

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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What do you see as the key issues for *you*, as a donor-conceived person, with respect to information disclosure?

- There are two key issues: DC people being told they're DC and DC people accessing information about their donor families.
- I believe DC people have the right to know they're DC.
- Not only is there a moral argument for this – that they should be able to have contact with their donor families should they wish (as is enshrined in the Human Rights Act (1998), which guarantees British citizens the right to a family life, and also the United Nations Convention on the Rights of the Child (1989) – see end notes) – there is a practical argument for it, namely that not knowing puts them at risk of accidental incest (however small this risk, it is unacceptable).
- I also believe DC people have the right to know where they come from. Any meaningful entitlement to a family life includes an entitlement to know who that family is.

Would you like to see the current regulations that relate to information disclosure changed in any way? If so, how and why?

- Retrospective access – access to any information clinics hold about donors, including identifying information, regardless of when you were conceived, as has just been implemented in the state of Victoria in Australia (in Victoria policy on assisted reproduction is much more progressive than in the UK because, unlike here, the welfare and interests of people born as the result outweigh all other concerns).
- Donor conception on birth certificates – to ensure that as many people as possible know they're DC.

How do you see the 'key issues' as differing for donor-conceived people, parents and donors? How should potential conflicts be handled?

- Some parents don't want to see donor conception put on birth certificates, believing it's an invasion of family privacy, it takes away DC people's right to decide who should know they're DC and parents shouldn't be forced to

tell before they're "ready". I've even heard it argued that there's no space for donor conception to be put on birth certificates! In terms of family privacy, this could be protected by effectively having two certificates, or a 'Part A' and a 'Part B', for everybody regardless of the manner of their conception - one of which is public and has just the person's name and date on it, and the other of which is private and conveys information about adoption or donor conception (with people being given both when the birth certificate is issued). Regarding DC's people right to decide who knows they're DC, it is ridiculous to use this to argue against a mechanism that would ensure DC people themselves know! You can't make a decision about whether or not to tell somebody something you don't know yourself. Having a public and a private birth certificate would resolve this anyway. And as for parents being forced to tell before they're ready, some parents will never be ready. My parents were still not ready to tell me even after 25 years and after I'd been led to believe there was a good chance that I'd suffer from kidney failure as the result of a genetic disease and pass this disease down to my own children. Unfortunately some parents need a push to do the right thing.

- Some donors undoubtedly would not want to see DC people given retrospective access to identifying information about them. But we should deal with this as they are planning to deal with it in Victoria – explaining to donors the importance of having information about them to DC people, facilitating contact between DC people and donors using trained intermediaries and giving both parties the option of putting a block on contact.
- Furthermore, DC people are the only party in the so-called donor conception triangle who do not choose to take part. This situation is foisted upon us. Therefore our needs should be paramount when making policy, ahead of the wishes of parents and donors, as has been recognised in Victoria.

How about members of the wider family? (eg parents or children of the donor; grandparents/ aunts/ uncles/ siblings within the family created by donor conception)? How might they be affected by disclosure in connection with donation?

What's your experience of accessing (any kind of) information about your donor? How important is such information in the context of your ordinary family life? Is there any information a donor-conceived person might want to share with their donor?

- Accessing information about my donor has been impossible.
- I've narrowed where I was conceived down to two clinics. One said it couldn't release any information without getting my mother's consent to look at her medical records. She gave her consent but then it said it

couldn't release any information because it would be a breach of confidentiality (whose confidentiality wasn't clear). The man I spoke to on the phone about this was very rude and hung up on me. HFEA guidelines actually state clinics are to share non-identifying information wherever possible, so it wasn't true they couldn't release any information. The other clinic looked in their records and said they couldn't find anything. The woman I spoke to there admitted the records were in a mess and said she would take a second look, but I never heard from her again (a friend conceived at that clinic was able to get some non-identifying information about his donor, so I believe they are just disorganised rather than being obstructive).

- In terms of my ordinary family life, I want to be able to tell my son something about his grandfather. Otherwise finding the donor is something I want to do for myself and my own sense of identity.

Openness about donor conception is now widely seen as being a good thing - but not in all cultures/communities. How should disclosure be handled in communities where donor conception itself is not approved of?

- The same as it should be handled in communities where donor conception is more acceptable.
- If DC people have the right to know they have the right to know, it's not ok to lie to them just because they're from a certain religious or ethnic background.
- Again their needs have to come before the wishes of their parents or their community.
- And DC people shouldn't suffer negative consequences as the result of any shame their parents feel about the method of their conception – they've done nothing wrong!

What role should the government, or professionals such as doctors, counsellors or social workers, or organisations such as the HFEA and infertility clinics, have in all this? Or are all decisions about disclosure up to individual families?

See answers to questions below.

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

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?

The disclosure of a child's donor conception is NOT a matter for each individual family to decide, because the child has the right to know where they come from.

If the family can't or won't tell their child that they are DC then the state has a responsibility to ensure that the child's rights are upheld. I think the easiest way to do this would be to record the fact of donor conception on the child's birth certificate. Finding out you're DC from a birth certificate wouldn't be ideal but it would be better than never knowing.

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

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

DC people need their donor's medical history from birth (see answer to the next question). As soon as they are old enough to understand they should have non-identifying information about their donor, and possibly identifying information too, so that they can fully develop a sense of their personal history (research has shown that people think about their lives in terms of stories (e.g. White and Epston (1990), who argue that "persons give meaning to their lives and relationships by storying their experience" (p. 13). I think it is their incomplete personal narratives that makes DC people who have no information about their donors, such as myself, feel psychologically uncomfortable). DC people should definitely have identifying information about the donor once they reach adulthood, so that they can pursue a relationship with them if that is what is mutually desired.

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?

Information about the medical history of the donor and the donor's family is clearly significant for the health and wellbeing of donor-conceived offspring. My story illustrates this. When I was 20 my dad was diagnosed with kidney failure as the result of Polycystic Kidney Disease (PKD). There is a 50% chance somebody afflicted with this will pass it on to their offspring, about half of people with PKD ultimately develop kidney failure and there is no conclusive test for the PKD gene. Consequently, not knowing I was DC and so believing I could be affected, I went for a course of genetic counselling and yearly ultrasound scans of my kidneys until the truth came out when I was 25. All of the stress caused by this, compounded by the difficulty of seeing the effects of kidney failure on my dad and the worry I would pass the gene on when I was pregnant with my own child, could have been avoided if somebody had told me about the way I was conceived (this is, of course, assuming my donor doesn't carry the gene for PKD!).

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

When inherited medical risk becomes apparent after donation has taken place the DC person must be told, whether that's by a doctor or by their parents with support from a doctor. I think the genetic counselling profession is probably best placed to advise on how this should be done. What I'm absolutely sure about is that the DC person should know about the risk they face so they can subsequently make their own decisions regarding any medical treatment, once they are old enough and have the capacity to make those decisions.

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 know many people believe DC people are more able to accept the means of their donor conception if they are told early in life. I would like to point to one study that contradicts this, Mahlstedt et al. (2010), which investigated the attitudes of 85 DC adults towards their conception. About half of this sample had been told about the means of their conception before the age of 18, yet their attitudes towards it were distributed evenly from 'very good' to 'very bad'. I also personally know DC people who were told young but have negative feelings about being DC. That said, there are other studies (e.g. Jadvá et al., 2009) that suggest being told later in life makes feelings such as shock, confusion and numbness more likely, so it seems that whilst telling early doesn't always prevent negative feelings it does limit any damage.

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?

Whilst my own relationship with my DC half-brother has broken down due to his serious mental health problems, I believe the vast majority of people who have made contact with donor relatives through UK DonorLink have found it a positive experience.

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

Donors have as much of a right to a family life that includes us as we have to a family life that includes them. They should be able to trace us if they wish.

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

I believe responsibility for telling lies with parents, unless they fail to meet it, in which case it becomes the state's responsibility.

What support is required in connection with these responsibilities?

There needs to be much more education and support for parents to encourage them to tell.

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.

References

Jadva, V., Freeman, T., Kramer, W. and Golombok, S. (2009). The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type. *Human Reproduction*. Vol. 24, p. 1909-1919.

Mahlstedt, P., LaBounty, K. and Kennedy, W. (2010). The views of adult offspring of sperm donation: essential feedback for the development of ethical guidelines within the practice of assisted reproduction in the United States. *Fertility and Sterility*. Vol. 93, no. 7, p. 2236-2246.

White, M. and Epston, D. (1990). *Narrative Means To Therapeutic Ends*. New York: Norton.

Relevant articles of the United Nations Convention on the Rights of the Child:

Article 2: No child should be treated unfairly on any basis.

Article 3: The best interests of children must be the primary concern in making decisions that may affect them.

Article 7: All children have the right to a legally registered name, officially recognised by the government. Children have the right to a nationality (to belong to a country). Children also have the right to know and, as far as possible, to be cared for by their parents.

Article 8: Children have the right to an identity – an official record of who they are. Governments should respect children's right to a name, a nationality and family ties.