

LIBERTY

PROTECTING CIVIL LIBERTIES
PROMOTING HUMAN RIGHTS

BY EMAIL: islingtondeafsecretary@googlemail.com

TO: John Savva at Islington Deaf Campaign

17th January, 2008

Dear John,

Thank you for your query to Liberty's voluntary sector advice service regarding the Human Fertilisation and Embryology Bill ("the Bill"). Please accept my apologies for the delay in responding to you. We were closed over Christmas and New Year and as your query raises some very difficult and complex issues, conducting the research to be able to respond to you has taken some time.

You should note that this is not an area or subject in which I have any expertise or knowledge and my response is by no means a complete exposition of the law or procedure in this area. I have done my best to address the concerns you have raised, but you should bear in mind that my knowledge of practice and procedure in this area is very limited.

1. Your Query

You sent a link to a letter produced by the British Deaf Association ("BDA") in response to a specific clause in the Bill (Clause 14(4)) which relates to conditions of licences for treatment. You are concerned that the clause would not be in accordance with human rights law. You asked for information on who to write to in order to voice your concerns and also whether Liberty would be able to provide support.

I have set out below some information on the provision in the Bill and my understanding of how it would work. I should emphasise that this is my own understanding from a reading of the text of the clause. I would suggest that you follow my suggested 'next steps' towards the end of this letter to get some clarity on the effect of the clause from the I have then addressed the concerns raised by the BDA in their letter on the effect of the provision followed by some information on the human rights issues raised by your query. The last section provides some practical information on who to contact and other organisations that you may wish to get in touch with to discuss the matter further.

Unfortunately, in terms of campaign or policy support, Liberty will be unable to provide assistance. Liberty is a small civil liberties and human rights campaigning organisation with very limited resources. As such, we have to focus our resources and

time on a small number of specific issues. Our resources are currently focussed on our Charge or Release campaign, which is a campaign to prevent the extension of pre charge detention in terrorism cases. The two staff members who are responsible for the policy work at Liberty are focussed on this campaign as a bill on this issue is imminent. They are also spending significant amounts of their time on the major Home Office Bill, the Criminal Justice and Immigration Bill. I am sorry to disappoint you, but I hope this letter will be of some help.

2. Summary of Conclusions

This letter is quite technical and lengthy despite my efforts to keep it simple. To make it a little more reader friendly, I thought a bullet point summary of my interpretation of the effect Clause 14(4) of the Bill may be helpful.

- When determining which of **two or more** embryos to implant in a woman, an embryo **known** to have a genetic abnormality involving a significant risk that a person with the abnormality will have or develop a serious physical disability must not be **preferred to those that are not known to have such an abnormality**.
 - This does not prevent a deaf couple from receiving IVF treatment, or from conceiving a deaf child through IVF. The effect is to prevent a couple from positively preferring an embryo known to have a “deaf gene” for example, over other embryos without a “deaf gene”.
 - This clause only applies where there are two or more embryos and when the embryos have been tested for an “abnormality”. As I understand it, couples are not obliged to have embryos tested.
- When determining the **persons who are to provide gametes or the woman from whom an embryo is to be taken**, persons **known** to have a genetic abnormality involving a significant risk that a person with the abnormality will have or develop a serious physical disability must not be **preferred to those that are not known to have such an abnormality**.
 - This provision does not prevent a deaf person from donating their gametes.
 - It appears to prevent a deaf donor from donating their gametes or embryo to a relative undergoing treatment where the relative wishes to prefer this donor in order to conceive a biologically related child.
 - It only applies to donors of gametes or embryos to be used for the treatment of others, not to gametes or embryos taken from a couple during a course of treatment for themselves.
 - A couple cannot ask to be treated only with gametes or embryos that are known to have a “deaf gene” where there is a significant risk that the resulting child will be deaf.

- Deafness is included within the definition of a serious physical disability, serious illness or serious medical condition.

3. Human Fertilisation and Embryology Bill

The Human Fertilisation and Embryology Bill amends the Human Fertilisation and Embryology Act 1990 (“the 1990 Act”) and therefore the Bill and the 1990 Act need to be read together.

The Human Fertilisation and Embryology Authority (“HFEA”) was established by the 1990 Act and is principally tasked with regulating the activities authorised by the 1990 Act by means of a system of licensing, audit and inspection and maintaining a code of practice giving guidance about the proper conduct of licensed activities.

The Bill is currently awaiting the Third Reading in the House of Lords before it is debated by the House of Commons. The clause of the Bill which the BDA objects to is clause 14(4) which inserts a new subsection (8) and (9) to Section 13 of the 1990 Act. Section 13 of the 1990 Act deals with conditions of licences for treatment.

Clause 14 (4) provides as follows:

“(8) Subsections (9) and (10) apply in determining any of the following—

- (a) the persons who are to provide gametes for use in pursuance of the licence in a case where consent is required under paragraph 5 of Schedule 3 for the use in question;*
- (b) the woman from whom an embryo is to be taken for use in pursuance of the licence, in a case where her consent is required under paragraph 7 of Schedule 3 for the use of the embryo;*
- (c) which of two or more embryos to place in a woman.*

(9) Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop –

- (a) a serious physical or mental disability,*
- (b) a serious illness, or*
- (c) Any other serious medical condition,*

must not be preferred to those that are not known to have such an abnormality.”.

The explanatory note to this Bill provides some information in relation to the thinking behind this clause:

“Embryo testing

- 109. Clause 14(4) contains a provision that relates to the provisions on embryo testing (see note on clause 11). New sections 13(8) to (11) amend the 1990 Act to make it a condition of a treatment licence that embryos that are known to have an abnormality (including a gender-related abnormality) are not to be preferred to embryos not known to have such an abnormality. The same restriction is also applied to the*

selection of persons as gamete or embryo donors. This would prevent similar situations to cases, outside the UK, where positive selection of deaf donors in order deliberately to result in a deaf child have been reported.”.

It seems to me therefore that there are two aspects to this clause. The first aspect is the prohibition on preference of embryos known to have an “abnormality” and the second is the prohibition on preference of donors known to have an “abnormality”. Both apply only in the circumstance where there is a preference over other embryos or donors not known to have such an abnormality. I have set out my interpretation of the effect of this clause for both aspects below.

The aim of this provision appears to be to prevent couples from testing for and then engineering the birth of a baby with a particular “abnormality”. I understand that this arose from a concern that advances in technology and testing and the fact that the Bill allows for embryo testing, could result in a move towards so-called ‘designer babies’.

Preference of embryos

The Bill amends the 1990 Act to allow for embryo testing in certain circumstances and prohibits preference of an embryo (where there are two or more embryos) *known* to have a gene “abnormality” involving a significant risk that a person with the “abnormality” will have a serious physical disability.

A licensed treatment clinic is not authorised by its licence to carry out any tests on an embryo except for a limited number of reasons. In a case where there is a particular risk that an embryo may have any gene, chromosome or mitochondrion abnormality, a licensed treatment clinic can be authorised to test the embryo to establish whether it has that abnormality or any other gene, chromosome or mitochondrion abnormality.

Even where a treatment clinic or a couple being treated believe there is a particular risk of an “abnormality” in the embryo, the treatment clinic cannot test the embryo unless the HFEA is satisfied that there is a *significant risk* that a *person* with the “abnormality” will have or develop a serious physical or mental disability, a serious illness or any other serious medical condition.

It is clear from the extract set out above from the explanatory note to this Bill that deafness is intended to be included within the definition of serious physical disability or other serious medical condition.

It is my understanding therefore that the prohibition on preferring an embryo with an “abnormality” relates to the situation where there are two or more embryos and:

- (1) the embryos are tested; and
- (2) it is *known* from the test results that one of the embryos has a genetic abnormality involving a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, serious illness or serious medical condition.

In such a case, the couple could not prefer the embryo with the genetic abnormality over or to the exclusion of the other embryo.

This does not mean that the embryo with the genetic “abnormality” has to be destroyed or not used. What it means is that it cannot be preferred above the other embryos to ensure or make it more likely that the couple have a deaf child. I think the couple could opt to have both embryos (the one with the genetic “abnormality” and the one without) implanted as there would be no ‘preference’ in doing this or to have the embryo or embryos chosen to be implanted selected randomly, again there is no preference.

What should be made clear is that the Bill does not prevent the implantation of an embryo that is known to have a deaf gene. It prevents the *preference* of that embryo over others that do not have a deaf gene.

Where there is only one embryo and tests show that there is a *significant risk* that a person born with the abnormality will be deaf, Clause 14(4) does not prevent the use of that embryo by a couple as there is no preference of that embryo over others that do not have such an “abnormality” if it is the only one. If you recall, Clause 14(4) in relation to embryos only applies in determining *which of two or more embryos to place in a woman*.

The issue of preferring an embryo known to have a genetic “abnormality” will also not arise if there is no embryo testing done in the first place. As set out above, Clause 14(4) relates to the situation where an embryo is *known* to have an “abnormality” involving a significant risk that a person with the “abnormality” will have or develop a serious physical disability etc.

I do not think that a deaf couple could be forced to have an embryo tested for genetic deafness if they do not wish to have this done.

Preference of donors

In determining the persons who are to provide gametes or the woman from whom an embryo is to be taken, a person *known* to have a gene, chromosome or mitochondrial abnormality involving a significant risk that a person will have or develop a serious physical or mental disability, serious illness or serious medical condition cannot be preferred.

I should make clear here that Clause 14(4) only relates to donors providing gametes or embryos for the treatment of *others*. This is very important to bear in mind. It does not apply to the use of sperm, eggs or embryos in the course of treatment for a couple that are taken from the couple themselves. It also does not change the regime for screening donors to that which currently exists. The current system of screening is set out in section 13 of the 1990 Act and the HFEA code of practice.

Section 13(7) of the 1990 Act provides that

“(7) *Suitable procedures shall be maintained—*

(a) *for determining the persons providing gametes or from whom embryos are taken for use in pursuance of the licence, and*

(b) for the purpose of securing that consideration is given to the use of practices not requiring the authority of a licence as well as those requiring such authority.”

The HFEA produce a code of practice which has recently been revised and a seventh edition is now available on their website. This code provides at Standard 7.6.7 of the that where individuals are considering donation, fertility clinics shall ensure

*“(a) that appropriate screening tests have been performed and are recorded,
(b) that appropriate consideration has been given to the suitability of the Donor, including an assessment of any risks associated with using gametes or embryos from that Donor to the health or welfare of recipients or resulting children.”*

The guidance in the code of practice further provides at G.4.8 that

“Before accepting gametes for the treatment of others, the recruiting centre should consider the suitability of the prospective donor. The views of all centre personnel involved with the prospective donor should be taken into account. In particular, the centre should consider:

G.4.8.1

*(a) personal or family history of heritable disorders; and
(b) personal history of transmissible infection; and
(c) the level of potential fertility indicated by semen analysis (where appropriate); and
(d) the implications of the donation for the prospective donor and their family, especially for any children they may have at the time of donation or in the future; and
(e) the implications for any offspring born as a result of the donation, in both the short and long term.”*

Donors of gametes and embryos are also required to be screened in accordance with current professional guidance produced by the British Andrology Society and the British fertility Society (G.4.9.1).

The guidance further provides that a prospective donor should not be accepted if the centre concludes that either a recipient or any child that may be born as a result of treatment using the donor’s gametes is likely to experience *serious physical, psychological or medical harm*, or where the treatment centre is unable to obtain sufficient further information to conclude that there is no significant risk.

A centre that refused a donation from a deaf person on the grounds of their deafness alone would need to demonstrate that the child born of treatment using the donation was likely to experience serious physical, psychological or medical harm. I do not know enough about this area to say whether a genetically deaf person would be rejected as a donor as a result of this wording.

The effect then of Clause 14(4) on donors is to prevent the preference of gametes and embryos from donors where they are *known* to have a gene, chromosome or mitochondrial abnormality involving a significant risk that a person will have or

develop a serious physical or mental disability, serious illness or serious medical condition. I suspect it will always be known whether a donor has such an “abnormality” due to the assessment of potential donors and the screening tests that are carried out, as referred to above. Nothing new has been added to this process by clause 14(4). What the provision does is prevent a person from preferring such a donor to those not known to have such an “abnormality”.

It would still seem possible for a patient to ask for a random selection of embryos or gametes to be used from donors, including from donors known to have genetic deafness, thereby leaving the possibility of conceiving a deaf child to chance rather than positively preferring a gamete or embryo from a deaf donor where there might be a significant risk of the resulting child being deaf.

4. The British Deaf Association Letter and Human Rights

The BDA in their response to the Bill highlight a number of concerns about Clause 14(4). They argue that the language of the clause violates both Articles 12 and 14 of the European Convention on Human Rights.

“The [Human Rights] Act [1998] protects the right of deaf parents not to be discriminated against. For example, a deaf couple should not be told they couldn’t have children because they might pass deafness on. They must also not be told to end a pregnancy if there is a chance their baby might be deaf. Deaf couples also obviously have the right to fertility treatment.”.

The Human Rights Act 1998 (“the HRA”) incorporates the European Convention on Human Rights (“the Convention”) in to domestic law. It makes it unlawful for public authorities to act in a way that is incompatible with the Convention rights incorporated by the Act. Article 12 provides the right to marry and found a family and Article 14 guarantees the right to be free from discrimination in the enjoyment of Convention rights, it is not a free standing protection from discrimination as is often thought.

Clause 14(4) as it is currently drafted does not have the effect of precluding a deaf couple from having fertility treatment because they may pass deafness on to any child. They could also not be told to end their pregnancy if there is a chance that their baby might be deaf. As set out above, Clause 14(4) relates to *preferring* an embryo (where there are two or more) or donor with genetic deafness or donor over those that are not known to have such a gene. It does not prevent a couple from implanting an embryo with genetic deafness along with another or other embryos. Neither does it prevent an embryo with genetic deafness being selected at random from a number of embryos including some without an abnormality should the couple so wish. Similarly, if all of the embryos produced have such an “abnormality”, one or more of them could still be implanted in the woman as there is no preference being made. The Clause would operate to prevent them from preferring the embryo with genetic deafness above and to the exclusion of other embryos without such a gene.

Although deaf couples have the same right to fertility treatment as non-deaf couples, I do not think that there is a *right* to fertility treatment per se for anyone.

Article 12 of the Convention provides as follows:

Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right

Although the issue has not yet been considered, I think it unlikely that the right to found a family under Article 12 would extend to a right to found a family by medically assisted means. In any case, I do not think that Clause 14(4) interferes with the right to found a family. It imposes restrictions in the case of founding a family through medically assisted means.

A further point that the BDA make is that Clause 14(4) prevents people who hold carrier status for any genetically identifiable serious physical disability or serious medical condition from becoming gamete donors. Once again, the effect of Clause 14(4) is to prevent couples from *preferring* such donors, not to prevent prospective donors from actually donating. Unfortunately, I do not know enough about the process of screening donors to know whether the existing situation under the 1990 Act would prevent deaf people from becoming donors, but that is not the effect of Clause 14(4).

The BDA state that “[d]eaf people seeking fertility treatment will be denied access to these services if they possess genetic conditions that result only in the formation of embryos associated with deafness.”. The example given to illustrate this point is that of an infertile deaf couple wanting to have a child. Before fertility testing commences, genetic testing is conducted on the couple and results indicate that their children will be deaf. The BDA state that the effect of the Bill is to deny the couple fertility services because embryos associated with genetic deafness are not preferred. This is not my interpretation of Clause 14(4). As explained, I think that the effect of Clause 14(4) is to prevent a couple from *preferring* donors or embryos with genetic deafness to those not known to have genetic deafness in determining who the gamete or embryo is obtained from or which of two or more embryos to place in a woman.

In the example given by the BDA, there is no donor as the couple are able to provide their own gametes, but the tests show that IVF treatment with their gametes would result in deaf embryos being created. This would not result in the couple being denied treatment services. If all the embryos showed genetic deafness, any or all of them could be used in the treatment as the couple would not be preferring them over any others that did not have genetic deafness.

A further concern of the BDA is that in some situations, a couple may wish to actively prefer a deaf donor where that donor is their only biological relation. This situation is problematic for such couples, as the reason for preferring that relative over other donors may have nothing to do with trying to conceive a deaf child, but rather conceiving a biologically related child. Nevertheless, Clause 14(4) might operate to prevent that choice if the relative cannot be preferred where there are other, unrelated, donors available.

I think it is possible that this may raise issues with regard to discrimination against deaf donors. A non deaf donor would potentially be able to donate his gametes to a biological relation to assist the relation in their fertility treatment and can be preferred

by that relation to other unrelated donors. A deaf donor could not be so preferred by their relative undergoing treatment.

Article 14 of the Convention prohibits discrimination in the enjoyment of Convention rights. It provides as follows:

'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.'

Although disability discrimination is not specifically mentioned, it is accepted as falling within the scope of Article 14 under 'other status'.

Article 14 is not a free-standing prohibition against discrimination. For there to be a breach of Article 14, the area in which a person is discriminated against has to come within the scope of one of the other Convention articles. This means that the way in which you are discriminated against has to be connected with one of the other articles although there does not have to be a breach of that other article. I think the connected article which may be relevant here is the right to respect for a private life contained in Article 8.

Article 8 provides as follows:

- (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 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.*

In order to show that there has been discrimination (Article 14) in relation to the enjoyment of a person's right to respect for their private life (Article 8), there are four key questions that must be considered:

- (i) Do the facts fall within the ambit of one or more of the Convention rights?
- (ii) Was there a difference in treatment in respect of that right between the complainant and others put forward for comparison?
- (iii) Were those others in an analogous situation?
- (iv) Was the difference in treatment objectively justifiable? I.e., did it have a legitimate aim and bear a reasonable relationship of proportionality to that aim?

It may be possible to argue that being prevented from donating gametes to a relative in order to assist them in their fertility treatment to have a biologically related child would fall within the scope of the right to respect for private life pursuant to Article 8.

If so, there is clearly a difference in treatment between a deaf donor and a non-deaf donor in being able to donate gametes to a relative as the preferred donor. A non-deaf donor wishing to donate to a relative is in an analogous position to a deaf donor wishing to donate to a relative.

The key question I think then is whether the difference in treatment is objectively justifiable. The result of allowing the preference of a deaf donor may be that there is a significant risk of the resulting child being born deaf. It is clear from the explanatory note extract set out above that the aim of Clause 14(4) is to prevent the “*positive selection of deaf donors in order deliberately to result in a deaf child*”. So this is what the Government would argue is the “legitimate” aim of the provision. This raises a whole host of complex moral and ethical issues. Even if it is accepted that this is a legitimate aim, it will still need to be shown that the provision is proportionate to the aim sought to be achieved. So a court will consider whether a fair balance has been struck between the rights and freedoms of the individual and the general, wider interest.

5. Next Steps

Your query raises some very complex and difficult issues. Whilst doing my research on this issue, I found that there was much confusion on various discussion websites as to the effect of Clause 14(4) and so I have tried to clarify as far as possible my understanding of the provision. I have also tried to address the practical concerns that the BDA have in relation to the Bill. However, as mentioned at the outset, this is not an area in which I have any expertise or background knowledge and therefore this letter may not provide a complete picture of the impact of clause 14(4) on current procedure and practice in this area.

You asked for advice on who to contact further in relation to this matter. I would suggest that you write to the Health Secretary, Alan Johnson and the Public Health Minister, Dawn Primarolo for their response to your concerns. I would also suggest that you write to your local MP and ask them to raise your concerns with the relevant Ministers and in the debates on the Bill in the House of Commons. You can find the name of your local MP and their contact details from the following website: <http://www.theyworkforyou.com/> You should ask them to let you know what response they get to your concerns.

I would also suggest that you send a copy of BDA’s letter to the Joint Committee on Human Rights and ask them to consider the issues raised. The Joint Committee on Human Rights is a Parliamentary committee consisting of 12 members from both the House of Lords and the House of Commons. The committee is responsible for considering human rights issues in the UK. The contact details for the committee are as follows:

Joint Committee on Human Rights
Committee Office
House of Commons
7 Millbank
London SW1P 3JA
Tel: 020 7219 2797

Fax: 020 7219 8393

Email: jchr@parliament.uk

Web: http://www.parliament.uk/parliamentary_committees/joint_committee_on_human_rights.cfm

6. Feedback

I would be very grateful if you could spare a few moments to complete and return the attached feedback form to me. You can either complete it electronically by underlining your chosen answers or you can print out the form, complete and post it to VAS, Liberty, 21 Tabard Street, London SE1 4LA. Liberty is very grateful for any feedback received from our service users. All feedback we receive will be analysed and referred to for the purposes of developing and improving the service. Thank you in advance for taking the time to complete the form.

I hope the information contained in this letter is of assistance. Please do contact me if you have any questions or if I can be of any further help.

Yours sincerely,

Shamle Begum
Advice and Information Officer
LIBERTY