

Debating Deafness and Embryo Selection: Are We Undermining Reproductive Confidence in the Deaf Community?

Sarah Norcross

It's a great pleasure for me to introduce our chair this evening, Professor Graham Turner. He is Chair of Interpreting and Translation Studies at Heriot-Watt University in Edinburgh. For over 20 years he's conducted research in the field of Deaf Studies. His research projects have included exploring British Sign Language and deaf experiences in almost every field you can think of: education, law, theatre, mental healthcare, sports and the workplace. And he is a founding editor of a journal, *The Sign Language Translator and Interpreter*. I'll leave you now in his capable hands.

Graham Turner

Thank you very much. There aren't any formal outcomes intended from this event *per se*. It's an exchange of views, an exchange of knowledge. The outcomes are for each of us individually, and the organisations we work for, to carry forward after this event. So, don't look for a formal statement from me or anybody else at the end of the event as to what we've agreed. That won't happen. It's ideas, material for us to digest.

I hope that is okay, and everybody is happy to make a start on that basis. My first job is to introduce our first presenter, Anna Middleton. Anna has worked as a genetic counsellor for the last 13 years. Her research has predominantly focused on the attitudes of deaf people towards genetic testing. She is currently running a research project at the Institute of Medical Genetics at Cardiff University. Over to Anna.

Anna Middleton

Good evening. It's my job to set the scene, and give you information on the Human Fertilisation and Embryology Bill and the issues that we'll be debating tonight. Before I do that, I thought it might be helpful to give you some background which explains what qualifies me to be standing here involved in this discussion. I am a genetic counsellor, which means I would normally work within the NHS in a genetics department, seeing individuals who have questions or concerns about inherited conditions in their family. I am now running a research project at Cardiff University, which is gathering the views of deaf and hard-of-hearing people towards genetics. Both Dr Steve Emery and Professor Graham Turner are working on this project with me.

The Bill we're discussing tonight relates to the use of preimplantation genetic diagnosis, or PGD, used with IVF. It also relates to the use of donors of eggs or sperm in IVF. In genetics departments up and down the country, genetics professionals see amongst others families with serious life-threatening genetic conditions, which may affect several members of the same family.

PGD can offer a lifeline to such families, who may have already had several children die of the family condition.

Genetics departments will offer a test to the parents, to see if the family gene fault can be identified. If so, then the couple can be referred to a specialist centre to have IVF and PGD. Any embryos produced through IVF can be tested for the family gene fault – i.e., they undergo preimplantation genetic diagnosis. Those found not to have the genes for the serious condition can be implanted, thus hopefully offering the parents a chance to have a child without the life-threatening condition.

PGD has a low success rate, is difficult to get funding for, and is often fraught with similar emotional difficulties to those faced by couples having IVF. No couple would undertake this process lightly.

The Human Fertilisation and Embryology Authority, which guides the use of the technology and PGD, has granted a licence to offer PGD for deafness. Therefore couples can now test to see if they have embryos with the genes for deafness, which I'll call deaf embryos. Although this is technically possible, it is a service that has hardly been used. I don't know the exact numbers, but it is likely there have been fewer than 10 cases in the UK over the last few years. It is also likely that this has been used by families who already have several children with deafness, and are desperate for a hearing child. Is deafness a serious enough condition to be avoided at all costs by the use of this technology?

The research I have done has shown a mixture of views towards this. Most deaf, hard-of-hearing and hearing parents of deaf children do not mind having either deaf or hearing children. Some prefer hearing, some prefer deaf. Some feel they would consider the use of this technology for themselves. But most are concerned that this sort of technology is available, because to them deafness is not a serious condition.

Steve emailed me before Christmas with details of the Bill, and the outrage that the deaf community was beginning to feel towards Clause 14 Section 4(9). Since then, I've been involved in discussions about it both in writing and in facilitating access between deaf friends and colleagues and contacts in the genetics community. I would also like to say that I've not been doing this on my own. There have been several other genetics colleagues integrally involved in this: Maria Bitner-Glindzicz, Marcus Pembrey and Rachel Belk have all taken a similar role to myself.

The Human Fertilisation and Embryology Bill proposes to amend the 1990 Act of the same name. It passed through the House of Lords recently, and is being discussed at the moment in the House of Commons. Clause 14 was added because the government felt that legislation was needed to overarch the work of the Human Fertilisation and Embryology Authority, which up until now made these decisions on a case-by-case basis.

IVF is available to any couple with infertility problems. This service won't be affected by Clause 14; any deaf couples having IVF will continue to be able to do so.

A licence is available to test for deafness by PGD, as mentioned already. So couples can have their embryos tested for deafness now, and can choose to have the hearing embryos implanted. What Clause 14 does is make this a legal choice – i.e., couples will have to by law only implant a hearing embryo if there is an available selection of deaf and hearing ones.

It is worth saying that no one will be forced to have PGD. It is only available in certain circumstances where specifically requested.

Clause 14 states that a person or embryo with the genes for a serious medical condition must not be preferred to a person or embryo without such genes.

Put another way, this means two things. First, a person with a serious genetic condition cannot donate eggs or sperm for IVF, if there is an available person who doesn't have a known serious genetic condition.

Second, an embryo with the genes for a serious genetic condition must not be implanted if there is an available embryo without the genes for a serious known genetic condition.

One might assume this isn't even relevant to deafness, as the wording of the Bill refers to a serious condition.

However, the Explanatory Notes to the Bill state that this clause would prevent deaf couples from choosing to implant an embryo with the genes for deafness. This was supported further by Baroness Deech, former chair of the Human Fertilisation and Embryology Authority, who stated in the House of Lords that the deliberate choice of a deaf embryo will be prevented by Clause 14.

Therefore to summarise so far: if there is a mixture of deaf and hearing embryos, the hearing embryos must by law be implanted. If there is no choice and only deaf embryos are available, then it is okay to implant these. If there is no choice, and only deaf donors are available to donate eggs or sperm, then it is okay to use these. So basically, if there is a choice between a deaf and a hearing person or embryo, then the hearing one must be chosen.

There appear to be some exceptions to this, in that a deaf person is allowed to be a sperm or egg donor to their family, as long as they weren't specifically chosen with the intention of passing deafness on. How this would be policed is up for debate.

Choosing to select a deaf embryo is controversial. This has become the focus of the media interest in Clause 14, with misleading headlines such as 'Deaf demand right to designer deaf children', from the *Sunday Times*. Tomato Lichy and Paula Garfield, a deaf couple, have done numerous TV and radio appearances to discuss their views. They don't mind having a deaf or hearing child. They would not want to deliberately create a deaf child, but if through IVF a deaf embryo already exists, then they would not want to be forced to discard it.

Lichy and Garfield feel that even theoretically having to choose the hearing one places a value judgment on what it means to be deaf. This contradicts their own positive identity.

The research I've done has shown very few deaf and hard-of-hearing adults say they would use genetic technology to select for a deaf child. Indeed, practice supports this. As far as I'm aware, in the UK there have been no requests for this. Therefore I raise the point of whether it is necessary to legislate against something that hardly anyone would do. The current situation of considering each couple wanting PGD on a case-by-case basis works perfectly well at the moment. Is there any need to change this?

The debate tonight was initiated by the Progress Educational Trust, which has been instrumental in helping gain access to the people in the Department of Health who wrote the Bill. These people are here tonight, and would welcome your feedback.

A meeting occurred on 19 March between various people opposed to the Bill, together with the Department of Health. One of the issues raised related to the fact that none of the public consultation done prior to Clause 14 being written was delivered in British Sign Language. And therefore, the deaf community was not made aware of the issues at stake. This is being addressed already, and the Department of Health has ensured there is a publicly available British Sign Language version of that meeting. It's also open to others who have concerns about Clause 14. Indeed, they've already met the Islington Deaf Campaign group.

Another key issue that was presented was the fact that deafness is not perceived by many as a serious condition, and so Clause 14 should not apply here. The Department of Health said it would look towards removing the reference to deafness in the Explanatory Notes, and then it would be up to the Human Fertilisation and Embryology Authority and clinical judgment, together with the parents, to decide what is a serious condition. However, a licence for PGD for deafness is already available, and so deafness has already been interpreted by the Human Fertilisation and Embryology Authority as a serious condition. Removing deafness from the Explanatory Notes won't change this.

I'll now leave you with a number of questions ready for debate.

- The wording of Clause 14 refers to a serious medical condition. Would you classify deafness in that way?
- Just because we have the technology to be able to test for deafness, should we use it?
- If PGD is available to select against deafness in the name of equality, should it also be available to select for deafness, or should PGD not be available to either?
- Should all people have a choice, and be able to test for anything and everything they want – deafness, blindness, and when it becomes possible to test for non-serious traits such as linguistic ability or intelligence, should this be allowed? The Bill we are discussing proposes not.
- To what extent should parents be able to control the sorts of children they will have? Does a parent have a right to choose to keep certain embryos and not others? If the answer is yes, should the government be involved in this decision?
- Finally, how feasible do you feel it is to apply this legislation in practice? And I direct this specifically to those of you in the audience who work in the medical profession.

These are some of the issues that I hope we'll be able to discuss tonight. Thank you.

Graham Turner

Thank you very much Anna. I move to Steve Emery, who works as a Research Associate at Heriot-Watt University, Edinburgh. Steve's research has primarily focused on issues relating to citizenship and the deaf community, and as Anna mentioned, he is currently associated with the research at Cardiff University that Anna is leading. Steve.

Steve Emery

I would like to start by thanking the organisers, the Progress Educational Trust, for setting up the meeting. I think it is such an important topic, and such an important opportunity for us to debate. I have to try and be brief in what I say, and my explanation of why I oppose Clause 14. I want to be brief because I want to give you the opportunity to come and express your views.

I am not an expert in genetics. My area of research is citizenship, that's really my area of expertise. I have interviewed deaf people on their experiences of genetics.

I don't object to the full Bill, I should say. I object to Clause 14 Section 4(9), and I'll explain the reason for that. There are four reasons why I object.

First, I believe Clause 14 is a form of eugenics. I've seen signs like 'wipe-out' – how you sign eugenics, I'm not sure – and signs along the lines of 'born perfect'. I'm not sure if you have signs you use to translate the meaning of eugenics, so I use the sign 'born perfect'. Is that okay? That's what it means. It's not trying to wipe out; we're not talking about genocide, that sort of wiping out a group of people. Eugenics is a different meaning. My argument is Clause 14 is a form of eugenics.

Second, Clause 14 links us to the medical model. No social model, it's just in the medical model.

Third, it ignores the value of the deaf community, its language and culture.

Fourth, it affects deaf people and their citizenships.

These are the four reasons why I object to the clause. Hopefully, that will kick-start a bit of a debate tonight.

As I said, I believe it's a form of eugenics.

Anna already mentioned the media's reaction, talking about deaf people wanting a deaf designer baby. This is what the media has reported.

But in reality, Clause 14 will allow hearing people to have hearing designer babies, not deaf designer babies. It's about creating hearing babies, not deaf. If a couple want to go for IVF, if they decide they want to test the embryos, to decide whether they're hearing or deaf, and if there is a mixture of deaf embryos and hearing embryos, that couple is not allowed to choose the deaf embryo. They must select the hearing embryo. They don't have a choice. This is why I say it's a form of eugenics.

Then you have the donor. So if a couple are looking for donor, maybe my sperm is not good quality and my partner's egg isn't good quality, and we're looking for donors. I have to prefer a hearing donor. For us in the deaf community, we're a small community, we know one another. And maybe us as a couple looking, there may be one, two, three people who could be potential donors and they're all deaf. But I have this pressure of science saying I have to prefer a hearing donor. Maybe we don't necessarily want a deaf baby, or don't necessarily want a deaf donor, it just happens. But we have to prefer the hearing donor. So, again a form of eugenics.

I feel we should leave it to nature. Leave it to nature whether they're deaf or hearing, it really doesn't matter. Just leave it to nature, let nature take its course. I understand that Clause 14 gives hearing people a choice, but it doesn't give the same choice to deaf people, and that's the argument, and I think we should leave it to nature.

My second point, talking about the medical model – Anna already explained this area. The Clause itself doesn't mention the word 'deaf', so why are deaf people so annoyed? As Anna said, it's clearly because of the Explanatory Notes. The Bill links to some Explanatory Notes and those notes give an example of trying to stop deafness, so the Explanatory Notes mention deafness. Also Baroness Deech in the House of Lords gave the example of deafness as something that shouldn't be allowed. So there are two things, two areas where deafness is mentioned.

The health authorities talk about the word 'abnormal'. Abnormal physical disability, serious physical disability. What does that mean? The Bill doesn't describe exactly what it means, doesn't explain it. It can't give a full explanation of every possible example, but it does mention deafness in the notes. So that's why we object to the clause, or I object to the clause.

One really important point. The health authorities also say that we're not allowed to choose a donor or a gene for intelligence, or for being a great athlete, or for the colour of their eyes or hair. The health authorities say no, you're not allowed to do that. They allow hearing people to choose hearing babies, but not deaf people to choose deaf babies. Clause 14 doesn't allow that, so again, this is why we object.

So we're talking about the medical model, but also about the value of deaf people. The third point is the value of deaf people. We're being ignored, our language and our culture is being ignored. There has been no consultation, for example. No consultation. If there had been a consultation, the health authority would have sat down with us and learned the value of our language, the value of our culture, and would recognise that deaf people have a value. They have a language, a culture that is valuable. But there was no consultation and this is where we've arrived at, this is the point we've arrived at.

For example, the value of sign language. I'm not talking about sign language and helping deaf people, I'm talking about baby signing. I know baby signing isn't a perfect language, but the idea is that a parent or a mother or father can communicate with their hearing baby before speech is developed, and that has come from sign language from deaf people, so that's an example of the value. Deaf people were involved in the development of the internet, the development of cars, they got the idea of the rear view mirror. Deaf people have been involved, and there is a value that deaf people have given society, and all this has been ignored. We're just talking about the medical model, and they ignore the value of sign language. That's my third point.

And my final fourth point is how this affects our citizenship. First, it gives us this medical model of being less than perfect. Second, the donor – deaf donors don't have the same rights as hearing donors. I have to prefer a hearing donor to a deaf donor, so there is inequality. And the government has a lot of laws, legal rights, the Disability Discrimination Act – many different laws and acts trying to promote equality. But then at the same time, it has this very medically based clause, so the two things are completely at odds with one another. So are we better not being born? We're adults, we're professionals, we have professional lives, but it's better we weren't born?

So the four points in summary. First, as I've said, it's formal eugenics. Second, it relies on this medical model. Third, it ignores the value of sign language and culture. And it also affects our citizenship in the fourth point. This why I object to the clause, and I hope this will encourage debate. Thank you.

Graham Turner

Thank you very much Steve. We're running a little behind time, so to keep this swift, I'll introduce very briefly our next presenter Colin Gavaghan, who is a lecturer in Medical Law and Ethics at the University of Glasgow. His first book on the subject of today's session, *Defending the Genetic Supermarket: The Law and Ethics of Selecting the Next Generation*, was published last year, and he has published a range of articles on preimplantation genetic diagnosis and testing. Colin.

Colin Gavaghan

I don't know if any of you know much about Glasgow, but one of the things for which it is well-known is people have a habit of speaking very quickly. And I have been well warned tonight to avoid doing so. All over the world I've learned to speak slowly in seven or eight languages, and I have a hunch tonight it will be sign language as well. I will try.

Before I start, can I ask how many people here heard or read the online transcript of John Humphrys' interview with Tomato Lichy on the *Today* programme a few weeks ago? It became quite notorious, I think.

What happened was John Humphrys interviewed Lichy, and when Lichy made it clear he objected to Clause 14 and he saw no problem with either selecting an embryo which was known to be deaf or not making the choice on those grounds, Humphrys responded with his characteristic bluster – characteristic of John Humphrys, not Welsh people generally – incredulous that Lichy could feel this way. He made no attempt whatever to understand Lichy's views. I don't know if any of you then went on to look at the Radio 4 website. I did, because I have a professional interest. Things got worse, with certain posters accusing Lichy and Paula Garfield of child abuse or neglect.

I think John Humphrys was wrong in what he said, and I certainly think these posters on the website were wrong to accuse Lichy and Garfield of what they did. I don't think this because of politically correct reasons. I'm not even saying it because the posters were insensitive to the views of other people, although there may be many who think that too. I think John Humphrys' objection, and the view of those posters, rests on an enormous philosophical confusion. It's the same philosophical confusion that underlies Clause 14, the Clause we're talking about this evening. Let me try to explain.

When I started looking at this subject about 14 years ago, I guess my position was probably the intuitive one that a lot of people would leap to, and that is the assumption that people who wanted to use the kind of technology that Anna described would want to use it to ensure their children were free of serious genetic disorders – things like cystic fibrosis, muscular dystrophy, that's what I assumed people would want to use it for. It never occurred to me anyone would want to use this technology to actually select to have a deaf baby.

Since then I have read a lot on this subject, and since then I've had my eyes opened to the kind of reasons why people like Lichy and Garfield may want to do this. But more fundamentally, in the time that I have been looking at this subject, I've had my eyes opened to a very different way of looking at these questions; what are sometimes referred to in the literature as genesis questions, questions about the creation of new lives. And my view on it was very much influenced by a professor named Derek Parfit.

Derek Parfit is a very clever man. He is also a role model to a lot of academics, because he has set on an absolute formula for his career. He wrote a book in 1984 which has been very, very influential and we've been waiting 24 years for the follow-up, and yet his career doesn't seem to have suffered at all. I'd love to know how he managed to do this. In this book Derek Parfit wrote, that seems to have made his career, he was very concerned with questions to do with personal identity. He asked things like: am I the same person I was when I was two years old? If we catch a Nazi war criminal today and he's 98 and has no memory of what he did in the war, should we still punish him? All these philosophical questions about identity. But the one that related to this subject was a question, a hypothetical question he posed, which was to do with a choice of which of several possible children to create. And it was one of those arguments that you read and you think, that can't be right. And you go back and read it again.

What Parfit emphasised was, to apply it to this evening's debate, there is a very big difference between making a baby deaf and making a deaf baby. This is a very important distinction, and it's one that I think John Humphrys and all of these posters on the Radio 4 website failed to understand. Because if, for the sake of argument, Lichy and Garfield were successful in having a deaf baby, it's completely unintelligible to argue that the child would be better off with hearing. Quite simply, the choice for that child was to be born deaf or to never be born at all. To argue that the parents would have been better selecting a hearing embryo would be to say that the child should have been replaced with a hearing sibling. When you think about it that way, it becomes rather difficult, I would say, to understand what Clause 14 is actually for. Who is it supposed to be protecting? Who is it supposed to be safeguarding? To go back to the arguments on the website, what child is Lichy abusing or neglecting? For the child, the only alternative to this life is no life. And it seems to me a very strange way to try to protect the child from deafness, by protecting it from existing in the first place.

I should make two things clear, and it may be things the other panellists don't agree with. I'm not saying it would be wrong if a couple of would-be parents decided that they wanted to have a hearing baby. I don't think it's wrong if Lichy and Garfield want to have a deaf baby. People have their own views on these matters, people have their own reasons for making the choices they make. In neither case would a baby be hurt. In neither case would a baby be harmed. That being so, I don't really think the government or the law has any business telling these people what they have to do.

The thing that should be made clear – people may disagree on this – I am not saying there could never be a case where a child could suffer so badly from a genetic illness or disorder that we might actually think there should be a place for the law to interfere. Things like Tay-Sachs disease or Lesch-Nyhan syndrome inevitably interfere in the child's life, there is an enormous amount of suffering before it dies, and the nature of the disease is such that there are very few opportunities for compensatory things in that child's life. You may say there is never an illness, never a life so bad that the child should never have been born, and we can certainly discuss that. What I would say is that those are the only incidents in which it would even be meaningful to talk about protecting the child by interfering in these decisions. It's certainly not intelligible to talk about deafness in those terms. It's completely unintelligible to think about a life with deafness as being a life that's not worth living, a life so burdened by disability that we're justified in preventing the birth of that child.

I'm behind time, so I'll finish up with something that Anna said towards the end of her question, and I'll attempt an answer to it. Anna asked: is deafness a serious enough condition to be avoided at all costs?

Well, for me the only answer to that is, I don't feel qualified to enforce my views on that question on everybody else. And I don't think the law has a legitimate interest in imposing one position on that very difficult question on everyone else. Unless we have good reason to interfere in these private, personal, intimate decisions that people make, I think it is one of those areas where we're all entitled to an opinion; we're not entitled to force that opinion on someone else. Sometimes the law has to recognise some of the decisions people make in their lives are their business and no one else's. Thank you very much.

Graham Turner

Thank you, Colin. We're going to take a break shortly but before we do, I am going to have some instructions for you about how we're going to handle the second part of the evening. First though, we have an opportunity to hear from Ted Webb from the Department of Health, who is one of the people involved in discussions with deaf community organisations of various kinds about the issues we've been discussing this evening.

Ted Webb

Hello. I would like to thank the Progress Educational Trust for arranging this. When we announced the review of the Act, one of the main reasons was because people in Parliament were concerned that the Human Fertilisation and Embryology Authority was making decisions about selecting embryos. Questions were asked about whether it should be for the Human Fertilisation and Embryology Authority, or the patient, or the patient and doctor in culmination, to decide what is a serious condition. All those issues are now going forward again in relation to this debate. So, this is an opportunity for Parliament to look at these issues, and decide what it should say in the Bill – whether to have certain criteria that makes this more specific, or leave it as it is.

I also want to reiterate something that some people have said, which is that this provision in the Bill is there to give patients the choice to have embryos tested for serious conditions. It's not forced on patients. If deaf people want to have a child through IVF, they can do. You can have a child through IVF; there is not a requirement to screen. So it's there for somebody who does want to screen their condition.

It's right that Parliament should be aware of this and the points that come out. We've been listening very carefully today, and we'll see what comes up in the next few months when Parliament debates this important issue.

[Break]

Harry Collins

This is a question about a couple of the arguments I heard, one from Steve Emery and one from Colin Gavaghan. Steve Emery's was an argument about deaf community and culture, but it seems to me an argument simply from that point would apply equally if a hearing child was born to a deaf couple. It might be proper then to deafen that child in order to preserve the culture, and I wondered how logically that argument worked. Then for Colin Gavaghan, he argued there was a philosophical mistake being made because it wasn't a question about whether the child should be born deaf or hearing, but a choice about whether that child should be born at all. It seems to me, if you

are making a choice about an embryo, you are also making a choice not to have another embryo implanted. Therefore it seems you are inevitably making a choice about the non-birth of a child, so the philosophical argument seems fallacious.

Graham Turner

Can you identify yourself and if you are representing an organisation.

Harry Collins

I'm only representing myself, but I'm a professor at Cardiff University. My name is Harry Collins.

Steve Emery

Thank you very much for that question. I would like to clarify my argument, which is I think nature should take its course, whether a child is born deaf or hearing. But there is a value in deaf people and a value in hearing people. Most deaf couples actually bear hearing children, or if you have a mixture of deaf and hearing couple, they often bear hearing children. And I think the media has confused two issues here – the issue of requiring or wishing to have a deaf baby, and the issue of creating a deaf baby. Those are two separate issues. I think wanting a deaf baby, valuing a deaf baby, a small percentage of people who may really wish for that to happen will celebrate the birth of a deaf baby. There is a value in that child born deaf, but creating a deaf baby is not the issue and nobody is talking about wanting to create a deaf baby. What we're talking about is it's a natural thing that some are born deaf some are born hearing.

Colin Gavaghan

I entirely agree, and I recognise that choosing to implant a deaf embryo means not implanting a hearing embryo. Equally, implanting a hearing embryo and not a deaf embryo. In neither case can I identify any party harmed by that choice. Unless we see the embryo as a kind of entity that could be harmed by being rejected, I know some people hold that position. It's not my position. My position is whatever choice is made, either way it's difficult to identify who is harmed by that choice. If the deaf child is born, the life is worth living. If a hearing child is born, the hearing child has a life worth living. No one is harmed either way. In that way, the government doesn't have a legitimate interest in making that decision for people.

Maggie Gregory

Hi, I'm Maggie Gregory.

Graham Turner

One question.

Maggie Gregory

This question is mostly for Colin. Has any account has been taken of the United Nations Convention on the Rights of Persons with Disabilities, which received its twentieth ratification on 3 April? That then triggers the entry into force of the Convention and Protocol 30 days later. This is a major milestone in the effort to promote, protect and ensure all human rights and fundamental freedoms. Surely this is something which is going to cut right across Clause 14 4(9)? I wonder if Colin has a point on that?

Colin Gavaghan

I entirely see your point, but there is no recognised legal right in terms of the kind of thing you are talking about to have access to this kind of technology, IVF or PGD. Reproductive rights are viewed in a negative sense. People are protected against compulsory sterilisation or abortions. It's never been recognised in Europe as a positive right to have access to IVF or PGD. Whilst I share the sentiment, I suspect the legal argument is not going anywhere.

Penny Beschizza

Hello, my name is Penny Beschizza, and my question is about equality in medicine and in the media. There has been clear discrimination in the media when we're looking at deafness. The Stop Eugenics group has helped me to gain confidence to write to the newspapers and challenge what they talk about, and what they say about Paula Garfield and Tomato Lichy as well. This is an issue that needs to be raised, and it is related to IVF and compatibility. I think it has an effect on people's attitude, and I don't feel it has been professionally expressed by the media at all. When you look at disability in race groups, you can see really clearly when there is racial discrimination, and I think this hasn't been picked up as a discrimination issue from the media as yet.

Robert Adam

My name is Robert Adam, I am from London and I am very interested in listening to the debate and arguments and points today. Deaf people have a right to marry each other. Deaf people and hearing people have a right to marry each other. There are many deaf people who come from a deaf family who marry another deaf person who comes from a deaf family. There is a high percentage chance of them bearing a deaf child. So where does the law come into this? What about this freedom in choosing your own partner, and therefore you may end up having a baby? If you have a deaf person from a deaf family or a couple from deaf families, then of course they have a right to choose to be married and then to bear children.

Marcus Pembrey

Good evening. I'm Marcus Pembrey, a retired clinical geneticist. Because I worked for many years as a medical geneticist, obviously the medical model as it were, or working within that, is really where I come from. The first thing to realise is that PGD is a medical act. It has to be regulated, under some sort of registration and so on, as a medical act. It is also an act tied in with clinical genetics. And there was a lot of discussion in the past about the goal, the purpose of clinical genetics. My predecessor at Great Ormond Street in the 1960s and 1970s thought that the object of genetic services was to reduce the birth incidence of people with genetic disorders. But there is a problem with that definition, because it is the couples who come to you who make the choice, and in fact the goal of medical genetics is to help families with what they perceive to be a genetic disadvantage, to live and reproduce as they wish. The phrase 'reproductive confidence', which is in the title of this debate, was a phrase I introduced to try and explain what the positive side was of offering genetic testing, and of offering prenatal genetic diagnosis initially, and now preimplantation genetic diagnosis. Clearly, families where there wasn't an opportunity to select an embryo through PGD or prenatal diagnosis would just have to stop having children, rather than in their view bringing children to suffer in various ways, I'm not just talking about deafness here. And therefore it is appropriate to offer this restoration of reproductive confidence to those adults as part of medical practice. I make no objection to operating in a medical environment, and they are free to come for help or not and if they don't come and they don't want to have the test, they don't have to have it. So, I support the Human Fertilisation and Embryology Bill in virtually every aspect, but I do feel that Clause 14 could be improved in various ways. But overall, I think the intention is correct.

Sylvia Simmonds

Hello, my name is Sylvia Simmonds, I am from the British Deaf Association. So many thanks to the speakers we've had today, this the very first time we've had such an opportunity for the deaf community to engage in this type of debate. Now Parliament is actually discussing this and will make the decision, and I think it is very sad that in five months' time, we may find ourselves in a position where our views are no longer being heard. There has been no consultation in British Sign Language, it's all been consultation in English, and I have some concerns about that. So my request to the Department of Health: will you please have an extension, so the deaf community can be properly consulted in the way that we should have been? Again, I'd like to thank the geneticist and other professionals we have here today, for coming and talking to us and sharing their views. My question is, who decides about having deaf children or any child? This is a one-off event, but where are the other people who aren't here? This may seem like tokenism. There are very few deaf people here, because it's a very small event. Where will everybody else's views be heard? Will the Department of Health consider an extended consultation, so that we can raise these issues with Parliament directly – how we feel on the subject, and some of the issues we'd like to raise?

Ted Webb

I'm afraid the timetable for the Bill is not in our control, it's a Parliamentary process. With hindsight, perhaps there was something we could have done earlier in the consultation. But as I said before, this is the opportunity now, to get in touch with Parliamentarians. There are a number of months before debate will take place. So I would say, get in touch with MPs, write to the ministers, and make your views known. It's really MPs who need to make the decision.

Richard Jones

Hello, my name is Richard Jones. I would like to thank the Progress Educational Trust for allowing this debate to happen today, and thank you again to the speakers for bringing this to us. I feel a little bit relieved from what I've heard, I feel like I've understood a bit more. It's certainly a slippery slope, and hasn't necessarily engaged the deaf community, and I think it's great to have people here to talk about this, for us to have a greater understanding. Where there are families who have genetic deafness, or where there are families who may have heart disease and decide to check for, say, heart disease and deafness, and they say 'right, we have some – we have heart disease and deafness in our families'. What happens then? Do we have to choose between what we get tested for? And what if we choose to, say, have a hearing child with heart disease over a deaf child with no heart disease? Can you test for everything in every baby you are testing, and is every baby tested for everything?

Anna Middleton

I can respond to that. At the moment, PGD is only offered for single conditions. So if you were concerned about a family history of early onset cancer or heart disease, say, and wanted to have PGD for that, then you could have that single condition tested for. And if by chance all the embryos happened to be deaf, that's okay. That's not being tested for, so you could still have them implanted.

Richard Jones

What if deafness shows up?

Anna Middleton

If that's not what you are testing for, you wouldn't know. Do any genetics people want to add anything?

Betty Trujillo

Hello. My name is Betty Trujillo, Islington Deaf Campaign. Thank you for giving us the opportunity to come here today, because I was a little disappointed that there weren't as many deaf people contributing. I have tried to maybe have a deaf contributor, more deaf contributors would have been helpful, to talk about Clauses 14 and 8. We've talked about Clause 14, but missed out Clause 8. Medical power. There is no medical power. I'm concerned about that. The letter says that it is a guidance policy from the Human Fertilisation and Embryology Authority. But it is very powerful. And we need the parents, not the HFEA, to have the power. So Clause 8 is very important as well. People need to wake up. That's it. I would also like to thank Liberty, they have written an 11-page letter which supported us, and copies of that are on our website. So thank you for that to them.

Susan Daniels

Susan Daniels, National Deaf Children's Society. I think it's disingenuous to say that you may have the choice. If a couple have a very, very serious genetic condition in their family and have three embryos with a heart condition, and three embryos that are deaf, what does the Department of Health say in terms of embryos that have to be reimplanted?

Ted Webb

I'm not sure that scenario would exist, because if deaf people wanted to have deaf children, why would they have PGD?

Susan Daniels

If they want to screen out for the heart condition.

Ted Webb

So PGD would be for the heart condition, and therefore the deaf condition wouldn't come into it. The PGD would spot the heart condition, not the deaf condition. And if they had PGD and the embryo was for a deaf condition and that was spotted, then they could choose to have the deaf embryo, because there is no question of preference. So I hope that helps. Thanks very much, but we have a train to catch.

Deborah Casey

Hi, my name is Deborah Casey. I am from South Wales. I have got three children – two deaf, one is hearing. It doesn't affect the hearing child at all, and it doesn't affect the deaf children. They're all fine. Why do I have to choose? It's crazy. Why don't we just allow Mother Nature to take her course?

Gareth Foulkes

I'm Gareth Foulkes, and like Deborah, I am also the deaf parent of a deaf child. It is also worth mentioning that I used to be married to a deaf lady who had cystic fibrosis. So I have some experience of severe terminal genetic conditions. One thing I'd like to say though, is that it's so difficult to place a value on somebody, whether they've got cystic fibrosis or whether they're deaf. Because my late wife was very successful, she contributed to the economy, she had her own business, she was an artist and she contributed to the enjoyment of people across the UK. And I have come to the conclusion that it is a child's postcode that is more relevant to their life outcomes than their genetic code. It is the families they're brought up in. It is not the genetic makeup that is the crucial factor.

Rachel Belk

Hello, my name is Rachel Belk. I was one of the genetic counsellors mentioned by Anna. I would like to make a broader point, but it is linked to the debate, and that is really to thank my deaf colleagues that I work with in Manchester and the university, for what I've learned about deaf culture over the last few years. My broader point is related to what Ted Webb said. My worry about his point that this had been put into the Bill so it could be debated in the Commons and in the Lords is that individual MPs and members and Lords, individual members of Parliament, don't have – haven't had – the opportunity to learn about deaf culture. My worry is that you can write to your individual MPs and try to argue your case, but the community is doing a fantastic job of becoming more visible and showing the beauty of sign language. And I think it is that long-term process that needs to continue, so that people become more visible, and so that the Houses of Parliament – that are entirely hearing, with the odd 'deaf with a small d' Member of Parliament – have a deaf voice. So perhaps something more concerted, that shows people more about the deaf community and deaf language, is what's needed to get the message across to Parliament. What I wanted to say as a genetic counsellor is we can learn as individuals, and I would be confident that my colleagues – we spend our career trying to put ourselves in place of the person who's coming to see us, and understand things from their perspective. So I hope I would be right in saying that the person you are seeing if you went for genetic counselling would be doing their utmost to understand things from your perspective. But I think it's broader society that needs to understand the point.

Graham Turner

Thank you. Even if this is the most contentious contribution of the day, this will be the last question or comment from the floor. Okay.

Jeff Brattan-Wilson

Now the pressure is on, because I'm the last person. My name is Jeff Brattan-Wilson, and I have obviously been thinking about this a lot – deafness, deaf genes, the language barrier, and the problems deaf people have finding jobs. It's all about deafness and how awful deafness is, but in Britain we have a law that looks after black people and Asians through the Race Relations Act at work, at school, and with discrimination within the family. But there is still racial discrimination at work, there are still tribunals, still areas where white people get jobs and black people don't

get jobs. Women, gay men, lesbians, lots of different minorities. But deaf people seem to be off the agenda. You know, if a black couple want a black baby, people wouldn't force that child to be white. They want a black child, so they can pass on their culture. But with a deaf person who wants a deaf child, they say 'oh, you don't want them to be deaf, you can't get a job, can't do this or that'. What's the difference between a black person wanting a black baby, and a deaf person wanting a deaf baby? What's the problem? There isn't one.

Graham Turner

Thank you very much for that last comment.

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