

Summary of Action Points from Meeting with Department of Health to Discuss Clause 14(4)(9) of the Human Fertilisation and Embryology Bill

Date of Meeting: Wednesday 19th March 2008

Present:

Group 1: Representatives from the Department of Health bill team: Ted Webb, Dr Katy Berry

Group 2: Representatives from the Progress Educational Trust: Sarah Norcross, Sandy Starr

Group 3: Representatives from the StopEugenics Campaign: Alison Bryan, Dr Steve Emery

Group 4: Representative from the British Deaf Association: Francis Murphy

Group 5: Individuals from the Genetics Community with a specialist interest and knowledge of deafness: Dr Maria Bitner-Glindzicz, Dr Anna Middleton

Interpreters: Susan Booth, Kathy Yeoman

Groups 2-5 stated that Clause 14(4)(9) should be dropped from the HFE Bill. The Department of Health (DH) stated that it was unlikely for this to be possible; but that they would ensure the raised concerns were fully taken into account in Bill policy considerations. DH explained that decisions about Bill clauses and provisions were ultimately for Ministers and Parliament.

The following points were raised by Groups 2-5 and the DH has agreed on various forms of action in relation to these. This document has been written and approved by all 5 groups.

1. Lack of Consultation

Groups 3-5 informed the DH that there had been no public consultation in British Sign Language (BSL) prior to the drafting of the Bill; the Deaf Community in the UK had not been made aware of Clause 14(4)(9) and accompanying Explanatory Notes, even though express mention was made of deaf people in them. Through this lack of consultation, there was not an opportunity to express concerns about the relevant clause and negative impact.

Whilst the DH carried out public consultation, this did not reach out to the Deaf community. Government policy recognises that deaf and disabled people have traditionally been excluded, and this is what the Disability Equality Duty (now incorporated into the Single Equality Scheme) attempts to rectify, and to this end promotes positive discrimination. See Appendix for further information.

The DH team promised to find out what consultation had been done for the Deaf community and also promised to look into future consultation involving the Deaf community in BSL.

2. Language in Clause 14(4)(9)

Groups 3-4 informed the DH that the language in the Bill: 'serious illness/disability/condition' should not be interpreted as applying to deafness. Therefore it was surprising that the Explanatory Note 109 to Clause 14(4)(9) makes specific reference to deafness. The Deaf community do not perceive deafness as a disability and thus are offended by these descriptions. Due to current wording of the Bill and explanatory notes, this has steered debate in parliament, and it has now been implied that deaf people have a 'serious condition', this is concerning and may have a persuasive effect for the purposes of future statutory interpretation.

The DH team promised to find out if Explanatory Note 109 could be revised, thus not singling out deafness in relation to Clause 14(4)(9).

3. Practical Application of Clause 14(4)(9)

Group 5 argued that in a clinic setting it would be very difficult to apply the Bill in practice. For example, within the IVF process it is usual for many embryos to be produced, these may be of mixed quality – some more likely to be successful with implantation than others. If those of ‘best quality’ happen to also be the ones with the genes for deafness (referred to as a ‘deaf embryo’ from herein) or another genetic disorder then there should be the choice to have these implanted, thus ensuring a better chance of an actual pregnancy. If Clause 14(4)(9) is passed only select embryos without the genes for a disorder could be implanted. The Bill does not allow for parents to change their mind while undergoing PGD – something that can happen and is the parents’ prerogative while having, for example, pre-natal genetic testing. For example, although a couple may seek out PGD initially because they prefer to have a hearing child, it is possible that when the actual IVF process is complete and the embryos tested the ones most likely to implant happen to have the deafness genes, if the couple see this as their last chance to have a child together they may wish to proceed with the deaf embryos.

The DH team said that if all the viable embryos had the deafness genes then there was no room for a ‘preference’ to be made and the deaf ones could therefore be implanted i.e. the Bill would not force preference of unviable unaffected embryos over viable affected ones. Groups 2-5 felt that as the wording of the Bill was not explicit on this and also the fact that Baroness Deech in the House of Lords has specifically said that Clause 14(4)(9) is in place to prevent the choice to prefer a deaf embryo, they were not reassured that it would be possible to implant a deaf embryo.

More broadly, if decisions need to be made in the genetics clinic when there are multiple embryos at risk of developing different conditions, then the legal consequences of which potentially problematic embryo is preferred over another one are unclear and difficult to apply in practice.

The DH promised to clarify use of the word ‘preferred’ and make it explicit that it would be possible to implant a deaf embryo or other embryo with a genetic condition if this is what the parents wanted as long as it was not preferred to an unaffected embryo. This would also need to be within the context of other guidance and professional guidelines.

4. Equality

Groups 3-4 argued that d/Deaf and hearing people have equal rights in society, protected both in wider government policy and also in law, most notably the Disability Discrimination Act 1995. The government has also recognised BSL as a language as its own right in 2003. This means that deaf and hearing people have equality; however, there is inequality in Clause 14(4)(9) since hearing ‘persons and embryos’ must be preferred to deaf ‘persons and embryos’ (i.e. they are not equal). This is contradictory, to wider policy and legislation. The group felt that either deaf and hearing parents should ALL have the right to choose deaf or hearing embryos or NONE should have this right. Therefore, the reproductive rights for deaf and hearing people should be the same. Groups 2 and 5 also feel that there should be reproductive freedom for all – both deaf and hearing.

It appears that the entire purpose of Clause 14(4)(9), according to Explanatory Note 109, is to prohibit the selection for deafness. The active selection of a deaf embryo is controversial. Both research into the preferences of deaf and hard of hearing adults about the use of genetic technology to enable deafness to be passed on as well as the actual requests in practice, indicate that very small numbers (less than 1% of the deaf population) would be interested in this.

The DH stated that the purpose of clause 14(4) which inserts new section 13(9) into the 1990 Act is to prevent embryos that, following preimplantation genetic diagnosis, have been identified as having a significant risk of a serious medical condition, being preferred to embryos that do not have the condition.

The intention of the Bill team was never to specifically exclude deaf people in any way. DH also said that the current Bill is based on guidance already created by the HFEA, however groups 3-4 pointed out that current guidance fails to promote equality, due to traditional exclusion (which legislation and government policy recognises). To solely base a Bill on existing guidance does not seek to re-address institutional discrimination.

The DH said they would discuss the issue of equality and choice and get back to the other group members. More specifically, whether it was feasible to make comment about equality of reproduction – either to allow both deaf and hearing couples to use the technology or neither.

5. Gamete (egg/sperm) Donors

As Clause 14(4)(9) refers to both ‘persons’ AND ‘embryos’ it also restricts the donation of eggs/sperm of deaf adults.

Groups 2-5 felt that deaf adults should be able to donate gametes to friends as well as family. The DH team said that deaf adults would not be prevented from donating gametes to their friends or family, providing there were no other reasonable alternatives.

At present there are not sufficient gamete donors to meet needs and couples often have to recruit a known donor in order to receive treatment.

Groups 2-5 stated that due to the dynamics of the Deaf community, Deaf people are perhaps more likely to pick someone outside their family, say a friend, who happens to carry deaf genetic traits, on the simple basis they are a known willing donor. Members of the Deaf community may also be in a situation where they can only recruit Deaf donors and therefore if Clause 14(4)(9) is passed would thus be precluded from treatment unless the situation is clarified. The precedent alluded to in the Explanatory Notes of selection for deafness is an example of gamete donation and therefore arguable NOT significant to the regulation of preimplantation genetic diagnosis.

Whilst DH had already stated ‘a gamete donor who has a specific genetic abnormality ... could not be preferred to a donor without that abnormality solely on the grounds that they had the condition. However if a donor with a genetic abnormality was being selected for other reasons and there was no other suitable donor (perhaps because it was important for the couple to have a relative donate), then such a choice would not be prohibited by the Bill’

From experiences of Deaf parents, through their choices of donors, they are often labeled as wishing to create a deaf child (whether this was the case or not), and may be discriminated against by virtue of the community they live in.

Even if Explanatory Note 109 is removed, groups 2-5 felt legislative wording is wide, and could be open for misinterpretation later, irrespective of the intents or reassurances from the DH. From past experience of medical settings, it leaves Deaf people in a position constantly having to justify and fight for their reproductive choices and open to criticism.

The DH team said they would discuss the issue of policy change about reference to donors and get back to the other group members.

6. Briefing Notes Attached to the Bill

Prior to the meeting the DH team emailed a list of briefing notes about the Bill, these were reassuring in places (e.g. saying it is possible for deaf adults to donate gametes to relatives etc). However, as these are

not part of the official Explanatory Notes nor part of the wording in the actual Bill there is much room for interpretation and the liberal use of Clause 14(4)(9), as stated within the Briefing Notes, may be lost . Concerns were also raised due to the Explanatory Note 109, parliamentary debate already interpreted deaf people as coming under 14(4)(9) which would have persuasive effect when interpreting legislation in future. Groups 2-5 felt that if there was room within Clause 14(4)(9) to allow reproductive freedom to deaf adults then this should be made clear in the Explanatory Notes to the Bill.

The DH said they would re-draft the explanatory notes and circulate to the attendees at the meeting. They also said they would provide a note for further clarification of how the clause in the Bill might be interpreted in practice. This will be made available in BSL.

Appendix

Legal and Policy Background Notes:

The Disability Discrimination Act 1995 places a legal obligation on public bodies to consult with disabled people (including deaf people)¹ and to have due regard to including but not limited to: promotion of equality of opportunity, promotion of positive attitudes towards disabled people, and to take steps to meet disabled people's needs even if it means favourable treatment.^{2,3}

In addition, public bodies should not wait to be confronted with such policy concerns, '[t]he Disability Equality Duty is usually anticipatory: public authorities need to tackle barriers ... before disabled people present themselves.'⁴

Department of Health's own Single Equality Scheme⁵ recognises the social model of disability, and this very concept is fundamental for subsequent policy decisions:

*'DH uses the social model (as opposed to the medical model) of disability: i.e. it is the barriers (physical, attitudinal) that society puts in the path of disabled people that prevents disabled people from living fuller lives, rather than any inherent factor. **This concept** – which has gained wider credence due, in part, to equality legislation – is **fundamental, for it informs subsequent strategy and policy decisions relating to health and social care.**'⁶*

The same document goes on to highlight that equality needs to be at the heart of policy development, and specific attention to the needs and aspirations of disabled people:

*'Policy Development. DH recognises that **disability equality needs to be an underlying theme in policy development** and the delivery of national priorities, for disabled people make greater use of health services than non-disabled people. It is not therefore possible to elevate standards in the overall health and social care system **without paying specific attention to the needs and aspirations of disabled people.**'⁷*

¹ See Disability Discrimination Act 2005, particularly Part 5A (amending the Disability Discrimination Act 1995).

<http://www.equalityhumanrights.com/Documents/Legislation/DDA2005.pdf>

² See Office for Disability Issues, 'Disability Equality: A Priority for All'

<http://www.officefordisability.gov.uk/docs/disability-equality.pdf>

³ Also highlighted in the Department of Health's 'Single Equality Scheme 2007-2010', specifically at pages 96-97:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075463?IdcService=GET_FILE&dID=141695&Rendition=Web

⁴ See Office for Disability Issues, 'Disability equality: A Priority for All', Page 12

<http://www.officefordisability.gov.uk/docs/disability-equality.pdf>

⁵ The Department of Health 'Single Equality Scheme 2007 – 2010':

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075463?IdcService=GET_FILE&dID=141695&Rendition=Web

⁶ Department of Health, 'Single Equality Scheme 2007 – 2010', Page 15:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075463?IdcService=GET_FILE&dID=141695&Rendition=Web

⁷ Ibid.

To this end, the Department of Health is required to undertake an Equality Impact Assessment, as part of compliance with equality legislation, including, *'to be able to relate impact assessments to present and forthcoming legislation'*,⁸ in addition to a revised Cabinet Office framework, *'assessments should be rigorous and robust examinations of the policy's impact upon each of the equality strands'*.⁹ The action plan for this objective is detailed in the department's Single Equality Scheme,¹⁰ and requires *'[To] ensure that all elements of the team's work take forward equality and human rights in policy development ...'*¹¹

In addition, it should be noted that that the Secretary of State for Health is also obliged to publish at the end of 2008, a report on disability equality in their policy sector, which includes gathering evidence of progress, and address whether critical disability issues are being addressed.^{12 13}

In terms of reaching out or distribution to the Deaf community, the Department of Health's own document specifies, amongst other points:

- *'When DVDs or similar types of media are produced, they will be signed or subtitled as a matter of course – an issue raised at the involvement workshop (see Appendix 5).*
- *All information intended for the public will be in accessible formats.*
- *Information for the public will be drawn up with the help of disabled people*

*DH understands that different sections of the community prefer to receive information in different ways; and indeed that different communications styles are more effective with some people than with others. DH will thus seek to be informed by specialist groups about preferred or most effective communication methods, and will try to be a learning organisation when it comes to understanding how barriers to accessing information and services are perceived by the intended recipients'*¹⁴

⁸ Ibid., at Page 33

⁹ Ibid.

¹⁰ Ibid., at pages 65-84, particularly at page 65.

¹¹ Ibid., page 76

¹² See Office for Disability Issues, 'Disability Equality: A Priority for All', Page 9-10

<http://www.officefordisability.gov.uk/docs/disability-equality.pdf>

¹³ See Department of Health, 'Single Equality Scheme 2007 – 2010', Pages 27-30

¹⁴ Ibid., Page 47