

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.

NUFFIELD CONSULTATION QUESTIONS

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

The main ethical consideration, in my view, must be to prioritise the needs of the offspring. Although they are not party to the original transaction, they ultimately have to live their whole lives with the consequences, so their needs in terms of developing into healthy well-adjusted adults must be put to the forefront when policy is developed. The needs of parents / recipients and of donors, the medical profession and the fertility industry must take second place.

Four factors point to openness being the best policy for them.

Firstly, there is ample evidence of the toxicity and corrosiveness of secrecy within families. When the facts are too uncomfortable, be it for fear of blame or shame, they can become like the proverbial elephant in the middle of the room: everyone is aware of something important, some members know the details, but the rest just know it is unmentionable, and the effect is one of underlying anxiety. Although parents may sincerely believe they are protecting their children, the existence of secrets often undermines healthy family relationships. (see M.S.Paul & R.Berger, Topic Avoidance and Family functioning in Families conceived with D.I., Human Reproduction, Vol.22/9, June 2007, and Old Lessons for a New World, Chapter 1, E.B.Donaldson Adoption Institute, Feb.2009)

Secondly, it is far too often the case that a family secret that has been kept for years will be disclosed in the worst possible circumstances, during a family row, or inadvertently by an outsider who was unaware it was a secret. There are many cases of donor-conceived people finding out when their parents were separating, or at the death of one of their parents, when they are already facing grief and loss, that they were not biologically related to one of their parents. The truth is then tainted by the circumstances, and the individual feels they have lost the sense of who they were and who they can trust, realising they have lived a lifetime of deceit. (V.Jadva, T.Freeman, W.Kramer & S.Golombok, The Experiences of Adolescents & Adults Conceived by Sperm Donation, Hum.Rep. April 2009 found that the age of disclosure correlates to the offspring's feelings about being donor conceived).

Thirdly, we also know that a strong and steady sense of identity is an important feature in becoming a stable adult. People benefit from having a

sense of belonging and being accepted and respected, in their family and community. Finding out that your true biological origins have been kept a secret will undermine confidence and self-esteem, whereas the evidence seems to be pointing to the fact that most people who grow up knowing they are donor conceived have few hang-ups about it and are generally well adjusted and contented adults, even if they have varied attitudes towards the information they want for themselves. (see Human Reproduction. Sep;26(9):2415-24. Diane Beeson, Wendy Kramer, Patricia K. Jennings***).

Finally, it is becoming clear that donor conceived young people and adults have varying views about what they want to know of their donors, but they consistently believe that they have a natural right to information, including identifying information. Many believe that the United Nations Convention on the Rights of Children Article 7 grants donor conceived children the right to know who their biological parents are.

(see <http://donorconceived.blogspot.co.uk/>)

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?

I do not believe that families (or anyone else) have the right to opt out of telling their children about being donor conceived. If there are disagreements between the parents (or other adults in the extended family), there needs to be skilled and accessible support services to help them recognise the priority of the children's needs. Ideally, this should happen before they go ahead with conceiving their children.

In principle, I believe that the family should be the setting where children find out about their origins. However, it is clear that some families find it difficult to disclose at an early stage. Once they are no longer attending the fertility clinic, it is far too easy to distance themselves from the truth. Thus I believe we need to find ways of promoting and supporting early disclosure. The first resource is the provision of accessible training and materials, such as the workshops and children's books produced by the DCNetwork.

Secondly, I feel that it is necessary for the facts of donor conception to be included somewhere in the formal records, so that an individual can confirm it from an impartial source. I do not believe it should be evident on the Birth Certificate, as donor conceived adults have the right to keep this private, but I believe that if parents know their children will eventually find out from their records, it will encourage them to inform their children themselves beforehand. I believe this needs to be more than on the HFEA records, which will only be obtained if the donor offspring requests: it needs to be formally recorded somewhere the individual will inevitably be exposed to it, and parents must be reminded.

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

I'm not sure that there is any definitive list of facts about the donor that will enable parents to carry out their role. I believe they need to be able to present the fact of donation in a clear and emotionally positive way. They need to understand the information they have been given, and the process available for their children to obtain more information if they can.

Ideally, the parents should have an idea of the donor's physical characteristics and some description of them as a person – their interests, education and work and family relationships. A thorough medical history, including relevant facts about siblings and parents, should also be required.

There is an issue about how much information is needed at the stage of choosing a donor, and very interesting cultural differences between the USA and the UK. My view on this is that all available information should be provided to parents, as however much I dislike the notion of 'gene shopping', I am far more worried by the idea of doctors making the choice for their patients, or clinics/sperm banks selecting the information they want to put forwards.

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

In my experience, donor conceived children and young people who are interested at all mainly want an idea of what sort of person their biological parent is. This will include looks and personality, interests, education and career, and their family background as well as any family they subsequently have. Some are curious about what the donor's motivation was at the time of donation. As adults, they may become more interested in health issues, including the records of the donor's immediate family.

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?

VERY Significant. Unfortunately, this only becomes obvious when things go wrong, for instance when a teenager develops heart disease or some other inherited disorder, or when several offspring are diagnosed as having autistic spectrum disorders. I know several instances of this – two severely autistic children, twins with an inherited skin condition, Narelle Grech, who has been very active in the Australian Donor Conception Support Group and might have had her genetically linked bowel cancer diagnosed earlier than Stage 4, had she known to seek screening. There is ample record of many families thus affected on the Donor Sibling Registry.

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

I believe all concerned should be told immediately – whether the fact becomes apparent in the donor or her / his family, or the offspring. Although

the information will come via the Registry (wherever that resides), it needs to be dealt with sensitively and respectfully, by trained professionals. I do not believe that the Registry itself needs to be the source of support, as I think the skills involved are quite different to the skills involved in keeping the Registry. Such a service could be provided in a variety of ways, but I believe that there are several areas of need which, if aggregated, would warrant a stand-alone specialist service, which could develop expertise and links and resources:

- the support needs of young people who seek the identity of their donor or half-siblings or might need help planning a meeting.
- parents who are struggling with disclosing the truth to their children at a later stage.
- older children / young people and their families who are just discovering the truth, or struggling with it.
- Donors and their families will be needing expert advice when their offspring start obtaining their details.

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?

Most of the children I know never 'found out' about their donor conception, rather it's just a fact that they have always known, in the same way that children grow up knowing they have a cousin or they live at no.19. For these children, what they find out is that it is special or different, and I believe there are two factors that influence how it affects them.

Firstly, it will be the way in which this information is referred to in the family. If it is a fact that is openly referred to and discussed, if it is the matter of cosy bedtime stories and intimate moments between mother and child, then it will be accommodated as a positive feature of the child's developing identity. If it is the subject of formal declarations and solemn talks, then it may be seen as a difficult or awkward issue.

Secondly, the child's personality is an important factor. Some children relish being special, others hate anything that may be seen as 'different'. Some children will move between these two positions at different stages in their life, or indifferent contexts. The parent(s) needs to be sensitive to this, and able to provide the reassurance and affirmation for their child to build the resilience they will need in life, for this as for so many other issues they will come across.

For children of solo mums, the question they face first is usually 'where is the dad?', and only subsequently (often several years later) how they were conceived. The way children handle the questions will be age appropriate, although there is often a stage at which they can describe the mode of conception in a way that is quite outside the grasp of their peers, for whom there has been no need yet to learn about assisted conception.

Children in families headed by lesbian couples will learn to deal with the same questions and curiosity, and later on with the prejudices, in the same way: their family structure will be evident and evoke curiosity and questions.

Children in conventional families are different insofar as the facts of their origins will not be evident or elicit questions from outsiders, so it can remain within the family as long as they wish. Some will relish this 'special' feature and tell their friends early on, tell the whole class in 'show and tell' sessions or when they are studying family trees or genetics, while others will be happy to keep it to themselves, as it is of no particular interest to them or anyone else. Late disclosure: there is evidence that late disclosure is more difficult – see McGee, Brakman & Gurmankin, Hum.Rep. 2000 and Jadva, Freeman, Kramer & Golombok, Hum.Rep.2009. Daniels et al (Hum.Rep.vol 26/10) found that 5 out of the 7 families in their study wished they had told their children earlier.

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?

I have several friends who have made contact with their children's half siblings. The experience varies according to the age of the child, but I know of no negative outcomes, except where the other family has withdrawn, causing confusion and regret.

- a mother of young twins who spent a week's holiday meeting up with a family with a single child from the same donor. The children were under 5 and had a good time and played happily together, despite not speaking the same language. The experience was highly valued by all parents, and continued contact is planned, though visits will be infrequent due to distances.
- a donor conceived teenage girl who knows about several half-siblings in the USA and has contact through emails and facebook, though they have not yet met. These are very special and positive relationships to her, and seem to be helping her cope with the emotional upheavals of adolescence, providing a stable and completely confidential sounding board (her mother's report, not hers directly!)
- three teenage half-sisters, all only children, who have made contact and have close relationships, calling each other sisters, and seeing each other most long holidays despite not living in the same city. The families regularly take all three girls away on holiday, which has enriched their lives in many ways, giving them the opportunity to visit places they would otherwise not have seen and to learn about life in different families.
- I know two families who know of a half-sibling but the other family does not want the children to have contact. In both cases, the child who knows would like to know more and to meet the other child, and this causes some sadness and bewilderment. In both cases, the children are older (over 10), and the other family has not explained their withdrawal from contact. This inevitably leaves room for doubt that the withdrawal may be for personal reasons such as disapproval.

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?

I am not sure what this question means: does it mean 'how is it in their interest?' or 'why are they interested?'. I can't answer the second question, except to say there are examples of donors who have made their curiosity public (e.g. Sylvia Barr of the film 'Donor Mum: the children I've never met', and the many donors who register on the Donor Sibling Registry).

In terms of 'is it in their interest?', I believe that there are medical issues that would definitely be relevant to the donor and his / her family, which may first be identified in the donor offspring.

I also feel that the donor's future children (or existing children, if there were any) have the same need to know about the existence of half-siblings as the donor offspring. It is important when they are making decisions about future partners and starting their own families, and to avoid the risk of future disclosure that could threaten trust and respect within the family.

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?)

In this country, when something is accepted as being beneficial to children, the government take responsibility to promote it in many different ways, from publicity and information to more active encouragement such as policy decisions and supportive services. Our culture accepts some social responsibility for promoting child welfare, so I feel that the need for donor conceived children to access the truth about their origins should be a matter for public policy, and if at all possible, for public services as well. I do not think that providing services takes away the responsibility of parents, but rather that it must complement it and back it up with practical help.

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

I feel that the support needs to go beyond what can be provided by self-help groups such as the Donor Conception Network. Although the service it provides is wholly commendable, it does not reach many families who may feel alienated for a variety of reasons, and I believe that a more formal / impersonal service such as a helpline would be invaluable. As there are so many different situations with very particular variables, I believe it needs to be a highly professional and dedicated service.

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.

The main issue I feel it is important to acknowledge is the fact that more and more people are travelling abroad for their treatment. UK clinics are developing commercial links with foreign services, which mean they do not

have to recruit their own donors. I believe that we could include an expectation that if there are financial benefits, these should be conditional on the UK service setting a standard of service equivalent to that which their patients would receive if they stayed in the UK. Thus, clinics could insist that identity release donors should be available, encouraging a change in practice. I believe that the knock on effect might be to improve practices here, and improve supply of gametes, so that fewer people would have to travel. I have been in contact with many single women seeking to start a family with the help of donor conception over 20 years, and I am still surprised at the variations and new questions that arise. I believe that this field is growing and changing, and is likely to continue to do so for some time yet. We must recognise that in the services we design, and incorporate flexibility and responsiveness. We must ensure that the experience of the service providers is properly collected so we can learn from it and adapt appropriately.

I think the most important factor, that has often been forgotten, is that the interests of the medical profession and of those facing infertility have often been the only needs considered at the time of treatment, but the needs of the resultant children and young people throughout their lives must be given due consideration. As a rule, this will mean precedence over all other considerations.