

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.

Professor Carol Smart and Dr Petra Nordqvist

We are currently undertaking a research project into the experiences of parents as well as grandparents of donor conceived children entitled 'Relative strangers: Negotiating non-genetic kinship in the context of assisted conception' (funded by the Economic and Social Research Council). As part of this project we are investigating how the parents and grandparents of children conceived using donated sperm, eggs or embryos approach the question of sharing information with the child and other significant people. We are exploring what the process of sharing this information is like for parents and how family members live with the decisions they make about information sharing. We are also investigating how parents and relatives understand and thus deal with information about donor conception and genetic difference. We are particularly interested in how such knowledge might impact upon a sense of relatedness and on family relationships. We have conducted over 70 in-depth interviews with families of donor conceived children; we have talked to lesbian and heterosexual parents of donor conceived children, as well as grandparents in both of these family structures.

It is relevant to our findings that the couples we have interviewed went through different procedures with different degrees of emphasis on disclosure. We interviewed 22 heterosexual couples all of whom went to infertility clinics for treatment (mostly in the UK, but some abroad). Fourteen received sperm donation and 8 received egg donation. The year¹ that couples accessed donor gametes through clinics in the UK was significant for all our couples. Thus 10 heterosexual couples had fully anonymous donors, eight received gametes under conditions of identity release, three had known donors and one had a mixture (i.e. different children were born under different clinic regimes). We also interviewed 22 lesbian couples; 12 of these conceived in a clinic setting, 7 self inseminated, 2 did both of the former, and one used an internet company to acquire sperm (now illegal). Twenty of the lesbian couples accessed sperm donation and two accessed sperm and egg donation. Only one lesbian couple received sperm from a clinic under fully anonymous conditions, seven were under conditions of identity release, ten were known donors and one was a mixture (i.e. children were born under different clinic regimes). **It has to be borne in mind that the combination of different**

¹ Donors of children conceived in England and Wales prior to 2005 remain fully anonymous, after this date they are anonymous but with the potential for identity release. Couples who went abroad were subject to the policy requirements applied in those countries.

procedures, different degrees of proximity to the donors and different types of gamete can all have a bearing on attitudes towards disclosure.

Our study highlights some of the issues that are important to bear in mind when it comes to considering the disclosure of genetic origin as raised in the Consultation Questions. However, it is important for us to stress that we do not take an ethical stance on what parents 'should' do. We see our role as contributing to an understanding of what parents and grandparents actually do and the kinds of issues they have to deal with in their everyday lives.

1. Our study suggests that it is important to consider the different consequences of using sperm, egg and/or embryo donation², and the way that these different procedures affect relationships. Attendance at a clinic shapes expectations to a degree and it clarifies legal relationships. It follows therefore that it tends to be assumed that donors are somewhat distant figures who can be discovered (to a degree) later on in life. However we found that both egg and sperm donors could be known to couples, indeed they could be family friends and thus would be known to the child. It would also mean that grandparents and brothers and sisters and so on would know the donor.
2. For couples (exclusively lesbian in our study) who accessed sperm outside the clinic, knowledge of the donor could be on a continuum from a complete stranger through to a close friend who becomes an involved father figure. In cases of substantial involvement we found that the donor's parents could also become important figures in the life of the child. (However the possibility of an egg donor's parents becoming involved with their genetic grandchild seemed much more remote.) **When discussing disclosure, and who should make decisions about disclosure, it is important to consider the complexities of these families. Disclosure involves the lives of people beyond a narrowly conceived nuclear family.**
3. Although parents might agree *in principal* with the idea that a donor conceived child should know about her or his genetic origins, information sharing is not a straightforward process. Disclosure is often complicated and multifaceted as well as being emotionally loaded. For example our study shows that telling the child and others, is not a one-off event, but has to be done repeatedly. Surprising as it may seem, young children (as well as others of course) can forget, and need to be reminded. This 'forgetting' is understood where young children are concerned and parents are advised that they need to tell their children often and in age appropriate ways. But grandparents and others can 'forget' too and this seems to be because they do not want to differentiate between their grandchildren. The strong desire to treat all children of the

² We have additionally information on 30 families from grandparents and these interviews included two cases of embryo donation.

family in the same way diminishes the significance of genetic difference. **The insistence on disclosure and the emphasis on difference seem to run counter to an ethic of family inclusiveness.**

4. Decisions about openness can also be linked to finding the experience of infertility extremely painful. Not being able to conceive one's own genetic child was usually associated with grief and distress. This means that repeated 'disclosure' entails repeatedly revisiting this grief. For example, one man in our study who learned that he was infertile (but went on to have a child by sperm donation) said about the donor conception that 'you never accept it, you learn to live with it'. For many, difficult feelings could linger after the birth and as the child grows up. **Sharing information with the child and, most particularly, reminding him or her regularly about his/her donor origin, can therefore stir up difficult feelings in the parents, and so affect family relationships and dynamics.**
5. This difficulty can be compounded where one parent is genetically related to the child while the other is not because their different 'statuses' can never be overcome. **It is therefore important to consider how the 'downsides' of disclosure can be managed and supported.**
6. It is important to consider the need some families may have for privacy. Some parents chose to keep the information very private, and might tell only the child and a select few. For example one lesbian couple we interviewed lived on a very deprived housing estate and they felt that their child might suffer if his status as donor conceived became known (e.g. through the local school). Moreover some felt that the information 'belongs' to the child and they felt it was not their right to place it in the public domain. Because a young child could not be expected to keep such knowledge a 'secret' **it was feared that he or she would inadvertently sacrifice their own right to privacy as a consequence of having a right to know.**
7. Parents could also refrain from sharing information widely because they worried about stigma and feared that grandparents, or other significant relatives, might not see the child as part of the family (especially where there is no genetic connection to that 'side' of the family). Others worried about disclosure leading to stigma in their local community or faith group. For some, being open was simply not an option, because it was seen as potentially very damaging to the relationships in which the child was already embedded. In one case in our study, a lesbian mother decided not to share with her wider family that she was a lesbian and that her child was donor conceived. Her own parents were informed, but they so disapproved of her sexuality that they lied about how the child was conceived to the more distant relatives in the family, including the mother's own grandmother. This mother lived on a very

small income and relied on her parents for child care and support, and she feared that open disclosure might damage relationships to the extent that it would have severe consequences for both her and the child.

8. Many of our interviewees did decide to share information quite openly. However, it would be wrong to assume that doing so was an easy process. Parents who decided to share information with the grandparent generation could find, for example, that the grandparents could not cope with talking about donor conception. Grandparents could find it too difficult or too emotionally challenging for them to be party to such news. Sometimes they did not understand the implications of what they had been told (confusing assisted conception and donor conception), and some could not frankly understand the need to talk about it in the first place. Others found that family members were not sympathetic and reacted with disapproval. **Thus generational differences about privacy and openness could lead to conflict.**
9. It was also the case that once parents let go of precious information, they lost control over it altogether, and this could have difficult social consequences. For example, one woman had told her brother about how her children were conceived but felt very uncomfortable hearing him telling others about this on social occasions. The fact that he did so led to a rupture in their relationship, and in the relationship between the children and their uncle. **This raises the question of 'whose information' it is once parents lose control of it.**
10. Our research highlights how decisions about disclosure must be understood as embedded in webs of relationships with other kin/people. When it comes to family relationships, they must be understood as interlinked, making this a very complicated process. This means that in practice, the boundaries of what is meant in the Consultation Document as 'an individual family' is actually very fluid and flexible. In cases of known donors, the donor him/herself as well as his/her family (e.g. parents, partners, siblings, children) might be involved or known to some extent to the donor conceived child and the parents. In one case in our research, a lesbian couple had a private agreement with a donor who would be known to the child but not involved as a father. As time went by, however, the donor's father gradually got to know the child, and formed a very close relationship and bond with him. In fact this paternal-by-way-of-donation-grandfather became the closest and most involved grandparent in the family. In another case of a known egg donor, the birth mother was open to her child about the conception story but insisted that the donor should not allow her own children to think of themselves as siblings to her son.
11. These findings show that one cannot easily speak of 'one individual family' which needs to make a decision whether to disclose or not. Instead it is more

helpful to talk of parents and children being connected in numerous ways, both within their own kinship network, and possibly also to the donor's. This means that decisions about openness are situated in complex webs of relationships that characterise everyday life. **In this sense the decisions are fundamentally relational and have widespread and sometimes unforeseen consequences.**

12. **Our research suggests that parents want to be 'honest' but that total openness and complete loss of control over information was usually far too worrying.** One interviewee spoke of 'gentle lies' which captured the difficult tightrope parents had to walk. Those who felt it was the child's information did not, for example, want relatives telling all their friends about it before the child him or herself could make informed decisions. Generational differences could mean that while parents were fine with disclosure, grandparents were really upset about it. Equally frankness about conception could lead to problems when very young children shared with their friends their knowledge about sperm and conception. (For example, in such a situation is a mother obliged to explain to the mother of their child's nursery school friend that her partner is infertile?)

Our research focuses on the practices of disclosure rather than the principles or ethics of disclosure. We were not able to find parents who were completely against disclosure or who had kept the method of conception secret from everybody and so we cannot represent their views. But we can represent the views of families who are broadly in favour of disclosure and yet who find the process both difficult and challenging in practice. These are the people who are most likely to be affected by policy changes and so we would argue that our research is able to raise issues for policy implementation. **Thus our most important recommendation would be that any decision about whose responsibility it is to reveal information about donor conception must consider the complex social consequences that disclosure can have for families and relationships.** While there are inevitably strong ethical reasons favouring truth telling, the manner and the pace of such telling can produce difficult or destabilising effects on family relationships. Removing the responsibility for disclosure from families would be a strong step to take unless the full consequences of such a course of action had been thoroughly considered.