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Original Citation

Blyth, Eric, Crawshaw, Marilyn and van den Akker, Olga (2009) Disclosing donor information: A new code of silence? BioNews.

Published by the Progress Educational Trust

Disclosing donor information: A new code of silence?

09 March 2009

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Appeared in BioNews 498

One of the first publicly-recorded actions of the HFEA's apparently ironically-named 'Opening the Register' (OTR) Working Group has in fact been to recommend reversal of the HFEA's current policy of disclosing gamete donor codes to patients and to 'strongly advise' centres to follow its lead (1).

Neither of the Human Fertilisation and Embryology Acts (HFEA) of 1990 or 2008 includes any provisions as to what information could or should be disclosed to parents of donor-conceived children, thus leaving to the HFEA's discretion determination of what - if any - information to provide. Since passage of the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 (2), the HFEA's policy has been to encourage clinics to 'respond as fully as possible to patients' requests for non-identifying information about the donor or donors used in their treatment' (3) - a policy it continues to endorse in the draft 8th edition of the Code of Practice (4). Further, it has advised clinics that any 'non-identifying codes or designations assigned by the clinic to the donor or donors used' could be disclosed, so long as disclosure does not compromise the donor's identity (3, 5).

The review of current policy is founded on two principal concerns:

1) The requirement that from 1 October 2009 the HFEA will be required to disclose identifying information to a donor-conceived person about any genetically-related donor-conceived sibling who has consented to the disclosure of their identity where both parties have reached the age of 18 (6).

2) An oddly-assorted mix of reported operational problems:

- Codes issued by clinics are not unique donor identifiers, since different donors can be assigned the same code by different clinics, thus risking erroneous 'matching';
- Since the Code of Practice itself does not discuss donor codes, 'some' clinics are not clear about disclosure of donor codes and 'many' prospective donors are not aware of possible

disclosure of their code to recipients (apparently despite the Chair's letter of 28 October 2004 (3));

- Not all donor codes may be disclosed, since some clinics incorporate potential identifiers (such as the donor's date of birth) in donor codes;
- A donor who obtains their code and belongs to the same networks as children seeking genetically-related donor siblings may be able to learn the identity of children born as a result of their donation;
- A donor gamete recipient who obtains the code and subsequently becomes an embryo donor and belongs to the same networks as children seeking genetically-related donor siblings may be able to learn the identity of children born as a result of their donation who may not have consented to disclosure of this information.

As regards the first of the operational problems, self-evidently what has happened in the past cannot be undone. But this proviso could be issued alongside any information given, together with advice to undertake further checks - for example through DNA profiling - before confirming any 'match'.

The second seems irrelevant, since no donor who donated prior to the letter in October 2004 would have been advised of this either. The logic of this argument would mean that clinics and the HFEA itself do not currently disclose codes of 'pre 2004' donors. In the absence of evidence to the contrary it is highly unlikely that such distinctions are currently made.

The third problem is legitimate as far as it goes, although the opportunity could be taken by the HFEA to stop this practice if so minded. The fourth problem seems irrelevant since the policy under discussion relates to giving codes to recipients, not to donors. The same general comment can be made in respect of the final reported problem, with the added factor that the number of individuals who would fit these criteria seems to us improbably small.

Very limited stakeholder consultation was undertaken by the HFEA prior to drafting the OTR Working Group recommendation, which included Donor Conception Network, the National Gamete Donation Trust, Department of Health officials and individuals 'involved in adoption'. The HFEA received arguments both in favour of, and opposition to, the existing HFEA policy.

Proponents of the status quo noted the potential benefits to young donor-conceived people who are interested in discovering half-siblings, the alignment with the field of adoption where contact with siblings throughout childhood is considered to be good practice and the potential disadvantages of postponing the possibility of such contact until those affected have become adults - a view the HFEA itself notes as 'ethical[ly] ….. the most compelling reason for continuing to disclose these codes'. On the other hand, terminating donor code disclosure was advocated on the grounds of the risks of identification between donors and donor-conceived individuals and the alleged 'discrepancy' between the HFEA's current facilitation of contact between genetically-related donor siblings under 18 and new legislative provisions regarding voluntary contact between genetically-related adult donor siblings.

In acknowledging that the (undoubtedly real) operational problems relating to disclosure of donor codes could be resolved, the OTR Working Group's proposal appears to rest on two dubious premises: first, a perversely restrictive interpretation of legislation that was designed to increase information disclosure in regard to donor conception, that since legislation now affords specific legal rights to donor-conceived adults, these rights must not be granted to anyone until they are adults; second, an overtly paternalistic and negative view of parents of donor-conceived children who it perceives as motivated to 'bypass the legal restrictions and who apparently can't be trusted to act in their children's best interests.

In recent years the HFEA has earned a well-deserved reputation both for transparency in decision-making and for engagement with a wider public before implementing major policy changes and proposes to codify this reputation in a set of five principles (7). That it has failed to live up to its own high standards on this occasion, including two of the five principles (to 'consult widely - listening to and learning from those with an interest in what we do' and to ' exercise our functions consistently, proportionately, openly and fairly') is a matter of regret. This proposed heavy-handed policy flies in the face of all recent trends - including the HFEA's own continuing policy - towards openness in donor conception. It also represents a missed opportunity to reform the acknowledged chaotic system of allocating donor codes, since no plans for reform are mentioned (and the principal motivation for doing so has been conveniently removed). Even if the HFEA accepts and implements the policy, it can merely 'strongly advise' - and cannot compel - clinics to follow suit, and since some clinics have apparently ignored the Chair's letter of 28 October 2004, compliance cannot be taken for granted. Furthermore, if the policy is implemented, it is hard to see how the HFEA could mount a respectable defence should any aggrieved parent decide to mount a legal challenge. At the time of writing, the HFEA's intentions as regards this policy recommendation are not known. However, we strongly hope that it will reject this retrograde proposal and so save both itself and donor-conceived families the inevitable trouble and inconvenience that would result from its implementation.

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