11 Screening and embryo selection: eliminating disorders or people?

Box 11.6 Case study: Christopher Nolan

Christy Nolan was deprived of oxygen at birth and suffered from cerebral palsy. Nolan couldn't walk, talk or use his hands. He spent his short life (he died aged 43 in 2008) in a wheelchair.

Until Nolan was 11 he couldn't communicate with words at all. Then a new drug Lioresal made it possible for him to use a 'unicorn stick' on a headband.

In 1987, with the help of his mother Bernadette, Nolan published his autobiography entitled *Under The Eye of the Clock*. Nolan's mother held his head whilst he picked out the letters he wanted. He managed a couple of pages a day.

The book won the Whitbread Award and was described as 'astonishing' for its extraordinary use of language, comparable, it was said, to Yeats and Joyce.

Here is Nolan's description of the process of writing:

'My mind is just like a spin-dryer at full speed; my thoughts fly around my skull while millions of beautiful words cascade into my lap. Images gunfire across my consciousness. Try then to give expression to that avalanche in efforts of one great nod after another.'

Box 11.13 Case study: 'Of course a deaf couple want a deaf child'

Adapted from the article by Dominic Lawson *The Independent* Tuesday 11 March 2008. http://www.independent.co.uk/opinion/commentators/dominic-lawson/dominic-lawson-of-course-a-deaf-couple-want-a-deaf-child-794001.html.

Few broadcasters convey outrage as skillfully as the BBC's John Humphrys. Yesterday it was not a 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 heard Mr Lichy speak: he answered Humphrys' questions in sign language, and someone translated his answers into spoken English for our benefit.

Tomato Lichy and his partner Paula are both deaf, as is their child Molly. Paula is in her 40s and the couple believe they might require IVF treatment to produce a second child. They very much want this child to be deaf and are prepared to undergo IVF to achieve this.

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 Paula would be legally obliged to discard the very embryos they wished to implant: 'I couldn't participate in any procedure which forced me to reject a deaf embryo in favour of a hearing embryo.' Mr. Lichy argued this legislation was discrimination against deafness. 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 stems from a case in the US when a lesbian couple, Sharon Duchesneau and Candace McCullough, both deaf, selected a sperm donor for his family history of deafness.

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 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 more like Jewish or black.'

This is a clear exposition of the concept of 'cultural deafness'. Adherents of this philosophy believe themselves to be members of a 'linguistic community'. Mr. Lichy said he felt 'sorry for' John Humphrys for not being able to appreciate 'deaf plays'. The proponents of cultural deafness, in virtue of their separate language, describe themselves as an ethnic minority. This makes any legislative attempt to weed them out as embryos analogous with the most insidious racism.

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 practical disadvantages. A deaf boy might have fantasies about being a soldier or a fireman, but fantasies are what they will remain. Humphrys tasked Tomato Lichy with the fact he would never be able to enjoy the music of Beethoven – a low blow as Beethoven himself was tormented by increasing deafness.

But if you have never been able to hear music, then you cannot be said to miss it. I know one or two people, completely tone deaf, who are not in the least miserable about it: their only irritation lies in having to hear 'noise' rather than silence. The idea that congenitally deaf people are 'suffering' strikes me as mere presumption.

It is not as if the implantation of an embryo thought likely to be deaf is equivalent to deliberate mutilation. The choice isn't whether that embryo could be 'made deaf' or not. The choice is whether to discard an already existing embryo for another one believed to be less at risk of turning out to be deaf.

The real issue here is whether the state should be able to dictate to the Lichys which of their embryos to select, and which they should be compelled to reject. I am not surprised he can't understand why he and his partner should be legally prevented 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.

Box 11.15 Case study: The Whitakers

Jamie Whitaker was born in 2003 so that he could save the life of Charlie, his older brother.[34]

Charlie has Diamond–Blackfan anaemia (DBA), a rare genetic condition treatable only by a stem cell transplant from a matching donor.

The boys' parents, Michelle and Jayson Whitaker, selected the embryo that became Jamie, after IVF undertaken solely in the hope of producing a genetic match for Charlie.

The Whitakers had to travel to the United States for treatment because the Human Embryo and Fertilisation Authority in the UK refused to grant the Whitakers' application because there would be no direct benefit to the unborn child.[35]