

Rebecca Atkinson: I wouldn't have minded if my baby had been born deaf, but the embryology bill suggests I should

Rebecca Atkinson—October 8th, 2008

Earlier this year my first-born arrived. Like all new parents, I spent hours gazing in wonderment at this tiny creature who had fallen from the moon to be the centre of my world. The way his fingers danced in the air as if he was pulling the strings of an invisible harp in his sleep. How his little body flinched in response to the smallest of sounds: the rustle of paper or the ping of a sofa spring.

I was struck by his sensitivity to sound, but the fact that he is hearing came as no surprise. My partial deafness is caused by a recessive gene, so my hearing partner would have to carry the same gene for our son to be deaf. Not impossible, but unlikely. Would I have minded if he was deaf? Did I hope he would be hearing? I can honestly say I had no preference.

While my deafness is only partial and spoken English is my first language, my sister, her husband and his family are all profoundly deaf sign language users. I will make every effort to pass on their wonderful expressive language to my son, so that he can communicate with his extended family and grow up knowing that communication through both sound and silence hold equal merit.

But this notion that hearing and deafness can somehow stand side by side, equal but different, is a rare one. A generation ago, the Disability Discrimination Act was passed, affording a degree of equality to deaf and disabled people. However, when it comes to equal rights in the realm of reproduction, it appears that a double bind is at play. No, you can't chuck someone out of your restaurant on the grounds of their deafness but yes, you can determine that more folk like them don't get born in the first place. The human fertilisation and embryology bill, which is due to reach report stage in the House of Commons this autumn, contains a little-known clause that the deaf campaign group Stop Eugenics has argued will curtail the reproductive equality of deaf parents and the rights of potential deaf babies.

According to clause 14 of the bill, any embryo known to have a serious illness or disability "must not be preferred to those that are not known to have such an abnormality". In other words, to implant an embryo known to have deafness when other hearing ones are present will become illegal. Additionally, ambiguous wording means the bill could conceivably be interpreted to forbid an individual with a genetic condition from becoming an egg or sperm donor.

Tomato Lichy and Paula Garfield, a deaf couple from London, appeared on Radio 4's Today programme earlier this year to discuss their opposition to Clause 14. The couple argued that they would actively want a deaf child were they to undergo IVF in the future.

But why would anyone want a deaf baby? Sheer madness? To understand a desire for deafness to be passed down through generations requires a paradigm shift in the way that we view the condition. There are an estimated 9 million people in Britain with some degree of deafness (most will be over-60s with age-related hearing loss). Of these, an estimated 70,000 use British Sign Language as their preferred means of communication, many of whom come from families with as many as eight successive generations of deafness. For this group, Deaf with a capital D denotes membership of a unique cultural and linguistic minority, rather than a medical aggregate of people with a hearing loss.

To them, Deaf, like “black”, is not just a description of a physical attribute, but an expression of pride, belonging and cultural identity.

The idea of wanting a deaf baby still remains unfathomable to most, but let us not forget that the popular notion of deafness is one constructed around our fear of what it might be like to have our hearing taken away rather than direct knowledge. Surely the experts on what it’s like to be a deaf child are not those who wish to cast value judgment based on assumption but those who have been deaf children themselves. Yet no deaf or disabled people were consulted during the drafting of the bill.

The media debate and moral condemnation that followed Lichy and Garfield’s radio appearance was steeped in misunderstanding. The couple were perceived as barbaric parents wishing to genetically pierce the eardrums of an embryo that otherwise left alone would grow into a hearing child. If this were the case, then no person in their right mind would advocate an amendment to Clause 14.

But this is not about tweaking the genes of a hearing embryo, a technical impossibility. It’s about laying two potential children in embryonic form side by side and affording more right to life to the hearing one by making it illegal to issue preference to the deaf one. It’s about dismissing the opinions, experience and claims of deaf people as madness in favour of the majority view that deafness is something best avoided. In short, this is not about creating a hearing child and then making it deaf. It’s about not being able to give life and therefore equality to an embryo that is already deaf.

I had no preference as to the form my son came in, and I would never use IVF to screen in or screen out, but as a deaf person I can’t help but feel slightly affronted that the bill affords more right to life to you the hearing reader, than me the deaf writer, were we to be lying side by side in embryonic form in a petri dish. Indeed, it makes it illegal to choose me over you.