Dominic Lawson: Of course a deaf couple want a deaf child

**It is not as if the implantation of an embryo thought to be deaf is equivalent to mutilation**

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Few broadcasters convey astonishment with an undertone of outrage as skilfully as the BBC's John Humphrys. Over the years the Today programme presenter has had a lot of practice. Yesterday, however, it was not an equivocating politician who got Humphrys to hit his top note. It was a bloke called Tomato – Mr Tomato Lichy, to be precise. The programme's listeners never actually heard Mr Lichy speak: he responded to John Humphrys' questions in sign language, and someone else turned his answers into spoken English for the interviewer's – and our—benefit.

Tomato Lichy and his partner Paula are both deaf. They have a deaf child, Molly. Now Paula is in her 40s and the couple believe they might require IVF treatment to produce a second child. They very much want such a child also to be deaf.

Here's where it gets political: the Government is whipping through a new Human Fertilisation and Embryology Bill. Clause 14/4/9 states that, "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 serious physical or mental disability, a serious illness or any other serious medical condition must not be preferred to those that are not known to have such an abnormality."

This, Tomato Lichy signed to Mr Humphrys, means that he and his partner would be compelled by law to discard the very embryos that they wished to have implanted: "I couldn't participate in any procedure which forced me to reject a deaf embryo in favour of a hearing embryo." Mr Lichy argued that this
legislation was specifically designed to discriminate against deafness. As a matter of fact, he's quite right.

The explanatory notes to the clause inform legislators: "Outside the UK, the positive selection of deaf donors in order deliberately to result in a deaf child has been reported. This provision would prevent (embryo) selection for a similar purpose." This all stems from a single case in the US six years ago, when a lesbian couple, Sharon Duchesneau and Candace McCullough, both of whom were deaf, selected a sperm donor on the basis of his family history of deafness. It caused outrage – outrage which clearly filtered through to the British Health ministry.

The most revealing account of this most unusual conception appeared in an email interview in the Lancet. Duchesneau and McCullough wrote: "Most of the ethical issues that have been raised in regard to our story centre on the idea that being deaf is a negative thing. From there, people surmise that it is unethical to want to create deaf children, who are, in their view, disabled.

"Our view, on the other hand, is that being deaf is a positive thing, with many wonderful aspects. We don't view being deaf along the same lines as being blind or mentally retarded; we see it as paralleling being Jewish or black. We don't see members of those minority groups wanting to eliminate themselves."

This is as clear an exposition as you will see of the concept of "cultural deafness". Adherents of this philosophy refer not just to "deaf culture" – Mr Lichy said he felt "sorry for" John Humphrys for not being able to appreciate "deaf plays" – but to themselves as members of a "linguistic community". This idea of a separate language enables the proponents of cultural deafness to describe themselves as, in effect, an ethnic minority – and thus any legislative attempt to weed them out as embryos to be analogous with the most insidious racism.

Another deaf British couple, whose child is also deaf, told the BBC's disability magazine that "it is important that our culture is passed on from one generation to another ... the threat of losing our culture would be devastating because we have so much to show and to give."

In the most obvious sense, the argument that deafness is not a
disability is self-evidently wrong. The absence of one of our most valuable senses brings with it many disadvantages on a purely practical level. So many careers are all but closed to the deaf – a deaf boy might well have fantasies about being a soldier or a fireman, but fantasies are what they will remain. Humphrys tasked Tomato Lichy with the fact that he would never be able to enjoy the music of Beethoven – a low blow, this, as Beethoven himself was vilely tormented by increasing deafness, which also put an end to his ability to conduct his own music.

Yet I don't share Humphrys's apparent incredulity at his interviewee's dismissal of the joys of music. If you have never been able to hear music, then you can not be said to miss it, or suffer from its absence from your life. Indeed, I know one or two people who are completely tone deaf, who are not in the least miserable about it: their only irritation is in occasionally having to hear what to them is just undifferentiated noise, when they would rather have silence. The idea that congenitally deaf people are "suffering" in some intrinsic sense, strikes me as mere presumption.

Moreover, it is not as if the implantation of an embryo which is thought likely to be deaf – and science at the moment would be very hard pushed to forecast such an outcome with any reliability at all – is equivalent to deliberate mutilation. What we are talking about is an already existing potential person; the choice isn't whether that embryo could be "made deaf" or not. The choice is whether to discard that already existing embryo for another one believed to be less at risk of turning out to be deaf.

Given that the fertilisation process within IVF generates many more test-tube embryos than are selected for implantation, there are always going to be vast quantities of 'normal' embryos which will be destroyed.

The real issue here, as Mr Lichy observed, is whether the state should be able to dictate to him and his partner which of their embryos they should be allowed to select, and which they should be compelled to reject. I am not surprised – still less, incredulous – that he can't understand why he and his partner should be prevented by law from choosing the embryo which might most turn out to resemble them.
John Humphrys argued that most people would regard his demands as profoundly selfish: Mr Lichy and his partner might want a deaf child, but what about the views of the child itself? I suspect that the child in question would be intelligent enough to be able to understand that the only alternative deal for him or her was never to have existed at all.

Nevertheless, if Clause 14 of the HFE Bill does pass into law, I do hope that Mr Lichy and his partner will find it in them to love and cherish a child who is not deaf. We hearing people are not so useless, when you get to know us properly.

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