NUFFIELD COUNCIL º BIOETHICS

Summary of report Donor conception: ethical aspects of information sharing

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The donation of sperm, eggs and embryos makes it possible for many people, who would otherwise not have been able to have children, to create families of their own.

In contrast with practice in the past, parents of donor-conceived children are now strongly encouraged to tell their children about the way they were conceived. Donors are also encouraged to provide biographical information about themselves, so that donor-conceived people can find out more about them, if they wish. Identifying information about donors will be available in the future to people born as a result of donations made after April 2005. Donors who donated before this time remain anonymous, unless they choose to make themselves identifiable.

Some people feel strongly that information about a donor is essential for a donorconceived person, while others feel information about the use of donor sperm, eggs or embryos in fertility treatment is private to the parents and donors.

The Nuffield Council on Bioethics has published a report which makes recommendations about the responsibilities of those involved in sharing information about donor conception including donor-conceived people, parents, donors, and health professionals. Recommendations are also made to fertility clinics, to the Human Fertilisation and Embryology Authority (HFEA), and to the Government. The Council concludes:

- When, if and how to disclose should remain a private decision for families to take, but evidence suggests that it will usually be better for children to be told, and to be told at an early age.
- Measures that aim to support, encourage and empower those making decisions are preferable to measures that remove choice. Thus the state has a 'stewardship' role in providing conditions that support and enable parents to make informed choices.

Policy affecting prospective parents

- The state should ensure that parents are informed in an understandable way about the best available evidence in relation to disclosure.
- Prospective parents should not be screened in connection with their plans to tell, or not tell, their children that they are donor-conceived.
- The state does not, and should not, have a role in informing donor-conceived people of the circumstances of their conception, for example through entries on birth certificates.
- As a matter of good professional practice, clinics should provide counselling sessions as part of the routine series of appointments attended by prospective parents. An additional support session later in pregnancy or after the birth of the child should also routinely be offered.
- The option of anonymous donation should not be reintroduced.



Policy affecting parents and donor-conceived people during childhood and adulthood

- Materials routinely sent to pregnant women and new parents should include information about donor conception, including details of support organisations.
- Parents need clear information about the screening procedures that the donor has undergone to reassure them that the risk of their child developing a serious strongly heritable condition is very low. The current guidance on the screening and assessment of donors should be reviewed and updated.
- Appropriate counselling and intermediary services should be made available for those who, in the future, may contact the HFEA for identifying information about their donor.
- A clear mechanism should be set up to enable significant medical information that emerges after donation to be shared between donors and donor-conceived people.

Policy affecting donor-conceived adults who do not have access to information

- The rules about anonymity for donors who donated before 2005 should not be changed. However, the state should take action to increase awareness among past donors that a willingness on their part to become identifiable would be highly valued by some donor-conceived adults.
- The HFEA should issue guidance to clinics setting out what is expected of them with respect to making information from pre-1991 records (where such records exist) available to donor-conceived adults.
- The HFEA should make sure for example through the creation of a dedicated donor conception website that factual information about the implications of seeking treatment with donor gametes abroad, or through unregulated methods, is readily accessible to those contemplating these routes to parenthood.

Policy affecting donors

- Clinics should ensure that sessions with a counsellor are scheduled as part of a routine series of appointments that donors attend before deciding whether or not to donate. Where donors have partners, clinics should strongly encourage partners to attend these sessions.
- The HFEA's National Donation Strategy Group should further consider what information about donors would be likely to be helpful to recipient parents and, in time, the donor-conceived person, so that it is routinely recorded on donor information forms.
- Clinics have a responsibility to support donors to think seriously about the information that they provide when they fill out the donor information form.

Copies of the report are available to download from the Council's website: www.nuffieldbioethics.org/donor-conception

To order a printed copy please contact: Nuffield Council on Bioethics Telephone: +44 (0)20 7681 9619 Email: bioethics@nuffieldbioethics.org