HUMAN FERTILISATION AND EMBRYOLOGY ACT 2008

EXPLANATORY NOTES

COMMENTARY ON SECTIONS

Part 1: Amendments of Human Fertilisation and Embryology Act 1990

Section 24: Register of information

- 144. Section 31 of the 1990 Act requires the HFEA to keep a register of information obtained by it which relates to the provision of treatment services, or the keeping or use of any gametes or an embryo taken from a woman, or the procurement or distribution of sperm for certain purposes. It also requires the HFEA to keep a register of information obtained by it about people born as a result of treatment services.
- 145. Section 31 makes provision for people conceived as a result of donated gametes since the 1990 Act came into effect to require the HFEA to provide them with certain information.
- 146. Donor-conceived people are able to find out whether, but for the provisions of the Act which determine parenthood in relation to people born as a result of certain treatment services (sections 27 to 29 of the Act), they would be related to the person they intend to marry and at age 18 they are able to find out whether the register shows that they were, or may have been, conceived using donor gametes. If so, they are able to obtain such information which is held on the register as is specified in regulations made under section 31(4).
- 147. Section 24 of the Act replaces section 31 with new sections 31 to 31ZG. New section 31 re-enacts the parts of the amended section 31 which deal with the register so that the HFEA must continue to keep a register of the information referred to above and must also record such information which it obtains after the Act comes into effect.
- 148. New section 31ZA re-enacts the existing provisions of section 31 of the 1990 Act which enable a donor-conceived person ("the applicant") to obtain information about their donor. However, the donor-conceived person will now be able to request this information from age 16. Only non-identifying information can be disclosed whilst the donor-conceived person is under 18.
- 149. New section 31ZA(2)(b) enables a donor-conceived person to obtain information, at age 16, and on request, about the number, sex and year of birth of their donor-conceived half siblings who were conceived using gametes of the same donor but are not the donor's legal children.
- 150. The HFEA has a discretion not to comply with a request for information about the genetic half-siblings if it is aware of special circumstances which increase the likelihood that the applicant would be able to identify the donor (in a case where the applicant does not have a right to obtain information about the donor's identity) or any such genetic half-sibling.

- 151. New section 31ZB enables a donor-conceived person to find out whether they are related to someone they propose to marry, enter a civil partnership or intimate physical relationship with or with whom they are having an intimate physical relationship. The consent of the person with whom they are having or intend to have, a relationship will need to be given to the HFEA. The consent of the person they are in or intend to enter into the relevant relationship with will need to be given to the HFEA. There is no age limit in relation to applications under this section by donor-conceived people who are intending to marry or enter a civil partnership. This is in line with the current provision in section 31. In order to make an application as a person who is in or is intending to enter into an intimate physical relationship, the donor-conceived person must be aged 16 or over.
- 152. New section 31ZC gives the HFEA the power to inform a donor of the fact that a donor-conceived person has requested information about him. Donor-conceived people will be able to request identifying information about their donor from 2023 onwards, in relation to donors who donated identifiably from April 2005. This could happen sooner if someone who donated before April 2005 elected to re-register as identifiable, and a person conceived from his or her donation requested identifying information from the HFEA. In practice, the HFEA would try to forewarn the donor before identifying information is given to the donor-conceived applicant. This might not be possible in all cases, for example if the donor has moved and has not updated their address. The HFEA may not disclose identifying information about the donor-conceived person to the donor.
- 153. New section 31ZD enables donors (including past donors) to be provided with information on request about the number, sex and year of birth of children born as a result of their donations. They may ask the clinic where they donated or the HFEA (if the clinic has closed or the clinic is not able to, or fails to, provide the information). The information can be withheld from the donor if the HFEA is aware that circumstances exist which would mean that releasing the information would increase the likelihood that the donor would be able to identify a child born as a result of their donation.
- 154. New section 31ZE enables donor-conceived people to request and obtain identifying information about their genetic half-siblings who were conceived using gametes from the same donor, where neither is the donor's legal offspring. The half-sibling whose information is being released must consent to the disclosure and both siblings must have had a suitable opportunity to receive counselling. There is also a proviso that the disclosure would not lead to the identification of a donor without the donor's consent unless regulations provide that his or her identity could be released to either of the donor-conceived people on request.
- 155. New section 31ZF introduces a power for the HFEA to set up, or keep, a voluntary contact register of people who would like to receive information about any person to whom they are genetically related as a consequence of the provision to any person of assisted conception treatment services in the United Kingdom involving donors before the HFEA's register began on 1 August 1991. New section 31ZG enables the HFEA to fund, on such terms and conditions as the HFEA considers appropriate, another person or body to set up and keep a voluntary register.
- 156. If the HFEA keeps a register under new section 31ZF, it may charge a fee to people wishing to join it, arrange for DNA samples of people who join to be analysed, with their consent, and matched with those of others on the register, and make arrangements for information to be disclosed between people who are genetically related. It is intended that the fee charged would recover all or part of the costs of keeping the register. Such a voluntary contact register, UK DonorLink, has been run as a national pilot project since 2004 by After Adoption Yorkshire, a voluntary organisation.