

Guidance on Donor Assisted Conception

Introduction

- 1.1 This guidance sets out the key background information to support practitioners working in a case where donor assisted conception is a factor. This includes:
- The legislative framework for medical treatments in the UK;
 - Birth registration in cases; and
 - The issues that may be encountered in Cafcass cases.
- 1.2 It is designed to complement the Cafcass Parental Order Guidance, which sets out the process for surrogacy in the UK, the Parental Order Reporter roles and responsibilities.

Legislation

- 2.1 The Human Fertilisation and Embryology Acts of 1990 and 2008 provide the legislative framework for medical treatments carried out in the UK. Donor conceived people who were born before the first legislation came in (August 1991) do not have the legal right to information about their genetic parent(s) and there is no legal requirement for any records to be kept.¹
- 2.2 The Human Fertilisation and Embryology Authority (HFEA) holds a central Register of Information, which includes details of all donations, licensed fertility treatments and subsequent births. Fertility clinics are required to submit a registration form which includes the name, place and date of birth of the donor, specified physical characteristics and medical history (including family medical history where known) together with their ethnicity, religion, marital status, occupation and interests. Donors also have the option to include a pen picture of themselves, the reasons that they donated, and a goodwill message to be passed on to anyone conceived. Parents have the right to some non-identifying information about the donor to aid them in raising their child. This is available either from the clinic where they were treated or from the HFEA.
- 2.3 All donor-conceived people born from donors who were recruited after 1st April 2005 have the right to apply for identifying information about their donor(s) once they reach the age of 18.² New rules regarding access to information were introduced as part of the HFE Act 2008, which came into force in October 2009. The register can now provide information for the following donor-conceived people:

¹ For this group, accessing information about origins is highly problematic, although the Department of Health has been funding a voluntary information exchange and contact register, UK DonorLink, since 2004, that uses DNA testing as the route to identifying genetic relatives (www.ukdonorlink.org.uk).

² A small number of donor conceived people were affected adversely by transition arrangements. All donors recruited for the first time after 1.4.05 were required to be identifiable but a small number of treatments were approved using past donations, for example to complete a family using the same donor.

- Those aged at least 16 requesting non-identifying information about (i) their donor(s) and / or (ii) donor-conceived genetic siblings.
 - Those aged at least 16 intending to marry, enter into a civil partnership, or enter into an intimate physical relationship who submit a joint application to establish whether they are genetically related.
 - Those aged 18 or above requesting identifying information about (i) their donor(s) and / or (ii) donor-conceived genetic siblings. If they were born before the new rules on anonymity were introduced in 2005, identifying information about their donor(s) will only be released if s/he has re-registered as 'willing to be identified'. Identifying information on siblings will only be released with the consent of both parties.
- 2.4 Where treatment takes place in an overseas clinic, this is subject to regulatory requirements of that country, if any. Where non-medical private arrangements are made (involving self insemination with sperm) such arrangements are legal but unregulated.
- 2.5 Donors can either be 'known' to the prospective parent(s) – such as a family member or friend – or unknown. Currently no more than 10 families can be formed through the use of one donor (i.e. the number of children may be greater if twins or triplets were born) though this does not include any children born to the donor outside of licensed treatments.

Background

- 3.1 Each year approximately 1500 children are born as a result of treatment at licensed fertility clinics in the UK that involve the use of donor assisted conception using sperm, egg or embryos. In addition, some children are born following such treatment overseas, or as a result of sperm donation through private non-medical arrangements.
- 3.2 Cafcass does not have a statutory role in relation to donor assisted conception independently, except where it involves surrogacy (for further information, refer to Cafcass guidance on Parental Order Reporters).
- 3.3 Although there are similarities to adoption in that one or both parents of donor conceived children may not be the genetic parent of the child, the assessment and preparation of prospective parents is very different across the two systems.
- 3.4 Fertility clinics are required by law to take into account the welfare of any child to be born as a result of, or affected by, the proposed medical treatment, including the need for supportive parenting³. This includes assessing whether or not there is a risk of significant harm or neglect; where they consider that there may be a risk they are required to seek further information before deciding whether or not to proceed.
- 3.5 It is the responsibility of the clinic to consider factors such as:

³ Refer to Section 13 (5) of the Human Fertilisation and Embryology Act 1990 (as amended by the 2008 act) which relates to welfare of the child (<http://www.hfea.gov.uk/5473.html>)

- Past or current circumstances of the prospective parent(s) that may lead to any child born, or affected, experiencing serious physical or psychological harm or neglect, or
- Past or current circumstances of the prospective parent(s) that may lead to an inability to care throughout childhood for any child who may be born, or that are already seriously impairing the care of any existing child of a family.

3.6 There is no longer a requirement for clinics to routinely check with GPs as to whether they are aware of any risk factors. However, they are required to take a medical and social history and seek further information from relevant agencies if there are concerns regarding the welfare of a child. Where prospective parents refuse permission for any further checks to be completed, treatment can still go ahead if the clinic believes that this will not lead to significant harm or neglect to any child born or affected.

3.7 There is no legal obligation for prospective parents of donor conceived children to attend any form of preparation or information sessions prior to treatment. Clinics must offer counselling, and some specify attendance as a condition of treatment, although this may only be one session and may incur a charge. There is no requirement on clinics to provide follow-up support once the child is born.

3.8 This means that many parents have had limited opportunity to discuss with a professional the additional issues and tasks that they may encounter in bringing up a child who is not genetically related to either or both of them.

Birth Registration

4.1 The Register of Births can hold records that do not reflect genetic parentage: there is no longer a presumption that the person shown as a parent on the Register is genetically related to the child. Children born as a result of sperm donation have typically been registered as the child of their mother's husband (although this was not legal until recently) and will have assumed that he is their biological father unless told otherwise. Children born from egg donation are registered as the child of the birth mother. Children born as a result of embryo donation are typically registered as the child of their 'social' parents. In no such cases does the birth certificate give any indication that they are donor conceived, meaning that the child neither knows they are donor conceived nor which parent (if any) is their genetic parent unless told. Children conceived after April 2009 may be registered as having a mother and a second female parent and from 2010 two men may be registered as the parents of a child born through surrogacy. Children registered as having two same sex parents will, of course, know that at least one of them cannot be their genetic parent but will be reliant on their parents to give them more information until they reach the age of 18 (see above).

Issues that may be encountered

5.1 When meeting parents of children born as a result of donor assisted conception, and the child themselves, the practitioner may encounter a number of issues that will need to be fully considered when preparing reports. They may find it useful when doing so to refer to

'Messages from Research', available on the intranet. Below are some illustrative examples of how donor conception could be a matter to be taken account of in Cafcass cases:

- In an adoption application (for example step parent application or application to become adoptive parents) parents may already have a child that was born as a result of donor assisted conceptions whom they have not yet told of his/her donor conceived status. Apart from the fact that this may need addressing for the well-being of the child/ren concerned, the parents' lack of understanding of the importance of children being aware of their origins will need careful attention as part of the adoption application. Secrecy within families about a child's origins can be emotionally and psychologically damaging for both the parents and the child/ren involved. In addition, parents may share the information with friends or family members, thus heightening the risk of accidental disclosure by a third party. Further, in some cases the donor may be known to the parents and this can bring particular challenges if the biological and social relationships have not been well managed following the child's birth and/or where the nature of the relationship is not clear to the child.
- Parents who separate may have children born through donor conception treatment. Any disagreements about openness with the child or any unresolved feelings about their use of a donor or about their (in)fertility may be an important factor to consider in seeking a way forward.
- Sometimes, a child may not have the same ethnic background as one of their 'biological' parents. The importance of promoting identity is essential. For donor conceived children this takes on a particular importance because of the added dimension of their genetic inheritance as part of their identity.
- Where more than one child in a family is donor conceived, they may have different access rights to information about their origins, whether in the UK or overseas, depending on the legislative framework in force at the time of their conception
- Given that some congenital conditions may not present until later in life, those affected (including parents) need to be aware of the possible need for future information sharing including via the HFEA or UK DonorLink.⁴ Misdiagnosis can occur if doctors have limited or incorrect medical history available to them.
- Where a child has been born through treatment overseas, there may be very little information available about the donor(s) and the child may have no legal rights to find their identity.

Links

Human Fertilisation and Embryology Act 2008

<http://www.legislation.gov.uk/ukpga/2008/22/contents>.

⁴ UK DonorLink (www.ukdonorlink.org.uk) is the UK's voluntary information exchange and contact register for those directly affected by donor conception prior to August 1991; the HFEA holds a statutory register of information for those concerned from 1st August 1991.

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