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# DEBATE

## Sharing information with donor insemination offspring

### A child-conception versus a family-building approach

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**This paper suggests an innovative approach to the sharing of information between parents and their donor-conceived offspring. The 'family-building' approach is offered in the hope that it will stimulate discussion and development. Traditionally, the emphasis has been on telling the child about his/her donor conception. This has the potential to unintentionally separate the child from the parents. The family-building approach presents donor conception as an issue concerning all members of the family, thus encouraging the child to see him/herself as an integral part of this family's history. Within this approach, the semen provider is acknowledged for his contribution and for having an ongoing significance in the family. It is important, however, to clearly differentiate between him as the genitor and the child's father as the loving and nurturing male in the family. Implications for professionals include the need to acknowledge that donor insemination does not only enable a woman to become pregnant but that it creates a family with a past, present and future. Therefore it will be helpful to provide information about and explore attitudes towards this type of family-building before couples start treatment.**

*Key words:* assisted reproduction technologies/donor insemination/family-building/offspring/telling

#### Introduction

Mr and Mrs A have made the decision that they want their daughter Jane to grow up knowing that she was conceived as a result of donor insemination (DI). Because they believe that it is important that Jane can never remember a time when she did not know about the nature of her conception (Rumball and Adair, 1999) they are going to talk to her when she is aged two. In preparation for the 'telling', they have discussed the matter extensively between themselves, with their doctor, and with the counsellor at the clinic. They know about the books for children that are available (New South Wales Infertility Social Workers Group, 1988; Gordon, 1992; Smith and Boley, 1996) and intend to use these as and when appropriate.

Mr and Mrs A are part of a growing number of couples, world-wide, who are adopting this open approach (Lieber-Wilkins, 1995; Hewitt and Hewitt, 1998). They believe that having a secret from their daughter is potentially damaging to their child/parent relationship. They also believe that, if they kept the nature of the conception a secret, they would, by implication, be accepting that what they had done was shameful, and that they would be reinforcing the stigma associated with male infertility and DI. In adopting this position, they have received extensive support from the DI consumers' organisation that they joined.

To many couples who have utilized DI, as well as to many professionals involved in DI service delivery, Mr and Mrs A's plans will create anxiety and uncertainty. The 'culture' of secrecy that has surrounded the use of DI has meant that this commitment to the sharing of information with offspring will be perceived as threatening and, to quote the words of one colleague, '...frankly dangerous'.

This paper is not concerned with arguing the case in relation to information sharing—there is now an extensive literature on this subject (Daniels and Taylor, 1993; Daniels, 1997; Klock, 1997; Leiblum and Aviv, 1997; Blyth, 1998; Looi and Cowen, 1999) Rather, the paper seeks to raise issues concerning the strategies to be adopted by parents regarding the sharing of information. Applying a conventional approach to information sharing, Mr and Mrs A would tell Jane about how she was conceived and we question the appropriateness of this. Building on this nowadays often accepted approach we suggest what we have called a family-building approach and this is outlined and discussed below. This approach is based on our experience in counselling couples and on studies of the impact of family secrets on all family members (Imber-Black, 1993). It is also based on evolving research on DI-offspring and their psychological needs (Cordray, 1999; Turner and Coyle, 2000). Although we exclusively refer to DI as this is our main area of research, this concept can be applied for family-building by gamete donation in general. The implications of this approach for semen providers and for professionals are considered. In advancing these ideas, we wish to encourage discussion and debate in what is an expanding rapidly, yet underdeveloped, area of work.

It is important to consider the terminology used in relation

to this topic. We prefer 'information sharing' (Daniels, 1995) to 'telling' or to 'secrecy and openness'. The latter two terms tend to have emotional conotations that can cloud discussion of the topic and polarize the issues e.g. to tell or not to tell and consideration of secrecy versus openness. Also, information sharing allows for degrees of sharing—e.g. distinguishing between secrecy and privacy (Snowden, 1993; Daniels, 1997). Generally when discussing this topic, the word 'offspring' is used in preference to 'child'. To consider information-sharing in relation to a 45 year old person, for example, means that the term 'child' is totally inappropriate. The use of the word 'child' may also mean that it is easier to adopt a paternalistic position on this matter (Daniels, 1997). In the discussion that follows therefore, the term 'child/ren' is only used to specifically refer to very young, and parent-dependent offspring. Finally the term 'semen provider' is used as this covers both those who provided semen altruistically and those who did so for monetary reward or a combination of the two. The word 'donor' is concerned with the act of 'donating' and therefore should preclude those who provide semen for financial return.

## A child-conception approach to information sharing

During recent counselling workshops and conferences in New Zealand and Australia (where information sharing by parents is prevalent), counsellors working with couples and individuals using DI are being increasingly asked for information and guidance on how to 'tell the child' that they were conceived as a result of DI. Our experience with couples attending seminars in Germany designed to prepare them for family-building using DI, is that they frequently talk of 'telling the child' about their conception. Recent experience by the first author in conducting three focus groups on information sharing issues (in Australia and the UK) have shown a similar orientation on the part of parents who have children as a result of DI. Much of the literature (Williamson, 1993; Ferriman, 1994; Midford, 1995; Blyth, 1998) has presented the issue of information sharing as one in which parents tell their child about their conception. The books that have been published for children (Gordon, 1992; Schnitter, 1995; Smith and Boley, 1996) have, in the main, adopted a similar position.

This focus on the child is understandable. The parents know the facts, the child doesn't, and there is a need, given a commitment to honesty and openness in the family relationships, for the child to be 'told'. The focus for most parents seeking guidance on this matter is to know when and how to tell the child about his/her conception. There are not, after all, well established and acceptable scripts available to act as guides for parents.

Our main concern with this conventional way of telling children is that the emphasis and focus is on the child and his/her conception. This has the potential to create an 'us and them' situation—'We, as parents, are telling you something about you, which means that you are 'different''. In such a situation, we suggest that there is the possibility of unintentionally separating the child from its parents and therefore from feeling a part of the family.

In our experience, many parents use, or intend to use, the notion of 'specialness' in relation to their child—'you are a special child'. In discussing this with couples they tell us that they want to make the child feel unique and valued. However, one aspect of being special is that it tends to set one 'apart', again emphasising difference. While parents may use the term 'special' to try to ensure that the child feels positively different, and not disadvantaged as a result of being conceived as a result of DI, this may not be how the child perceives it. Knowledge about child development also tells us that, at certain stages, the last thing the children want to feel is that they are different from their peers. In such a situation, 'specialness' relates to the mode of conception, in that it is different, rather than to the child.

## A family-building approach to sharing information

A family-building approach shifts the emphasis from the child to the family. In this approach, the emphasis is on 'us' as a family rather than 'you' as a child. It means parents are sharing with their child information concerning how they, as a family, were formed/built/created. Clearly, the major advantage of such an emphasis is that it highlights the inclusive approach and encourages the child to see themselves as part of this particular family. In a sense it represents the beginning of the immediate family's history, the child is then seen within an ecological model (Auerswald, 1971) with its emphasis on the interdependent aspects of family relationships. All of this is based on seeing DI as a means of family creation as well as a means of treating infertility. If the emphasis is on treating infertility, then it is likely that the main concern will focus on biological matters, and on the infertile couple. On the other hand, a more long-term perspective can be taken with the treatment seen as a step towards family-building. Then, all of the issues that families face, and, in the case of DI, particularly the issue of information-sharing, will play an important part in how professionals respond to the couple.

A major part of utilizing DI, from a psychosocial point of view, is that the partners have explored and considered the issues that inevitably arise when this method of family-building has to be 'resorted to'. Except in the case of lesbians, we have never met couples who have opted for DI in preference to the traditional method of becoming parents. The family-building approach to information sharing requires a great deal of confidence from parents. It also requires that there has been a high level of resolution of the psychosocial issues that arise when semen from another man is to be used. For the couple sharing the family's beginnings with their child, this is as much about the parents as it is about the child, and this means it is about the family. It is 'our family's' story that is being told to the child rather than the child's story.

## Implications for the semen provider and parents

The involvement of the semen provider in the family created with his gametes has traditionally been reduced to his providing his semen (Glezerman, 1981). It was assumed that neither he himself, nor the family created with his help, had any ongoing

interest in each other (Winston, 1999). Any interest in the outcomes expressed by men providing semen was viewed very negatively and their samples were not likely to be used (Johnston, 1981).

However, more recent literature indicates that the attitude of at least some semen providers is not one of indifference to the outcome of their contributions. Some men want to be acknowledged for their contribution and they indicate an interest in information about the children that they have helped to create (Blood, 1996; Harrison *et al.*, 2000). An increasing number of them are willing for offspring to establish personal contact with them (Daniels *et al.*, 1997). Legislative changes, a more open atmosphere, and different ways of recruiting semen providers, have contributed to this change (Adair, 1998).

Such semen providers consider their 'gift' as something that creates an ongoing effect/issue for both themselves, their families, and the family they helped create. This indicates that, although the semen provider is not an active and involved member of the DI-created family, he has an ongoing emotional and special significance for them. In effect, the semen provider is part of the DI family's history.

The importance of information concerning this family history is likely to vary amongst offspring and their families. In one family known to the authors, one sibling is very interested in obtaining information about his semen provider while the other son has no interest. A similar situation has been observed in adoptive families we have worked with. What causes these differences between individuals is not known; however, the critical issue is that, if offspring wish to know more about their biological origin and that of their semen provider then it is possible for them to do so. Sweden, which was the first country to introduce legislation giving offspring the right to know the identity of their semen provider experienced a decline in recruitment as a result. However, numbers have now built up again, (Daniels and Lalos, 1995) showing that men can be recruited within a pro-information-sharing culture. A similar pattern has developed in New Zealand where only men who are prepared to have contact in the future, should the offspring want this, are recruited (Daniels, 1999).

Many challenges emerge from this evolving policy, and, given the significance of these, it is understandable that there is a strongly held view that it is best to retain the traditional stance of semen provider anonymity and family secrets (van Berkel *et al.*, 1999).

One of the challenges we wish to highlight in this paper is how the two men involved in DI families are conceptualized. We have focused on this particular issue because of its importance in information sharing and because it is continuously raised with us by parents, and sometimes by offspring. Many parents use the term 'father' or 'biological father' or 'real father' when they are referring to the semen provider. They, of course, use the term 'father' to refer to the male partner who is parenting the child—often referred to as the 'social father'. The resulting confusion is illustrated by one man who explained 'If I had a child via DI, of course I would be the father. But the donor is also the father, he is the biological father. But I don't want my child to grow up not knowing who is the 'real' father. So I need to ask myself: who am I and who is he in relation to our child? And, how do we differentiate (between us) when we talk to our child about this?' (quote from an attendee at a DI Seminar in Germany).

This difficulty emerges, in part, because this is a new area and there are no established 'scripts' to act as guides. Appropriate language is still emerging. Semen providers, in our experience, do not see themselves as 'fathers' of DI offspring. We do not believe that it is helpful for parents to present the man who provided his semen as a 'father' of their child/ren.

For the child, the person who is the primary loving and nurturing male in their lives is the person they identify as being 'father'. To use the term 'father' for the semen provider, when he is not present physically, nor involved in loving and nurturing, is to create a situation which has the potential to cause confusion for a child. Our suggestion to parents is that they use the term 'the man who gave his semen' when they are referring to the semen provider.

Couples report that when they use this terminology, it assists them as parents to a better understanding of the different roles and relationships that are involved. This better understanding is almost certainly going to enable them to discuss their family history with their offspring in a more confident and helpful way.

The discussion and clarification of these issues, both for the semen provider and the would-be parents, seems an essential part of appropriate preparation for family-building with the assistance of DI.

## Implications for professionals

The concept of DI as family-building and information-sharing will have implications for medical and psychosocial professionals who work with couples seeking DI treatment. For the medical profession, it will become important to acknowledge that this type of medical treatment does not only enable a woman to become pregnant, it creates a family—a complex social unit—with a past, present, and future.

It has been the tradition for many doctors to recommend to the couple that they keep the type of conception a secret, both from the child and from their social network, in order to avoid stigmatisation. With more open debate, media awareness, internet web sites and a growing number of consumer organisations—debating and often promoting openness—more and more couples world-wide are challenging this and adopting the position of Mr and Mrs A. Such couples object to what they see as the paternalistic attitude of doctors (Erwin, 2000; Scheib *et al.*, 2000). Others may accept the advice of doctors at the time of treatment but will have different needs, and therefore different perspectives, on the issue, once the child is born or reaches certain ages. Additionally, the increasingly genetics-based practice of medicine, and the accompanying DNA testing, will, within a few years, mean that genetic inheritance will be known and thus will have the potential to reveal any deceptions over biological parentage. It will therefore be important to recognize such changing needs and to understand that, although the medical treatment itself will belong to the past history of DI families, it is this treatment,

and the contribution of the semen provider, that enabled them to become a family. It will therefore always be relevant/significant. To raise these issues when couples seek information about DI treatment will help to increase the couples' awareness about the future implications for them as potential parents.

Openness has been promoted much more strongly in recent years, and this is likely to continue. In the UK, a government discussion paper on the topic is to be released early in 2001 and submissions sought (Norton, 2000). Couples and offspring in this new environment are therefore very likely to require/seek more information about the semen provider. Discussion by the medical profession on how to provide/cater for this, and the implications for semen-provider recruitment, will therefore become important.

Psychosocial professionals have, in recent times, tended to place a strong emphasis on information sharing and openness (Blyth, 1999; Nelson, 2000; Turner and Coyle, 2000). Their focus has frequently been on the welfare/interests/needs/rights of the offspring, given their relatively powerless position in relation to decision-making that concerns them. In taking this position, we suggest that again the child/offspring may have unwittingly been marginalized—separated out from the family. It is our contention that the more inclusive focus on the family will mean that the parents, who act as the gatekeepers of the knowledge of family-building, will be empowered to acknowledge their history and seek to normalize this for themselves and their offspring. Our experience from group work for couples who are considering DI family-building, indicates the value of addressing these issues before the couple starts treatment/before the family is built. Providing information and exploring attitudes towards/about this type of family-building at this stage, helps/facilitates couples to become aware of the ongoing impact of DI treatment. It also helps them to understand implications of DI and the contribution of the semen provider—for all members of the family as well as for the semen provider himself. Those providing counselling and patient preparation find it helpful to apply such a time-line approach and thus helping couples to anticipate their feelings/emotions and preparing them to manage the situations that may arise.

Raising male infertility and the reasons DI was sought, will be important to help the couple develop their 'family script' to share with the child. Like 'telling' the child, sharing the family history is an ongoing process dependent upon the developmental stage of the child (Lieber-Wilkins, 1995; WA Reproductive Technology Council, 1997)

Counsellors will find it helpful to use consistent and distinct terminology when talking about the family members in a DI family, especially when referring to the two men in the family. By consistently distinguishing between the father and the semen provider and offering a variety of different words/vocabulary for the two men, counsellors will not only serve as a role model for couples but will help parents find the terminology and 'family script' which makes them feel at ease when talking with each other, their offspring and people outside their family. In order to be able to provide such a concept however, counsellors will have to consider their own personal views and understand their own attitude toward the concept of 'father'. What do they associate with the word 'father'?—the biological progenitor or the man who brings up the child? Living in a cultural setting where the two are usually the same person, it will require insight and consistent attention on the part of the counsellor to be in a position to differentiate when working with couples, DI families or semen providers.

## Conclusion

Information-sharing has probably been the most contentious issue arising from the provision of DI services. From a culture of semen-provider anonymity and parent and professional secrecy, there has been a significant move to a more 'open' approach in which information concerning DI is being practised by an increasing number of professionals, parents and semen providers.

This paper suggests that, as part of this development, there has been a focus on information-sharing as 'telling the child'. Some potential difficulties associated with this approach are outlined and an alternative mode—a 'family-building approach'—is presented. The paper explores some of the implications of information-sharing in general and the family-building approach in particular, especially for semen providers, parents and professionals.

Given the recent emergence of policies and practices concerning information sharing, we offer our ideas in the hope that they will promote discussion and development.

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