

**This response was submitted to the evidence call held by the Nuffield Council on Bioethics on Donor conception: ethical aspects of information sharing between 21 March 2012 and 15 May 2012. The views expressed are solely those of the respondent(s) and not those of the Council.**

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Medical Ethics and Law Introductory Course

Donor Conception: ethical aspects of information disclosure

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In April 2005 the anonymity of sperm donors was repealed. Children donor-conceived following this change have the right to access non-identifying donor information at sixteen years old and donor identifying information two years later (Human Fertilisation and Embryology Authority). However, notifying any such child of their genetic origin is not a legally-obligated action. There are many ethical issues that people closely associated with donor-conceived children (i.e. legal guardians and donors) must deliberate. Key areas to consider include; who can decide whether or not to divulge to a child details of their donor conception and subsequently when this should be disclosed, as well as what impact this information might have on said child at different life stages. Information regarding the donor may also be required to assist the parents in rearing the child. This essay will discuss and debate these issues and propose possible courses of action.

Once a set of parents have decided to go ahead with the donor-conception procedure, they will almost certainly want to know something about a potential donor's characteristics. Naturally, the parent will seek as much information as possible including physical features, ethnicity, relevant past medical and family history, personality type, underlying conditions and occupation. This raises the question, 'How much is too much?' The need to provide medical information to recipients can be offset by the reassurance that careful screening of all potential donors should prevent the inheritance of genetic disorders. Knowledge of ethnicity and physical appearance are also important factors since parents are likely to desire offspring with traits similar to their own. Counterarguing this point is the significant issue of possible creation of designer babies. Argument has raged for years in this area, with some people arguing that disclosure of excessive donor information will lead to abuse.

Beyond physical appearance, other issues could arise. Prospective parents might wish to know more regarding a donor's occupation, IQ and athletic abilities for example. Every parent wants their child to be fit, happy and healthy but donor selection may offer the advantage of having a baby with intelligence or ability to excel in certain areas. Similarly, would knowledge that a donor has previous criminal convictions deter parents from choosing them? In spite of there being so many aspects regarding the donor that parents might want to explore, it remains the case that they will only have access to basic information. Other information may be provided at the donor's discretion.

Following discussion, we propose that disclosure of donor conception to the child is ultimately a matter for the individual's family to decide. The parents, whilst not being the biological parents have effectively been guardians to the child from both a legal and emotional view. They are likely to understand their child far better than other professionals and so would know best when and how to disclose this life-changing information. Furthermore, the practicalities of a stranger disclosing such information are numerous. How and at what age would the information be disclosed and who would bear this responsibility? In such a scenario it would be the ethical duty of the disclosing body to

ensure that sufficient and appropriate support is in place for the individual, whilst this knowledge is absorbed and the resulting practicalities are significant. Thus we argue that parents have the sole right to disclose information to their child.

Nevertheless, the occurrence of disagreement between parents in whether to disclose requires further consideration, particularly as once revealed – perhaps in a careless moment – this highly sensitive information cannot be retracted or unlearned. A number of scenarios pose such ethical dilemmas. For example, one parent may favour disclosure against the wishes of the other, or members of the extended family may have conflicting views on whether to disclose such information, perhaps for religious or cultural purposes. We feel that ultimately if there is a disagreement it remains a family matter and so would ideally be dealt with within the family. If a consensus cannot be reached then perhaps a third party such as a family law mediator or counsellor would be able to offer perspective and mediate. Disagreements regarding disclosure may also lead to feelings of secrecy, mistrust and tension that the child could detect. Given the significance of this decision and its consequences perhaps the clinic involved has a moral responsibility to ensure that parents are fully aware of its impact on all concerned prior to treatment.

Apart from the parents, perhaps donors feel that they should have an input to the decision to disclose. Donors have demonstrated an altruistic nature in donating gametes and therefore may feel that the child should be aware of this. Conversely, we believe that donation should remain as an altruistic deed to help others and that it should mark the end of their involvement until such time as the donor-conceived child decides to make contact.

Once a child knows about their donor origins, they may wish to know more about their donor. The extent of information they may require will vary from individual to individual. Some may want to meet and get to know their donor and possibly even donor siblings. In such cases, providing abundant information could lead to them tracking down their donor parent without mutual consent, which could have implications for the offspring and the donor alike. If this were to occur, the new relationships formed between donor and child might significantly disrupt existing family life of either party. This disruption could extend to other children of the recipient parents, who will then have to process and deal with the knowledge.

Donor-conceived individuals may want to meet and establish contact with remote donor half-siblings, a possibility that has been made much easier via services like Donor Sibling Link, a service open to adults conceived after July 1991 (Human Fertilisation and Embryology Authority). Although such facilities can provide additional support by enabling users that have been conceived via donor conception from the same parent to make contact, it can lead to problems itself. What if after having met, two donor siblings take a liking to each other? Such a relationship is considered incest and potential offspring would

be predisposed to genetic anomalies as well as the psychological effects of such a relationship.

As we have outlined previously, it is important to consider how disclosure of information can affect the donor-conceived offspring and what affect it will have on them. This will depend on the age at which they are informed. From a medical viewpoint the age at which the offspring learn of their conception is not particularly relevant since their genes are now defined. Circumstances where knowledge could be relevant include if a donor-conceived adolescent falls ill or enrolls in the army or police and is asked about any significant family history. In this situation they would not know, as genetically their family history would be different to what they know about their parents. Significant family history of donors and parents may vary wildly and this could affect treatments or the ability to enrol.

We believe that the main issue to consider with regard to the age of disclosure is psychological. If individuals are told at an early age, they would probably adjust to the idea more easily and it would become normal for them and what they have always known. The problem with informing a young child would be that they might not actually understand the process or implications of being a donor-conceived child and they may believe that they do not have real parents. They may share the information widely to others also too young to fully comprehend, which may lead to bullying as it differs from the social norm. If the offspring are informed at an older age, they are more likely to understand that the person who brings them up are usually as much a parent as any biological parent is. However, finding out at an older age may lead to a loss of trust in their guardian parents since it had been kept a secret from them their whole life. As individuals mature, they develop a personality, morals and sense of self, which may be based around those of parents. Finding out that guardians are not biological parents could lead to a loss of identity.

In conclusion, we believe that it should be left to the donor-conceived individual's legal parents whether or not they should inform their child. This is because the process of raising a child gives them unparalleled insight into the child's mind. Furthermore, the child's best interest will undoubtedly be of great importance to the parents and they will do whatever their belief system considers right. No one can deny parents the right to raise their child in accordance to their beliefs. We believe that the choice to inform a child of the nature of their conception, or not, is a matter of conscience and as such it cannot be imposed by one party on to another. It is a choice that each person or group concerned would approach differently, view from a different perspective and understand in a different way. In this case there is no right and wrong choice, what matters is the freedom to make that choice.

## Bibliography

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