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Letters Reproductive liberty and deafness

Clause 14(4)(9) of embryo bill should be amended or deleted

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Response to Editorial Change and Stallworthy Letter

Our response is twofold. We first address an editorial change that we believe has altered the meaning of our original letter. The remainder of this letter is a response to Mr. Stallworthy's letter.

In reference to our original letter, please note that we would avoid the use of the term "normal" to describe the majority hearing population precisely because it has shades of a value judgement made by hearing people towards deaf people. Deaf people with the full range of perspectives towards their deafness are the people best placed to choose their own descriptors. The use of 'normal' glosses over this point; we raise this here having noticed that, during editing of our previous letter after submission, our term "hearing" was changed for "normal" without the nuances of the substitution being obvious to the editors.'

Mr. Stallworthy's letter supports Clause 14 (4) (9) of the proposed Human Fertilisation and Embryology Bill, arguing that outlawing genetic selection for deafness would result in less suffering in the world. We have two main concerns with the views set forth in his letter: that our views are misrepresented and that his reasoning is flawed.

Firstly, he has the same misunderstanding as many amongst the popular press and politicians who think the representatives of the Deaf community in the UK are campaigning for rights to select deaf embryos. This is not the case: for example, see the StopEugenics campaign www.stopeugenics.org. There is no campaign or movement that seeks to harness genetic technology to create deaf babies; what alarms us is the specific targeting of embryos with the genes for deafness as an example of 'serious abnormality'. Our

position with regards to the clause asks that reproductive choices be the same for both deaf and hearing people. This presents two options: either it will be illegal to use pre-implantation genetic diagnosis to select for or against deafness or everyone will have equal legal access to this technology (the current status quo). In the latter case, reproductive decisions are private and made by individuals through consultation with health professionals.

Secondly, Mr. Stallworthy errs in deriving general conclusions from his own particular experience. Two authors of the original letter are deaf and can empathize with Mr. Stallworthy's experiences; however, we reject the assumption he makes that being born deaf necessarily consigns one to second-class citizenship. We believe that most barriers to citizenship are socially constructed and therefore surmountable, including the example he gives of supplying visual train announcements as well as audible ones. We do not condone or excuse discrimination towards deaf people, but do not accept that preventing the existence of those who are discriminated against is the solution.

Mr. Stallworthy supports the reduction of deaf births as an aim in itself. As a measure of the 'success' of genetic counselling, a reduction in birth incidence of particular conditions was discarded years ago by genetic counselling professionals (1, 2, 3). It was seen as an unacceptable focus on the individual who would have the condition rather than on the society into which they would be born. Genetic counselling professionals shifted the focus onto aiming to provide non-directive information to support the autonomy of parents. This public health argument for purposefully seeking to prevent the number of deaf babies being born is therefore not acceptable in current practice.

We recognize that arguing for reproductive liberty requires logical consistency. In the case of non-syndromic deafness, which is not life-threatening and does not result in physical pain and suffering, the moral justification for selection is murky. This is undoubtedly also the case for other physical traits that are considered to be less socially desirable in the mainstream, such as short stature. Mr. Stallworthy cites the small number of people requesting this technology in order to select for deafness as evidence that the majority of deaf people do not wish to have deaf children. In fact, Middleton et al's paper (4) shows that more than half of Deaf parents and almost 40% of hearing and hard of hearing parents replied to the question 'Would you prefer to have deaf or hearing children?' with the response that they did not have a preference. We suggest that reasons for this answer may have more to do with a person's position regarding appropriate uses of biotechnology than whether deaf

people have better or worse lives than hearing people.

This discussion highlights society's value judgement of the worth of deaf citizens and their quality of life. Mr. Stallworthy implies that, although society is willing to tolerate and accommodate people who are born deaf, a better solution to avoiding individual 'suffering' might be if such births could simply be prevented from occurring. We believe that the difficulties of determining what sorts of people should live or exist is ethically problematic. In light of all current circumstances and with due regard to all current social and scientific factors, we suggest that preferences along these lines should not be codified into law.

The case of deafness illustrates how difficult it is to draw any lines regarding who ought to exist. Human communities form through commonality; the reality of Deaf communities worldwide is further evidence of this. The study of signed languages has provided opportunities for linguists to learn more about the development of language and the mind. More importantly, the existence of the wide diversity of human expression and solidarity has intrinsic value - to suggest that a group of human beings or a sociolinguistic community has less worth and ought not to exist is to diminish us all.

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2. Chadwick RF. What counts as success in genetic counselling? *J Med Ethics* 1993 Mar; 19(1): 43-6.
3. Clarke A. Response to: What counts as success in genetic counselling? *J Med Ethics* 1993 Mar; 19(1): 47-9.
4. Middleton, A. et al. Prenatal diagnosis for inherited deafness – what is the potential demand? *Journal of Genetic Counseling* 2001; 10(2): 121-131.

Competing interests:

None declared

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