1994–1995	38	26
1996–	36	24
Total	148	100

law was introduced up until 1997 were included in the study. They were sent a letter describing the study and a questionnaire to be completed. The parents were asked to answer the questions together. The questionnaires were returned anonymously; consequently, the reminder, mailed 1 month after the first letter, was sent to all the parents.

The questionnaire consisted of 17 questions, with both structured and open answer options. A condensed version of the questionnaire is given in Appendix A. The parents were asked if and when the child was informed about the DI, how the child had reacted to information about DI, and if the parents were satisfied with their decision to tell or not to tell their child. Parents were also asked if they had informed anyone else about the type of conception used. Parents who had not informed their child were asked to present the reason for this decision.

Nine of the letters were returned because the addressee was unknown at the postal address. The response rate from the remaining group was 80%. Sixty-two of the families had two or more children born as a result of DI; these parents were supposed to answer the questions with regard only to their first DI child born after the law but in a few cases the parents understood the instructions as referring to their oldest DI child. The children reported by the parents are presented by year of birth in Table I. When age of the child is referred to in the article, it is approximated from the year of birth.

## Results

A total of 94% of the couples were still living together at the time of the study. The sex ratio of the DI children was 53/47% (male/female). A total of 42% of the couples had an additional child conceived as a result of DI, and 18% had another child conceived differently (adopted child, biological child, step-child, or foster child).

One hundred and thirty-two of the couples (89%) had not told their children, and 105 of these commented on their decision in the open answer area of the form. In 61 of these 105 families, their intention was to tell their child about the sperm donation at a later time. The mean age of the children (approximated from the year of birth) in this group was about 3.5 years. In 16 families the decision whether to tell or not was not yet made. The mean child age (approximated from the year of birth) in this group was about 7 years.

Twenty-eight families intended not to disclose any information about DI to their child. Common reasons for not telling, as described in the open answer area, can be summarized as 'unnecessary' and 'may hurt the child.' The mean age of children (approximated from the year of birth) whose parents did not intend to tell was about 9 years.

**Table II.** Children who have been informed about DI origin, grouped according to age

Age of the child (years)	Total no. children	No. informed	% informed
12–15	16	1	6
8–11	39	7	18
4–7	37	5	14
1–3	56	4	7
Total	148	17	11

**Table III.** Children whose parents have told others about the use of DI, grouped according to age of child

Age of the child (years)	Total no. children	No. whose parents have told others	% whose parents have told others
12–15	16	5	31
8–11	39	20	51
4–7	37	24	65
1–3	56	38	68
Total	148	87	59

In 17 families (11%) the parents had told their child about the DI (Table II). In 14 of these 17 families, both parents had agreed to this. Fifteen of these 17 children were told about the DI before the age of 8 years with a mean age (approximated from the year of birth) of about 5.5 years.

A total of 59% of the couples had told someone else, in most cases a close family member, about the DI, and half of this group had told many other people. The frequency of parents revealing to persons other than their child that they had used DI differed depending on which year the child was born, with the highest frequency appearing to be in the latest group (Table III). Seventy (53%) of those who had not told their child had told others about the DI treatment. All of those who had told their child had also told others about their DI treatment.

The parents who had informed their child were satisfied with their decision to do so. No direct immediate negative effects had been noticed in the children.

## Discussion

According to Swedish law, a child born as a result of DI has the right to (when mature) receive identifying information about the donor. The majority of the children in the studied families were not mature or grown up, and this is one obvious reason why only 11% of the parents had informed their children. A total of 41% of the parents, besides those 11% who had already told their child, intended to reveal this information at a later date. The possibility that a child will not actually be told about the DI probably increases with the increasing age of the child.

A response rate of 80% must be considered high in this kind of survey, and the high frequency of answers to the open

questions probably reflects a keen interest in collaborating. However, one fifth of the couples who had conceived using DI did not return their forms. There are reasons to believe that the incidence of telling the child about DI is higher in the group that completed the questionnaires.

The results indicate that attitudes toward informing the child about DI have changed over time. The frequency of parents who had told their child increased from 6% in the group of children born 1983–1986 (i.e. before the new legislation) to 18% in the group born 1987–1990. Since the children were younger in the latter group, this difference will probably increase with time.

Attitudes toward informing the child seem to have increased over a longer time perspective as well. Results from a Swedish study (Milsom and Bergman, 1982) showed that only 1 of 92 couples interviewed intended to tell their child that they had been conceived using DI. More recently, however, Brewaeys (1996) found that the tendency to inform the child did not markedly increase over time, as deduced from 12 studies published between 1980 and 1995 in eight western countries. In these studies only 1–20% of the parents intended to inform their child. This is in contrast to the 52% who planned to inform their children in the present study (including those who had already done so).

One reason for the differences in disclosure patterns between Sweden and other countries may be that in Sweden it is possible to find out identifying information about the donor. Telling a child about DI treatment without having information about the donor available may be more difficult (Cook *et al.*, 1995).

Openness to telling people other than the child about a DI increased during the study period. The frequency of parents having told others increased from 31% in the group of parents with a child born 1983–1986, i.e. before the introduction of the new legislation, to 68% with a child born 1995–1998. Both these values are higher than those reported in an earlier study (Milsom and Bergman, 1982) in which only 15% of couples had told others about their use of DI. The values in the international studies reported by Brewaeys (1996) varied from 15–68%.

Whether the doubled frequency in telling others is an effect of the legislation in Sweden, or if it is due to changing attitudes over time, cannot be deduced from this study. If, however, telling others is the start of the process of informing the child, the values may indicate that the number of parents informing their children about DI will increase.

In the two centres which were the focus of this study, all the couples requesting DI consulted a social worker prior to making a decision about the treatment. The couples were thereby informed about the legislation and actively stimulated to inform their presumptive child about his/her biological background. They were also informed that the process of informing a child about DI is easiest if it is begun when the child is young, and if increasing amounts of information are added as the child ages. In view of this, the frequency of parents intending to inform their children may seem low. Some authors have argued that parents' willingness to tell their child may be influenced by the attitudes of the professionals with

whom the couples have consulted (Gillett *et al.*, 1996; Brewaeys, 1996).

Many parents do not agree that disclosure of DI is to the benefit of the child (Cook *et al.*, 1995). For that reason, it was suggested (Klock, 1997) that mental health professionals should maintain a neutral position regarding disclosure, and Shenfield (1997) proposed that parents' choices should be better respected. It is doubtful whether a neutral professional approach could be applied in Sweden, considering the intentions of the law. However necessary, it is a difficult task to respect parents' desires not to inform their children about DI, and at the same time work, as obliged, for the fulfilment of the intentions of the law.

The mean age of the children in the group of parents who had not yet decided whether or not to tell their children about DI was about 7 years. It should be noted that children below the age of 7 years are unable to understand the meaning of biological inheritance (Solomon *et al.*, 1996), and only those older than 7 years of age are capable of logical thought processes and reasoning (Piaget, 1955). However, a child grasps information more intuitively at an earlier stage (Piaget, 1955) and information given early to the child will be understood more easily and accepted later (Dudley and Neave, 1997). For instance, McWhinnie has argued that children may be told about their DI origin even from the age of 3 or 4 years, presuming the information is adapted to the child's capacity for understanding (McWhinnie, 1996). Another important aspect is that disclosure when the child has first reached the age of 10–12 years may affect the child negatively (LeLannou *et al.*, 1998).

Of the group of parents who had not informed their child of their DI origin (89%), 53% had told others about the DI. It stands to reason then, that even if all of the couples who said they intend to tell their children (41%) really do so, many children still risk receiving this information from someone else. If the situation is similar to that of adopted children (Golombok *et al.*, 1999), this may be hazardous to the welfare of the child. In a study from the Netherlands, 26% of parents had told someone other than the child about their use of DI, but did not intend to tell their child (Brewaeys *et al.*, 1997).

In the present study questions were given to both parents to be answered by them together. This may have influenced the answers. However, previous studies on differences in the attitudes of DI parents toward openness or disclosure have been inconclusive. Some authors found that openness was more preferred by the mothers than by the fathers (Schover *et al.*, 1992; Daniels *et al.*, 1996), whereas others did not find any differences (Berger *et al.*, 1986; Brewaeys *et al.*, 1997).

In conclusion, 52% of the parents studied had told or intended to tell their child about their use of DI. Compliance with the intentions of the Swedish legislation must therefore be regarded as low even though the number of parents willing to inform their child is high from an international perspective. Our results show that legislation alone is not sufficient to change personal attitudes in a population. We believe that stimulating ethical discussions within the responsible professional groups is of major importance as a complementary measure. Concern about those children who have not been

informed by their parents, but risk being informed by other persons in their surroundings, must be taken into consideration.

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## Appendix A. Questionnaire for parents

1. What year was your child born as a result of DI? Girl or boy?
2. Do you have additional children as a result of DI? Yes; no. Year of birth?
3. Do you have yet additional children? Yes (adopted child; other biological child; foster child; step child); no. Year of birth?
4. Has either of you ever told your child that he or she was born as a result of DI? Yes (if yes, continue with question 5); no (if no, please comment, and proceed with question 14).
5. Which of you informed your child? Mother; father; both together.
6. Were you in agreement that you would inform the child? Yes; no; don't know/don't remember. Please comment.
7. How old was the child when you first told him or her of their biological origin?
8. What made you tell him or her at that particular moment? Please describe how it occurred.
9. How many times have you spoken with your child about his or her biological origin? One occasion; several times.
10. Has the child brought up the subject of his or her origin? Yes; no. If yes, in what way?
11. Has the child asked about the sperm donor? Yes; no.
12. Do you think that telling your child about the DI has proved to be beneficial for him or her? Yes; no; not in agreement. Please comment.
13. Have you felt a need for assistance in telling your child about their biological origin? Yes; no. If yes, have you received any help in speaking with your child? Yes, as much help as we needed; yes, but not enough; no, no help.

If you have been assisted, who was it who helped you (for example, social worker, doctor, or a friend)?

If you did not get help, or not enough help, what type of assistance would you have desired?

14. Have you told anyone besides your child about the DI (for example, your own parents, other relatives, friends)? Yes; no. If yes, who have you told?
15. Did someone else inform your child about the DI? Yes; no. If yes, who told them? Did this occur with your consent? Yes; no. Please comment.
16. Do you (the parents of the child born as a result of DI) live together today? Yes; no.
17. What advice would you like to give other parents who have children as a result of DI?