

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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1. Generalities:

This response is in my capacity as an academic researcher and senior lecturer in law, with research interests in bioethics and specifically in assisted conception, its regulation and impact on family structure. The views expressed are my own. A list of my publications relevant to these areas is included at the end of my response.

1.1 Consideration of the question of disclosure of information following donor conception must be placed within the context of the limited empirical evidence to date on the views of the different stakeholders: offspring, parents, donors and medical professionals. It is also useful to look at other jurisdictions' approaches as the issues raised are common to most countries and cultures where donor conception is practiced. However, it should also be remembered that there are many 'sources' of donated gametes, including from abroad. The Consultation focuses on the ethical implications of disclosure, and my response will consider through which means the identified ethical imperatives could be assured in the context of licensed donor conception. As the current position in the UK reveals, if disclosure (whatever its scope) is found to be beneficial, it is likely that reform must be achieved through legislative will. Initiatives to 'encourage' disclosure to date appear to be of minimal success.

2. It is important to note at the outset that the question of disclosure goes to the heart of the act and consequences of donation itself. Since 2005, donor anonymity has been removed.¹ The identity of the donor may be made available to any offspring, once they reach majority. However, without disclosure of recourse to donated gametes, this information may never be sought. I believe there are two elements therefore to consider: (i) should disclosure of the donation be obligatory and if so, at what point in time? And (ii) should disclosure also reveal the identity of the donor at the point in time it is made? In my opinion, the fact of disclosure of the circumstances around one's conception may be more important than the actual identity of the donor.
3. The available empirical evidence would suggest that most donor offspring are curious to know about the fact of donation and information on the donor.² More evidence is available as to the damage that secrecy in a family may cause and the feeling of deception when the truth becomes known.³ In the light of the increased probability of the use of medicine *à la*

¹ Disclosure of Donor Information regulations 2004, SI 2004/1511, available at www.opsi.gov.uk/SI/si2004/20041511.htm. Subsequent amendments to the 1990 Act were introduced by the HFE Act 2008, inserting s 31ZA–ZG into the HFE Act 1990 on the disclosure of information.

² V Jadva et al 'Experiences of offspring searching for and contacting their donor siblings and donor' (2010) 20(4) *Reproductive Medicine Online* 523; P Mahlsteot et al 'The views of adult offspring of sperm donation . . .' (2010) 93(7) *Fertility & Sterility* 2236.

³ See amongst others, E Haimes 'Secrecy: what can artificial reproduction learn from adoption?' (1988) 2 *International Journal of Law, Policy and the Family* 46.

carte developed according to each individual's genetic make-up, it can be argued that it is more important than ever to make disclosure of donor conception the norm.

4. Obligatory disclosure of means of conception?

It is often said that the state of an individual's fertility is a private matter and consequently, that to force disclosing to a third party that there has been recourse to donated gametes amounts to a violation of that person's privacy. However, we know that privacy is relative and that an interference with an individual's privacy may be legitimate and justified for the purposes of others' rights and freedoms. In conception through intercourse, it would be hard to support the claim that biological parentage must be confirmed for every child born. We therefore accept that in most cases, children are brought up by their biological parents, even if in some cases, the child may be the fruit of an affair with another. Nevertheless, there is scope to differentiate in the case of donor conception because here it is known to all the (adult) parties that the parents are not both the biological progenitors of the child. Where the State intervenes to regulate the provision of assisted reproductive technologies (ART) it is legitimate to accept that the State should also regulate, where necessary, the consequences. Therefore, I would argue that the privacy of the parents may legitimately be interfered with for the greater need to allow the offspring to be informed of the fact of the donor conception. However, the means for imposing the disclosure should be proportionate and it should not mean that the fact of the donation be made known in the day-to-day life of the offspring.

4.1 It is interesting to note that in Germany, the 'right to know' about the circumstances of one's conception is seen as central to the fundamental principle of respect for human dignity. The jurisprudence of the European Court of Human Rights has not gone so far, but the most recent case-law indicates that an individual's right to a private life implies the right to obtain information (which is available in medical records) relating to one's conception.⁴ This is an interesting approach because it brings into relief the need to reconcile one individual's right with another's. It also supports the view expressed in the previous paragraph that if the fact of disclosure is imposed, it should not be by means which reveal the fact outside of the immediate family unit.

5. Enforcing disclosure:

There are two possible methods: (i) reforming birth certificate registration; or (ii) automatic informing of donated offspring at the age of majority of the fact of donation and indicating availability of identity of the donor.

5.1 If, as the evidence suggests, parents are unlikely to inform their children of the fact of donation where there is no compulsion to do so,⁵ then by making parents aware of the enforced disclosure (at whatever point in time) will act as a catalyst for parents to

⁴ See for example, *Jaggi v Switzerland* (2006) App No 58757/00 13 July 2006, para 38.

⁵ Department of Health *Donor Insemination Consultation: Providing Information about Gametes and Embryo Donors* (London: HMSO, 2001) refers to a European study which has shown that only 12% of mothers have the intention to reveal to the child the mode of conception, available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4018774.pdf.

disclose to the child, at an appropriate time in her development, the fact of donation. Therefore, by having enforced disclosure, family secrecy is strongly discouraged. Further, this also means that the child can grow up with increasing knowledge of what it means to be donor conceived and comfortable in the 'normality' of such conception. Positive evidence from the adoption experience can be used to illustrate how by informing the child of her adoption gradually, it never becomes an issue which suddenly has to be faced, upon majority, or upon the sudden disclosure of a secret.

- 5.2** As I have argued elsewhere (Callus 2012), I would support reform of the birth certificate registration process as I believe that the system is outdated and incapable of reflecting the lived reality of many parents and children. The question of disclosure of donor conception should be at the heart of any reform. It was suggested in the 2008 reform proposals of the Human Fertilisation & Embryology Act 1990 that some mention should be made on the birth certificate to indicate that donor conception had taken place, but this was not adopted.⁶ I would not support merely 'tagging' onto the existing birth certificate process, as this would not address the larger question of the relevance and purpose of birth registration in contemporary Britain. However, I would support reform which could lead to a two-part birth certificate, which could indicate both the donor(s) and the functional parents. In my article, I propose 'de-legalising' parentage: that is removing the automatic legal status of parent for the biological parent in all circumstances and allowing the birth certificate to identify the biological progenitors purely to acknowledge the social and individual importance of this knowledge for the child, while conserving legal parenthood for those parents who present themselves with the intention of being the child's parents, ie carrying out the day-to-day functional and psychological parenting. I therefore suggest that the purpose of birth registration is two-fold: (i) to identify the biological progenitors of the child in recognition of the importance of the child's identity (the 'rights' element); and (ii) to confer legal parenthood (status) which imposes responsibility for a child upon a number of adults. It would only be this second part of the certificate which would be used for all public administrative purposes. As a result, the fact of donation would not be revealed to any other third party outside of the medical clinic and the General Registrar's office. The first part would also be able to contain the identity of the donor(s) and this would support allowing this information to be available before the age of majority.
- 5.3** Indeed, the very idea of supportive and supported disclosure during the offspring's childhood suggests that the information (including the identity) should be available before the offspring's majority. However, this then forces us to turn to the donor(s) and to consider the implications of enforced disclosure on them.
- 5.4** The donor's private life is also in the balance. However, at least for all donations made after 2005, every donor will donate in the knowledge that their identity may be revealed to any offspring. Such would also have to be the case were the law to be changed to enforce disclosure by means of a reformed system of birth registration. Consequently, the limitation on the donor's private life incurred through enforced disclosure would be

⁶ See the proposals by the Joint Committee on the draft bill, Joint Committee on the Human Tissue and Embryos (Draft) Bill, 1 August 2007, HL 169-1 HC 630-I 2006-07, and academic commentary outlining possible solutions: E Blyth and L Frith 'Donor-conceived people's access to genetic and biographical history: an analysis of provisions in different jurisdictions permitting disclosure of donor identity' (2009) 23 IJLPF 174.

accepted *a priori*. Any potential donor who would not be comfortable with this, would therefore have the opportunity not to donate. Certainly, we should not ignore the fact that there is a need for more donors and any policy which indirectly discourages donation will not achieve this aim. However, such important policy decisions as disclosure must not be driven by a fear of reducing the pool of donated gametes. The question is a crucial one for the offspring and donors should only donate once they are aware of the important consequences of the act. Moreover, enforced donation will also impact upon the donor's decision whether to inform their own family. Once again, it is believed that openness about donation is beneficial, especially in the light of the removal of anonymity – it must be better for the donor's own children to know that they have half-siblings. If donors are uneasy about this, then this might reveal that donation is not actually for them.

5.5 If reform of the birth certificate as proposed is not acceptable, the alternative method of enforced disclosure would be by way of an information letter to the offspring upon their attaining majority. Once again, the knowledge that this will happen should encourage parents to reveal the fact of donation at an early age, in order to prepare the child for the delivery of this information. This may seem at first sight a brutal response, with the risk of sudden disclosure shattering the trust of offspring if the parents have not revealed the fact of donation. However, if all parents are suitably informed of such disclosure and are supported in their task of informing the offspring, then it would be hoped that this would encourage more parents to reveal the circumstances surrounding conception at an earlier stage. There are of course practical considerations – on-going follow-up, change of address etc. One way of minimising this would be for an individual's medical record to contain the information and prompt for the offspring to be notified upon reaching majority. Some will not be in the system because they may have moved abroad, but for the majority of individuals registered with the NHS, this should not prove a problem. Likewise, any important medical genetic information about the donor or the family should be kept on the off-spring's medical record, in order for that information to be used by a medical team, where necessary.

5.6 It must be noted that for most countries who operate licensed donor conception services, no State has adopted a system of enforced disclosure. Some, like the UK, have removed the anonymity of donors, but as noted above, this removal is of small consequence if the offspring are never informed of the fact that donor conception occurred. Some countries (eg Belgium) have adopted a twin track scheme, giving parents the option of choosing a donor who has waived anonymity or one who donated anonymously. However, there does not appear to be wide-spread support for such a scheme and given that the UK has already dealt with the issue of anonymity by allowing identifying information upon majority, then this would not be something we would want to consider.

6. The increase in different types of family groupings and the sustained recourse to donated conception in the UK means that the question of disclosure of information is one that is not going away. My suggestion to make disclosure ultimately obligatory does require a certain level of education of the general public and support for those undergoing treatment. The less attached society becomes to procreation within the unique model of the heterosexual

two-parent unit, the easier it will become for donation to be seen and revealed to the offspring. There are competing rights to respect for a private life of the central actors: the donor, the parents and the offspring, but I would argue that any decision must take as its focal point the interests of the offspring. Although there is only small scale empirical evidence - (and often the respondents are self selecting insofar as if they are unhappy with their position, they are more likely to respond to such studies) it would seem that there is a case to be made to justify why a certain group of people should be denied access to information which is available concerning their individual identity. If the adults concerned are uneasy with such an interference with their own private lives, then it must surely be questioned whether donation (whether as the donor or the recipient) is really the right avenue for them.

Dr Thérèse Callus: Relevant publications on parenthood and anonymity

T.Callus, A new parenthood paradigm for 21st Century family law in England & Wales (2012) *Legal Studies* (awaiting pagination). Please let me know if you would like an electronic pre-publication copy of the final article.

B.Feuillet, K.Orfali, T.Callus (eds), *Who is my genetic parent? Donor anonymity and assisted reproduction - a cross-cultural perspective*, (Bruylant, Belgium, 2011).

T.Callus, From total to partial anonymity: the (r)evolution of English law on assisted reproduction technologies in B.Feuillet, K.Orfali, T.Callus (eds) *ibid*, p.175-188.

T.Callus, La 'filiation' en droit anglais (2009) in *Recherches Familiales*, La réforme de la filiation, 7.

T. Callus, De l'anonymat assuré à l'anonymat affaibli : la (r)évolution du droit anglais en matière de procréation médicalement assistée in *Procréation Médicalement Assistée - Panorama International*, B.Feuillet-Liger (ed.) (Bruylant 2010).

T.Callus, Pluralisme familial et parentalité: le principe d'égalité et le juge anglais in *Le Pluralisme familial, Aspects juridiques et comparés*, O. Roy (ed), (Presses Universitaires de Paris Ouest, PUF/Flammarion, Collection Sciences juridiques et politiques 2009).

T.Callus, First 'designer babies', now à la carte parents (2008) *Family Law* 143.

T.Callus, Tempered hope? The qualified right to know one's genetic origin – *Odièvre v. France* (2004) 67 (4) *Modern Law Review* 658.