

INTERNATIONAL DONOR OFFSPRING ALLIANCE
HUMAN FERTILISATION AND EMBRYOLOGY BILL
BIRTH CERTIFICATES: THE CASE FOR REFORM
BRIEFING FOR MEMBERS OF THE HOUSE OF COMMONS

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SUMMARY OF AIMS

We assert that people have a moral right to know the truth about their personal history. Where the state has custody of relevant information it has a duty not to collude in deceiving or depriving individuals of such information.

It follows that:

The truth about a donor-conceived person's genetic and social parentage should be recorded on their relevant public documentation.

In the normal course of events of life it should be impossible for a donor-conceived person to fail to find out that they are donor-conceived.

The principal legal instrumentality of this should be the person's birth certificate, which should **make it clear that donor conception has taken place**. The **genetic parentage should be recorded on the certificate** itself or associated documentation available to the donor-conceived person concerned.

Note: *Donor conception* means facilitating conception of a child where the two people providing the gametes (sperm or eggs) have never met and/or it is intended that (at least) one party (the *donor*) will not play a parental role in raising the resulting child (*donor-conceived person*).

BACKGROUND

The International Donor Offspring Alliance “IDOA”

IDOA was formed in 2007. It exists to act as an advocate for those conceived through the use of donor gametes: eggs or sperm. It has members from the UK, US, Canada, France, Japan, New Zealand and Australia; they include both donor¹ offspring (of both sexes and ranging in age from 24 to 64) and academics and social work practitioners who have a professional interest in the field.

What we believe

IDOA believes that everyone has the right to know the truth about their own life and that that includes the manner of their conception and the identity of their biological parents. Where the state is involved in providing or regulating donor conception, it must not cause, promote or collude in deceiving people or depriving them of information about their own origins; nor may it discriminate against particular groups in terms of the provision of significant information about their own lives. It follows that the birth certificate of a donor-conceived person must enable them to know the identity of their biological parents.

The present position

In 2004 Parliament passed the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 (“the Disclosure Regulations”). The Disclosure Regulations, reversing the rule of anonymity of donors which had applied since 1990, provided that when people conceived by donor after April 2005 reached majority, they could find out (from the Human Fertilisation and Embryology Authority) the identity of their biological parent.

However it is acknowledged that the great majority of recipient parents (often contrary to intentions or commitments made when seeking and receiving treatment) do not tell their children that they were conceived by donor gametes. People who do not know that they are donor-conceived will not consult the HFEA about the identity of their donor – and thus Parliament’s reforming intentions are frustrated and discrimination against the donor-conceived is perpetuated.

¹ IDOA uses “donor” in its name because most people recognise what it means; it should be noted that in the great majority of cases throughout the world, those who provide gametes are paid

The Human Fertilisation and Embryology Bill: report of the Joint Committee

The only way to address this is by putting donor-conceived children on the same footing as everyone else, and requiring that complete and accurate information about their parentage be placed on their birth certificates. As is explained below, this can be managed without interfering with any legitimate claims to privacy. The Human Fertilisation and Embryology Bill (“the Bill”) offers the perfect opportunity to complete the reforming intention of the Disclosure Regulations. Recognising that, and having heard evidence from a number of witnesses², the Joint Committee on the Bill concluded that,

We recognise the force of the argument that the fact of donor conception should be registered on a person's birth certificate. This would create the incentive for the parent(s) to tell the child of the fact of his or her donor conception and would go some way to address the value of knowledge of genetic history for medical purposes. Moreover, unlike where children are born through natural conception, assisted conception by its nature involves the authorities and we are deeply concerned about the idea that the authorities may be colluding in a deception. However, we also recognise that this is a complicated area involving the important issue of privacy, as well as issues of human rights and data protection. We therefore recommend that, as a matter of urgency, the Government should give this matter further consideration.

The government, in its response to the Committee’s report, said³

69 ... The Government’s position to date is that it is preferable that parents are educated about the benefits of telling children that they were donor-conceived rather than forcing the issue through the annotation of birth certificates.

70. However, this is a sensitive area and the Government recognises the Committee’s concern, as well as the importance of allowing donor-conceived people access to information about their genetic background. We believe that the issues need to be considered carefully, including constructive dialogue with stakeholders, and we will keep the matter under review.

² 24 July 2007 Joint committee on the Human Tissue and Embryos (Draft) Bill - First Report Paragraphs 274, 275

³ Government Response to the Report from the Joint Committee on the Human Tissue and Embryos (Draft) Bill Cm 7209

It is very apparent that the process of education referred to in the first paragraph is largely ineffective: the great majority of recipient parents do not (often despite committing to do so when seeking treatment) tell their children that they were donor conceived.

At present, the “constructive dialogue” referred to in the second paragraph has either not happened or has not included donor conceived adults. We continue to be more than willing to engage with the government to explain our point of view. However we cannot wait to be invited: this is a pressing issue.

IDOA calls upon concerned Members of both Houses to support an amendment which will abolish the statutory fraud which constitutes a donor-conceived person’s birth certificate and end discrimination against the donor-conceived.

Equal treatment for the donor-conceived

It is essential that it be understood that IDOA is not seeking any special treatment for the donor-conceived.

Under UK law, birth certificates are required to contain true information. To provide false information to a registrar is a criminal offence. For over 30 years now, since 1975, the right of adopted people to have access to accurate information about their origins has been recognised in a developed system of certification. It is only the donor-conceived who are deliberately excluded from access to information about their biological background.

This is ethically and legally wrong. The ethical argument is simply stated. People have a fundamental need to make sense of their lives in terms of story: from grand religious and national narratives to highly personal, family-based anecdotes, we establish our connection with the past, the present and the future by seeing ourselves and those connected with us as part of a continuing story. No-one has the right to deceive another person about the significant elements in their story, nor to withhold vital information about their lives. In practice we cannot prevent such deception and deprivation happening on an inter-personal level but the state (where it has taken to itself the function of custodian of the facts) can and must refrain from endorsing or colluding in it.

The law clearly supports this position. The courts of the UK and the Human Rights Court at Strasbourg have both found, independently, that Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (the “ECHR”) requires that people be able to identify their genetic parents⁴. The ECHR also provides in Article 14 that it is unlawful for

⁴ See appendix *Legal Analysis: ECHR Case Law* for details

signatory states to discriminate against individuals in their enjoyment of the rights protected by the Convention on the grounds of those individuals' status or membership of particular groups⁵.

The **UN Convention on the Rights of the Child** (“UNCRC”) provides that signatory states will

- “undertake to respect the right of the child to preserve his or her identity” (Article 8)
- “assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child” (Article 12) and
- “recognize the right of the child to the enjoyment of the highest attainable standard of health (including) (f) ... preventive health care” (Article 24)

We acknowledge that neither the ECHR nor the UNCRC directly binds individuals and hence they cannot impose legal duties directly on biological nor social parents. But they do codify fundamental rights which must be protected and enforced by signatory states. We say that:

- An essential part of any person's identity is – objectively and demonstrably – their genetic inheritance;
- Children as they develop can only form views “in all matters affecting” them if they are equipped with relevant information;
- Information about inherited physiological and psychological predispositions is, increasingly, a significant element in health care and particularly in preventive health care

And that it follows that signatory states cannot lawfully endorse or allow the provision of deficient or misleading information nor do less than is practicable to promote, encourage and enforce the provision of complete and accurate information about individuals' genetic origins.

Listen to the offspring

IDOA is the voice of those who know what it means to be donor-conceived. Our experience leads us to assert that:

- Genetic heritage has objective existence, meaning and value;
- Everyone has a moral right to know about their genetic and biological origin and background;

⁵ See appendix *Legal Analysis: ECHR Article 14*

- Being deprived of that knowledge or deceived about ones origins is painful and damaging;
- Where the state intervenes by supporting or regulating the provision of donor gametes it has a responsibility to establish legal protection for that moral right by ensuring that the people brought into existence by donor conception are not deceived, nor deliberately deprived of information, about their genetic and biological parents.

It is for these reasons that birth certificates must provide accurate information. **Our proposals are as follows:**

Birth certificates

The fundamental proposition is that people have a right to know about their own lives and that that must include knowing who their parents are, including their biological parents – something which has been recognised in the case of adopted people since 1975. That knowledge can only be safeguarded and transmitted if it is recorded. It is not open to recipient parents or anyone else to decide on a child's behalf that it does not need to know or can justifiably be deceived or deprived of information. Requiring that birth certificates record the truth does not impinge on recipient parents' lives in any way but it safeguards information which properly belongs to the offspring. Including the name of the donor as well as the fact of donor conception is the only means by which donor offsprings' rights and their dignity as people can be honoured.

CALLING FOR CHANGE

What offspring say

“We want our true full parentage recorded on our birth certificates simply because we want our legal documents to record the truth, as they are supposed to do for every other member of society” – Tom Ellis

“The joy I felt upon learning my identity reminds me of the intense relief which ensues when an illness or pain finally passes” – Louise Jamieson

“People will always lie to their children for all sorts of reasons, some of them no doubt benevolent. But the state should not be party to such deceptions: the birth certificate of the donor-conceived person is a state fraud and that is wrong.” – David Gollancz

“It's time to step in and start trying to actually protect those people who need protecting here. The child first, the couple second. Everyone else has made a voluntary choice to be involved or not to be involved, and therefore their interests are far down the list” – Suzanne Ariel

What experts say

“It is a fundamental right to know both parents” - Prof. Eric Blyth, University of Huddersfield

“We would like to propose the following ... to address the importance of all people in our society knowing the truth about their genetic identify, whilst protecting their privacy. We suggest that a national system is introduced where people are issued with a certificate of birth showing legal parentage – people who have the parental responsibility – and then also another document/ certificate that shows a person's genetic inheritance, for example whether they are adopted or born as a result of donor conception.” – British Association for Adoption and Fostering

“Is it ethically acceptable to keep a secret from someone else, especially if that secret relates to the origins and identity of the person concerned? My contention is that most...would answer that it is not ethically acceptable.” – Prof. Ken R Daniels, University of Canterbury, NZ

What the courts say

“A human being is a human being whatever the circumstances of his conception and an AID child is entitled to establish a picture of his identity as much as anyone else.” – Scott Baker J in *Rose v Secretary of State*

“The Court has held that respect for private life requires that everyone should be able to establish details of their identity as individual human beings” - European court of Human Rights, *Mikulić v. Croatia*

SUPPORT FROM OTHER ORGANISATIONS

The Principle of accurate, complete and accessible documentation for donor conceived people is supported by *The Partnership Focus Group: on the Rights and Life Long needs of people created by donor assisted conception*. The Partnership Focus Group is a coalition of organisations and individuals with a professional and personal commitment to promoting the welfare of children during their childhood and throughout their life. Copies of and a list of supporters of the Partnership Focus Group Briefing can be obtained from *Julia.Feast@baaf.org.uk*.

IDOA has received support for its campaign from the following international organisations:

- Infertility Network, Canada
- CONCEBIR, (infertile parents association) Argentina
- Stork (obcianske zdruzenie Bocian), Slovakia

DONOR CONCEPTION: LEGISLATIVE HISTORY

Before 1990 there was no statutory regulation of donor conception. Anonymity of donors was the norm and recipient parents were encouraged to never disclose the truth about the conception to their offspring.

The HFE Act of 1990 made it a legal requirement that all donors be anonymous, but ensured that that a copy of donors' identifying information would be kept by the HFEA.

During the 1990s and early 2000s various groups, including the Donor Conception Network which represents recipient parents, and the Project Group on Assisted Reproduction (a coalition of social work professionals, academics and offspring sponsored by the British Association of Social Workers) campaigned to encourage openness and early disclosure to the offspring of the facts of conception. That campaign was greatly assisted when Baroness Warnock, whose Warnock Report had led to the framing of the HFE Act, declared her support for an end to anonymity.

In 2001 Joanna Rose (with a minor child as co-complainant) brought judicial review proceedings against the Secretary of State under the Human Rights Act, claiming that the government was obliged to set up a voluntary contact register for willing donors and willing offspring. The government agreed to do this and as a result the claim did not proceed to a full trial on the merits. See "Legal analysis" for more about the implications of this case.

In 2004 it was recognised in the (in the Human Fertilisation and Embryology Authority (Disclosure of Donor) Regulations 2004) that donor-conceived people had a right to know the identity of their genetic parents. The previous rule of anonymity was reversed, and all donor-conceived people born after April 2005 will be able to find out the identity of their genetic parent. The right to identification does not apply retrospectively to those conceived before April 2005.

Despite work to promote openness in donor-conceived families, the intent embodied in the 2004 legislation can be circumvented by recipient parents continuing not to tell. Thus it will not always be possible for a donor-conceived person to take advantage of the right to the identity of his genetic parent.

In 2007 the Joint Committee examining the proposed (then) Human Tissues and Embryos Bill concluded "We recognise the force of the argument that the fact of donor conception should be registered on a person's birth certificate. This would create the incentive for the parent(s) to tell the child of the fact of his or her donor conception ... We therefore recommend that, as a matter of urgency, the Government should give this matter further consideration."

Birth certificates for donor-conceived people that record the truth of genetic parentage should be seen as implementing legislation completing the intention of the 2004 decision.

BIRTH CERTIFICATES: ADDRESSING COMMON OBJECTIONS

“This is a matter for parental choice: anything else is an unwarranted intrusion into family life”

It is indeed for parents to decide how to tell their children about the special character of their conception. This proposal does not at all interfere with that: it merely provides that donor-conceived people, like adopted people and like every other citizen, should have accurate and complete birth certificates. As in the case of adopted people, the short form certificate in everyday use need not identify the holder's status as donor-conceived, so parents will still have a very large measure of control over when and in what circumstances their children see the certificate which discloses their status.

“Fewer people will donate gametes”

Most opponents of disclosure claimed that the number of donors would decline as a consequence of the abolition of anonymity but there is no evidence that that has happened. Use of donor insemination has been declining for at least 15 years, probably due largely to the increasing availability of ICSI. Reliable evidence about rates of egg donation is harder to come by because numbers are so much smaller but there is nothing to suggest that they have been affected by the abolition of anonymity.

However it is important to be clear that IDOA's position would not be affected even if donor numbers were reduced: there is no right to have a child but people, once born, have rights and they must be respected.

“Your family is the people who bring you up – why do you need to know anything else?”

Definitions of family are cultural constructs and we are not seeking to interfere in how people understand family nor to say that genetic connections are more important than others – only that people are entitled to know about their genetic connections. How they interpret that knowledge will vary.

“It should be the parents who decide when to tell: it's wrong to force their hand”

Simply recording the facts on a birth certificate merely creates a record which belongs to the donor conceived person. The short-form certificate, which is the one most commonly used, would bear no indication that the person is donor conceived. How and when they are told about their conception is still very much in the hands of the parents.

“Birth certificates are public documents. This is an invasion of a donor-conceived person's privacy”

The members of IDOA are donor-conceived, and we believe our right to truthful public documents far outweighs any potential privacy issues. We note that a system similar to that we are proposing has already been in use for adoption for decades, without contentious privacy issues.

“Some would-be users of donor conception will circumvent any potential legislation by travelling abroad where donor anonymity is still in force and standards of patient care may be lower”

IDOA believes that although the introduction of truthful birth certificates may cause some initial anxiety, it will rapidly become accepted as the norm. Potential parents are unlikely to travel abroad in anything more than tiny numbers. Although reform may initially come as a shock, with consideration they will discover they can easily accept honest birth certification.

As far as it concerns the offspring, the *“would-be parents will go abroad”* argument rests on the assumption that the number of parents who *do* go abroad, and later change their minds about telling the truth, cause more in harm than the good that honest birth certificates would do for the estimated 50% of donor-conceived people who would otherwise never find out that they are donor-conceived.

IDOA strongly disagrees with this assumption. We believe the numbers going abroad will be very small, whilst the benefits to be gained by ending discrimination against donor-conceived people are enormous.

In any case, it is not justified to deny a group of people their rights in the UK simply because some people will evade enforcement of these rights by going abroad.

LEGAL ANALYSIS

The case law has developed under Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms.

ECHR Article 8 – Right to respect for private and family life

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

Article 8 has been extensively interpreted as protecting not only the matters expressly itemised but those interests of individuals which are essential conditions of, or necessarily implied by, those matters.

Cases involving genetic parentage:

Mikulić v. Croatia (Application 53176/99) [2002] 1 FCR 720, 11 BHRC 68, [2002] ECHR 53176/99

In *Mikulić*, a Strasbourg case commenced in 1999 and decided in 2002, the Human Rights Court expressly recognised that the rights protected under Article 8 do not require that there be any family ties between a parent and their offspring. Extract from the judgment (our emphasis):

1. The present case differs from the paternity cases cited above in so far as no family tie has been established between the applicant and her alleged father. The Court reiterates, however, that Article 8, for its part, protects not only “family” but also “private” life.
2. **Private life, in the Court's view, includes a person's physical and psychological integrity** and can sometimes embrace aspects of an individual's physical and social identity. **Respect for “private life” must also comprise to a certain degree the right to establish relationships with other human beings** (see, *mutatis mutandis*, *Niemietz v. Germany*, judgment of 16 December 1992, Series A no. 251-B, pp. 33-34, § 29).

There appears, furthermore, to be no reason of principle why the notion of “private life” should be taken to exclude the determination of the legal relationship between a child born out of wedlock and her natural father.

3. The Court has held that respect for private life requires that everyone should be able to establish details of their identity as individual human beings and that an individual's entitlement to such information is of importance because of its formative implications for his or her personality (see *Gaskin v. the United Kingdom*, judgment of 7 July 1989, Series A no. 160, p. 16, § 39).

4. In the instant case the applicant is a child born out of wedlock who is seeking, by means of judicial proceedings, to establish who her natural father is. The paternity proceedings which she has instituted are intended to determine her legal relationship with H.P. through the establishment of the biological truth. Consequently, there is a direct link between the establishment of paternity and the applicant's private life.

The facts of the case accordingly fall within the ambit of Article 8.

R (on the application of Rose and another) v Secretary of State for Health and another [2002] EWHC 1593 (Admin)

Rose is a decision of the English High Court on whether or not article 8 ECHR is “engaged” (that is, whether it bears upon the dispute before the court) in a case where a claimant seeks to prove that the state is under a duty to ensure the provision of information about a gamete donor to their offspring. The court decided that Article 8 was engaged. This is an extract from the transcript of the judgment:

[38] The bottom line, so it seems to me, is that the donor provided half of (each Claimant's) genetic identity and it is this that creates the interest of the Claimant to seek information about him.

[45] What therefore are the principles to be drawn from the authorities that are relevant to this case? They seem to me to be these:

Private and family life is a flexible and elastic concept incapable of precise definition.

Respect for private and family life can involve positive obligations on the state as well as protecting the individual against arbitrary interference by a public authority.

Respect for private and family life requires that everyone should be able to establish details of their identity as individual human beings. This includes their origins and the opportunity to understand them. It also embraces their physical and social identity and psychological integrity.

Respect for private and family life comprises to a certain degree the right to establish and develop relationships with other human beings.

The fact that there is no existing relationship beyond an unidentified biological connection does not prevent art 8 from biting.

per Scott Baker J

ECHR Article 14

Article 14 – Prohibition of discrimination

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

It is often said that the Article 14 right is parasitic upon the other rights and freedoms set out in the ECHR: it does not create a free-standing protection from all discrimination, but provides that individuals must be afforded equal access to the protections conferred by the other articles of the ECHR.

Donor-conceived people suffer discrimination in the enjoyment of those article 8 rights recognised by the court in *Mikulić* and *Rose* because, uniquely in society, the state offers them no reliable means of identifying their genetic parents. While the Disclosure Regulations purport to provide a measure of protection for this right (albeit not exercisable until majority) in reality they are ineffective because they can be circumvented by recipient parents choosing – as the large majority do choose – not to tell their children that they are donor-conceived.

United Nations Convention on the Rights of the Child

The United Kingdom is a signatory to the UNCRC but has not implemented it in domestic law as it has the ECHR through the Human Rights Act 1998. Children's rights are particularly relevant to this matter because of the importance to a child's development of being able to access, absorb and come to an autonomous interpretation of the truth about their origins.

In the legal context the UNCRC should be regarded as a source of assistance in interpreting the application of the ECHR to children's particular needs and rights.

Article 3(1) obliges states to ensure that "In all actions concerning children...by... courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration"

Article 4 requires states to "undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources"

Article 8 says that states must "respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognised by law without unlawful interference"

Article 12 requires states to "assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child"

Article 24 ensures that states must "recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health" and in paragraph (f) "develop preventive health care, guidance for parents and family planning education and services".

Thus Articles 3 and 4 establish the primacy of the child's rights (over, for example, those of the donor, and potentially those of recipient parents where these are set up as being in opposition to those of the child) and requires states to ensure that adequate legislative provision exists to protect them.

Article 8 expressly recognises the preservation (and hence by necessary implication the prior establishment) of personal identity as a right.

Article 12 acknowledges that children as they develop have the right to develop an autonomous self and views about the world. As with Article 8 the existence of such a right necessarily implies a prior right to be put in possession of facts about the child's self and circumstances sufficient to form such views.

Article 24, in requiring states to provide the "highest attainable standard" of health care, and expressly including preventive care, must impose a requirement for the provision of genetically accurate information to and for the benefit of children.

The ECHR and UNCRC establish a basis in legislation for the proposition that individuals own, and have a right not to be deprived of, the truth about their personal history, including (crucially) their genetic background and the identity of their physical parents.

That right has been recognised by the courts in the UK and Strasbourg and by Parliament in the Disclosure Regulations. However those Regulations will remain ineffective and of symbolic value only until legislation requires accurate birth certification for everybody, including the donor-conceived. The continuing lack of any effective legislation in the UK to protect individuals' rights to essential information about their personal history, from a genetic and social point of view, amounts to a failure in the duties imposed by the ECHR under Articles 8 and 14. Insofar as it affects children it amounts also to a breach of the UK's obligations under Articles 3, 4, 8, 12 and 24 of the UNCRC. We urge Parliament to take the opportunity to legislate, consistently with the urgent recommendation of the Scrutiny Committee, to introduce birth certification for donor-conceived people which affords them equal treatment.

ENDORSEMENTS

This paper has been endorsed by the following:

- Tom Ellis
- David Gollancz
- Joanna Rose
- Bill Cordray
- Myfanwy Walker
- Lindsay Greenawalt
- Kathleen LaBounty
- Christine Whipp
- Damian Adams
- Catherine Victorson
- Elizabeth Howard
- Barry Stevens
- Janice Botsford
- Cleo Doig
- Lynne Spencer
- Charles Quekett
- Anna Huttenberger
- Joan Grant
- Karen Clark
- Kelly Tomlin
- Stella Kenrick
- Suzanne Ariel
- Rachel Sklar
- Carlyle Jansen
- Kali Coultas
- Ron Morgan
- Susanne Woodhouse
- Louise Jamieson
- Rebecca Symes
- Michael Grand
- Alexina McWhinnie
- Diane Allen
- Denise Priadkova
- Phyllis Creighton
- Sue Hurst