

Donor conceived children shouldn't have right to be told of their origins, says Nuffield Council

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Children conceived from donated sperm or eggs should not have an automatic right to be told about their conception, recommends a report from the Nuffield Council on Bioethics.¹

It should be up to the child's legal parents to decide whether to make the child aware that he or she was donor conceived, says the report. It adds, however, that parents need more support to help them make and follow through on this difficult decision.

The report says that the state has an ethical responsibility to ensure that appropriate support is provided to donor conceived people, their families, and donors at all stages. It says that this support could come from a variety of sources, including fertility clinics, which should increase the level of counselling offered to prospective parents, new parents, and potential donors.

Support services should also be available to donor conceived people who contact the Human Fertilisation and Embryology Authority to find out the identity of their donor, it adds.

Rhona Knight, the GP who chaired the Nuffield inquiry, said, "In recent years there has been a culture shift: advice from professionals has gone from the extreme of never telling to always telling."

She added that although the report said that children should not have the automatic right to know how they were conceived, the inquiry panel thought that it was usually better for children to be told, by their parents, about their donor conception as early as possible.

Katherine Wright, assistant director and project head for the donor conception project at the Nuffield Council on Bioethics, said that young children tended to accept the information more readily, whereas adolescents and young adults were more likely to be shocked or angry. She added that the number of parents telling their children was rising and that around 75% now said that they intended to tell their children, although not all would go through with the intention.

The council's inquiry rejected the suggestion that children should have a right to know that they were conceived through donation and that the state should enable this by making it mandatory to declare donor conception on a birth certificate. It considered the argument that children had the right to know whether they were at risk of any serious inherited diseases, but Knight pointed out that potential donors were screened for these.

The council recommended that a multidisciplinary group should review and update current guidance on screening of donors and whether any further medical information should be reported on

the donor information form for future use by donor conceived people.

Knight said, "We also think that a clear, well publicised mechanism should be set up so that if any significant medical information emerges after donation it may be shared between donors and the donor conceived person, and vice versa."

Since 1991 more than 35 000 people have been conceived in the United Kingdom through donor assisted conception in regulated clinics, and many more have been conceived in unregulated clinics or abroad.

Children conceived since April 2005 have the right to receive identifiable information about the donor and to contact the donor once they reach the age of 18. Donors cannot seek out children born as a result of their donation; they can find out only how many children were born and their sex and year of birth. It had been anticipated that the loss of donor anonymity would put off many would be donors but this has proved not to be the case, as donor numbers are rising.

Children conceived between 1991 and 2005 can find out information and contact the donor only if the donor has opted to join a Human Fertilisation and Embryology Authority register that enables them to be identified.² The authority holds no information about children conceived before 1991; limited information may be available through the clinic involved.

Laura Witjens, chief executive of the National Gamete Donation Trust, said that the inquiry considered whether anonymity should be removed from pre-2005 donors but decided against it. Instead it recommended that more effort be made to increase awareness among past donors that they could register their details with the authority. The authority cannot contact past donors because of data protection rules.

Witjens said that the authority should also do more to spread awareness among potential parents of the dangers of using unregulated clinics and of going abroad, because of possible lower levels of screening for serious inherited conditions and the prospect that the child would be unable to find out about and get in touch with their genetic parent in the future if they so wished.

- 1 Nuffield Council on Bioethics. Donor conception: ethical aspects of information sharing. 17 Apr 2013. www.nuffieldbioethics.org/donor-conception.
- 2 Dyer C. More than 100 sperm and egg donors prove ready to reveal identity to offspring. *BMJ* 2008;337:a2110.

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