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Donor conception and birth certificates - more steps in the right direction

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A springboard for revisiting the role that birth certificates might play in facilitating the ability of a donor-conceived person to access information about their genetic and biographical history (a proposal initially mooted by the Warnock Committee, but never acted on, in 1984) (1), was provided by the joint committee of the House of Lords and House of Commons scrutinising the then Human Tissue and Embryos (Draft) Bill in 2007 (2).

Several specific proposals have been advanced, including:

1) Inclusion on birth certificates of a symbol (which in due course would become recognised as denoting donor-conception) or text making a specific reference to birth by donor conception, ranging from the simple annotation 'by donor'/ 'by donation' to inclusion of the identity of the individual's genetic parents;

2) New systems establishing a formal link between the current birth registration system operated by the three General Register Offices and the UK-wide Human Fertilisation and Embryology Authority (HFEA) Register of Information;

3) Introduction of a new certificate - a certificate of genetic heritage - additional to the current 'long' birth certificate, for all individuals providing information of the individual's genetic parentage.

As the Human Fertilisation and Embryology Bill enters the next phase of parliamentary debate in the House of Commons, and following discussions during the Bill's passage through the House of Lords, the government has proposed further measures to facilitate donor-conceived people's access to information about their conception:

1) Encouraging parental disclosure through education, by funding the Donor Conception Network to produce materials on 'how to tell', and to run workshops on 'telling';

2) Proposing amendments to the Bill (a) requiring clinics to provide information to people
considering donor conception about the importance of disclosure and (b) requiring the HFEA to produce guidance to clinics on providing such information;

3) Proposing a future review of the role of birth certificates in donor conception.

A key question is whether these measures are sufficient and, if not, what more the government can and should do now rather than wait several years before initiating more substantive reforms.

Central to the debate so far has been a privacy issue - the extent to which the demands of some donor-conceived people for access to information to which they are entitled under provisions of the HFEA (Disclosure of Donor Information) Regulations 2004 to be facilitated may comprise the privacy of parents and other family members of donor-conceived people (including other donor-conceived people, not all of whom have necessarily endorsed the 'full disclosure' approach).

Currently, there are two forms of birth certificate in the UK - a 'long' birth certificate which provides details of the individual's name, place and date of birth, sex, and name of parents as supplied by the individual registering the birth, and a 'short' birth certificate, providing details of the individual's name, date of birth and sex. An individual who is subject to a parental order following a surrogacy arrangement or who is adopted will have a parental order or an adoption certificate in place of a 'long' birth certificate; under current legislation they are able to access their original 'long' birth certificate from one of the General Register Offices once they reach 16 (in Scotland) or 18 (in the rest of the UK).

The privacy dilemma occurs for two reasons. First, the 'long' birth certificate is increasingly being required as proof of identity for a range of purposes (although, ironically the certificate itself contains the explicit warning 'A certificate is not evidence of identity'), and so is accessible to an extensive range of individuals. Second, birth certificates are 'public' documents insofar as anyone armed with minimal information and prepared the pay the modest GRO fee can obtain a copy of the 'long' birth certificate of any other person. Adoption and parental order certificates are protected and so third party access to these is restricted, although these certificates are also being required, in preference to a 'short' birth certificate, for a wide range of civic and other purposes.

While the government's proposals in the Bill are welcome steps in the right direction, I believe that it can do more to secure the central aspirations of donor-conceived people to facilitate access to information about their genetic and biological history, both at relatively modest cost and without compromising the privacy of anyone. The following proposal is derived from recommendations in a 2005 report of the New Zealand Law Commission (3). While the proposal applies to both 'long' and 'short' birth certificates, it seems questionable whether the 'short' birth certificate now serves any useful purpose at all (in which case a decision to dispense with it altogether would make the proposal much simpler and also save money):

1) ALL 'short' birth certificates should include the following text: 'Further information relating to the individual whose birth is recorded on this certificate may be held on the Human Fertilisation and Embryology Authority Register of Information, the Parental Order Register or the Adopted Children Register'.

2) ALL 'long' birth certificates should include the following text: 'Further information relating to the individual whose birth is recorded on this certificate may be held on the Human Fertilisation and Embryology Authority Register of Information' [adopted people and people subject to a parental order will have an adoption certificate or parental order certificate respectively in lieu of a 'long'
This proposal means that all individuals will have access to a birth certificate alerting them to the existence of other registers, but would not single out any one individual or - by implication - their parents and other family members. This information could then act as a 'trigger' for the individual to make their own enquiries of the Register(s), subject to the legally mandated age limits for accessing such information. (There is also a good case to be made for reducing to 16 the age limit for accessing all information, but that argument is outside my remit here). Both in advance of undergoing a donor procedure and as part of the new provisions for parent education, adults contemplating building their family through donor conception will in future receive a clear message about the merits of early disclosure and advice about the new text on birth certificates. The latter would provide parents with an added incentive for early disclosure rather than risk a later, and quite possibly traumatic, disclosure.

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