

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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Consultation questions

Please note (a) the first and last answers are some general reflections on present values and ideologies. The intermediate ones, asterisked, are my personal private (!) opinions for the sake of this exercise. (b) The answers are all from the perspective of 'English' kinship, and restricted therefore in their application. (c) I have no special knowledge (case studies etc) of this area.

1. What ethical concerns arise in the disclosure, or not, of information in connection with donor conception?

1. My first response was to wonder whether disclosure in this (regardless of the nature of the information) is any different in kind from the disclosure of any personal information i.e. it begs the question of what is the nature of the public interest in private matters -- should there be any regulation at all? Of course the answer in favour of regulation is already enacted in current legislation. But I suspect this is another arena [thinking of HB] where the public / private divide is less helpful than it looks.

What is personal to someone is not necessarily private (e.g. their birth dates), so there is nothing axiomatic about designating the details of donor conception as a 'private' matter. The question is what is served in particular instances by the concept (value) of privacy. (There is an issue that normal assumptions about birth parentage may lead to third parties having a mistaken impression of a parent-child relation in particular instances, but given the huge variation in the kinds of arrangements by which people come to 'have' children, this does not seem a matter of great moment.

However, there is an added element, that the 'personal' also includes the *inter-personal*, especially when it comes to kinship. As far as family interests are concerned, interpersonal relations are diffuse, and do not rest only with the parents and children involved (there may well be grandparents, other siblings etc). At the same time they are differentiated, thus the issue debated here is premised on the possibility that disclosure for the child borne of donation has different implications for it than for its parents (differentiated again between donor parent(s) and other parental figures). Generally the law does not know what to do with interpersonal relations [they are usually seen as interfering with individual autonomy]. So the

issue is likely to come down to an opposition between (the 'rights' of) autonomous individuals – the (donor & other) parent or child -- each with its own expectations, life to lead, sense of identity etc. This seems to be what present legislation is based on: identifying information is put in the hands of one party not the other.

2. Is the disclosure of a child's donor conception essentially a matter for each individual family to decide? What if there is disagreement within the family? Who else should have a role in making this decision?

* Yes, as with other kinds of conception arrangements. One can't legislate as to how to solve disagreements. Families will vary as to who is in on the decision.

3. What information, if any, do parents need about a donor in order to enable them to carry out their parenting role? Please explain.

*The 'information' gained from genetic knowledge is a kind of 'practical' dimension of genetic kinship that is supposed to make the need for knowledge self-evident. But I am not sure how many people not borne of donor conception think about genetic ancestry (of course one may argue that the information is there in the links traceable through the birth parents should it be needed.)

The following might be of comparative interest, relating to a law suit in the US in 1992. It doesn't deal with donor conception but a case where a child sued her father's physician for not having informed her of the medical condition from which her father died. It went to appeal, and the debate on the two sides is interesting.

Janet Dolgin 2000 "Choice, Tradition, and the New Genetics: The Fragmentation of the Ideology of Family," *Connecticut Law Review*, Vol. 32, No. 2.

4. What information might a donor-conceived person need about the donor, either during childhood or once they become adult? Please explain.

* [The child as a person in a nexus of relations.] Present thinking puts great value on 'identity' (see 12). Identity includes whom one is related to. There is likely to be huge variation in the weight people put on such ascriptions of identity, and thus on the need for identifying information. As it is at present, the donor is assumed to have made the donation in the knowledge that he/she would have no control over being identified and should not take the initiative in seeking out the child. (Whereas the person conceived by donation, like any person being born, had no control over the circumstances of their birth.) I do not see any way in which the asymmetry could be 'resolved': parent and child are in an asymmetric relationship, and 'equal' access to all types of information cannot have 'equal' implications. (The senior generation always puts its future into the hands of the junior!)

5. How significant is information about the medical history of the donor and the donor's family for the health and wellbeing of donor-conceived offspring? Do you know of any examples or evidence in this area?

* [The child as a biomedical entity.] It can be made very significant in certain circumstances, and the limited information at present released automatically is likely to be far from sufficient. The question is whether these circumstances outweigh other considerations sufficiently to argue for general disclosure, rather than non-disclosure, as the default position. (Disclosure of identifying information enhances – brings with it -- medical information; the reverse need not be true.)

6. Where information about inherited medical risk becomes apparent after donation has taken place, who should be told, and by whom?

* N/A

7. What is the impact on donor-conceived offspring of finding out about their donor conception at different ages: for example medically, psychologically and socially? Do you know of any examples or evidence in this area?

* I think it is impossible to disentangle – indeed one probably should not want to – individual dispositions in this field from current society-wide thinking about genetics, identity etc. that renders those who ‘discover’ facts about their parentage, when it has been concealed from them, as victims of a knowledge deficit.

8. What is the impact on donor-conceived offspring of making contact with either the donor or any previously unknown half siblings? Do you know of any examples or evidence in this area?

*There is likely to be variation again in how people manage their affairs – all the way from (a) cynicism that all that is at issue in a person wanting trace kin is to find out more about own medical history to (z) an interest in pursuing relationships with ‘long lost’ relatives. Things change very rapidly but a book that came out in 2000 (Kaja Finkler *‘Experiencing the new genetics: Family and kinship on the medical frontier’*) contains detailed case studies from the US.

I dont know if any comparison has been made between half-siblings’ reaction to donor conception and those who discover in later life they are half-siblings through adulterous or clandestine affairs on the part of one of their parents.

9. What interests do donors and donors’ families have in receiving any form of information about a child born as a result of the donation?

* One might look at the range of expectations that surround disclosure of adoption.

10. What responsibilities arise in connection with the disclosure of information? Where do these responsibilities lie? (for example with government, fertility clinics, professionals or families?)

* It is an important aspect of contemporary (‘English’) kinship that (biological) knowledge cannot be concealed again – it has an automatic effect on the definition of kin relations [see 12], regardless of whether it is given great weight or not. While I

have every sympathy for the variety of reasons why people would wish to know about the circumstances of their conception, I feel a bit queasy about the thought that judgement as to what is best should be clouded by dogmas of transparency. That is, that transparency is given a positive value in-itself [so concealment becomes automatically negative]. Far too much cant is talked about transparency. Like everything else, there are situations where either transparency or concealment might be the humane (ethical) approach to take. But the two are not symmetrical. Concealment allows the option of future disclosure; transparency does not allow an option of future concealment.

11. What support is required in connection with these responsibilities?

*N/A

12. Do you have any other comments? Please highlight any relevant areas you think we have omitted, or any other views you would like to express about information disclosure in the context of donor conception.

12. As a general comment, perhaps it is worth reflecting that many of the issues surrounding donor conception arise from the particular value that 'the English' place on parentage – the parent-child relationship – as the social recognition of biological fact. There is a whole subsidiary set of ideas to with 'social parenting' (covering adoption, nurture etc), but these exist precisely as supplemental to the role of biology. Of course there has been a huge shift over the last twenty years since assisted conception became accepted practice. Indeed one might have expected people / the law to become fairly relaxed about parentage, except for the one fact that is in the forefront of the WP's deliberations: present day knowledge about genetics.

That the biological relationship between parent and child can be 'demonstrated' in terms of what we now understand as a genetic tie ('biological inheritance') invents 'biology' all over again. The more we uncover about genetics, the more significant it seems that people born of donor conception should be given access to the same kind of knowledge (medical histories etc) as those who know their biological parents. The same goes for personal identity. Given the nature of kin relations, the significance fans out into other close relationships too, both for donors and other parental figures, for behind particular parents and children are whole genealogies of kin, not excluding donor kin (so to speak).

Dramas of identity uncovered: when laws of inheritance and succession dominated pre-genetic understandings of kinship in previous times, tied to the legitimacy of the parents' marriage, dramas over discovering the facts of one's birth were dramas of class, fortune and misfortune, and the legality of property claims. This is what identity was about. Today it has a lot more to do with ideas about personal (genetic) make-up, which affects people very differently. Some care a lot, some not at all. Curiosity may play a part, but may be neither strong nor necessarily pursued. I wish

I knew more about the drive for disclosure – it is of a piece with people's desires to match up previously unknown donors and recipients of organs, strong in the US, against the initial objections of professionals, as well as with the drama of adoption. Once something becomes a drama, that is, there are 'heroic' tales of long-lost 'kin' re-uniting, it acquires narrative power.

I have a sort of hunch -- absolutely no more than that -- that some of the promotion of disclosure comes from distaste at the often sad consequences of the long legacy of illegitimacy. While this has paled into insignificance today, assisted conception has in some senses stepped into the role. Kin still live with secrets! Since it is now regarded as psychologically healthy for secrets to come into the open, keeping others' ignorant of donor conception becomes identified with keeping a 'secret', the secrecy itself having harmful consequences. (Donor conception is a kind of obverse of incest in this respect, the guilty secret not of too close a procreative union but of too distant a one.)

If one looks at illegitimacy in the past (the 'natural' child born out of wedlock), it was often the case that things were known in the sense of being suspected, or a matter for gossip, but not 'known' in terms of formal recognition. (I mean formal or public recognition of the illegitimacy, which of course meant public non-recognition of the child.) Of course there was great room for tragedy (girls sent away to have and give up their babies out of the family's sight) – it mattered hugely -- but there was also room for keeping the knowledge informal, not making a great issue for it – it did not really matter so much.

How to respond

We would prefer it if you could send your response to us electronically. Responses can be sent via email to Kate Harvey (kharvey@nuffieldbioethics.org), with 'Donor conception' in the subject line. It will greatly assist the Working Party if responses are in the form of a single Word document, with numbered paragraphs throughout.

Please ensure that you also include a completed response form with your submission, which can be found on page 7 of this document or downloaded from www.nuffieldbioethics.org/donor-conception.

If you would prefer to respond by post, please send your submission to:

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Closing date for responses: 15 May 2012, 5pm.

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