Special Section: Open Forum

Choosing Deafness with Preimplantation Genetic Diagnosis: An Ethical Way to Carry on a Cultural Bloodline?

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Introduction

> Consider the theoretical possibility of screening to ensure that only a disabled child would be conceived. This would surely be monstrous. And we think it would be monstrous because we do not believe it is just as good to be born with a disability.

These words were written by ethicist Jonathan Glover in his paper "Future People, Disability and Screening" in 1992.[1] Whereas screening and choosing for a disability remained a theoretical possibility 16 years ago, it has now become reality. In 2006, Susannah Baruch and colleagues at John Hopkins University published a survey of 190 American preimplantation genetic diagnosis (PGD) clinics, and found that 3% reported having the intentional use of PGD "to select an embryo for the presence of a disability."[2] Even before, in 2002, a controversy was generated by the case of Candace A. McCullough and Sharon M. Duchesneau, a lesbian and deaf couple from Maryland who set out to have a deaf child (then, Gauvin) by intentionally soliciting a deaf sperm donor.[3]

The whole debate on using PGD in order to choose what kind of children to bring into the world has been monopolized by the discussion of the different notions of "disability" and by the related topic of the treatment–enhancement distinction. In this debate, different definitions of "disability" seem to imply different normative judgments about parental reproductive choices.

I here adopt a different perspective, as I shift the debate from the level of "disability" to that of "impairment." Indeed, I take as premises the definitions of "disability" and "impairment" given by the social constructivist scholar Michael Oliver and contend that it is still possible to claim that choosing deafness with PGD is morally wrong, without claiming that deafness is a disability.

I frame the issue in terms of justice toward the future children and limitation of a reasonably broad array of different life plans. I also support my view in terms of the balance between self-determination of parents within their sphere of reproductive freedom and their determination of future children.

In the conclusions I mention the regulatory issue and some consequences of a consistent application of my line of reasoning.

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Different Regulations

Deafness is the most common sensory disorder, present in one of every 500 newborns. With almost 50 genes implicated in nonsyndromic hearing loss, it is also an extremely heterogeneous trait. The most frequent genes implicated in autosomal recessive nonsyndromic hearing loss are GJB2, the gene for connexin 26 (Cx26), followed by SLC26A4, MYO15A, OTOF, CDH23, and TMC1. A Cx26 mutation can be detected in ~30% of sporadic cases of prelingual hearing impairment. The likelihood of detection of a Cx26 mutation increases to more than half of the families with identified autosomal recessive transmission. Up to 95% of deaf children are born to parents with normal hearing.[4]

Countries have adopted very different legal approaches to the regulation of PGD. The United States has no federal regulation at all, but PGD issues are regulated by professional standards. In Canada, apart from a prohibition against nonmedical sex selection in the Assisted Human Reproduction act, regulations regarding the use of PGD are yet to be promulgated. In Australia, PGD is regulated partly by state legislation and partly under the National Health and Medical Research Council guidelines on the use of assisted reproductive technology (NHMRC ART Guidelines).[5] Europe is very heterogenous in this respect, as laws range from prohibitive (PGD is not allowed in Germany, Austria, Ireland, and Italy) to restrictive (where PGD is permitted only in cases of screening for disorders or in cases of tissue typing, as in Scandinavian countries, Spain, Belgium, and France). The lack of harmonized regulation at the European level has resulted in an increasing number of couples crossing borders seeking PGD.[6] The U.K. approach is certainly the most liberal, as PGD is allowed also for tissue typing and for screening for disease susceptibilities. In the United Kingdom, PGD is licensed by the Human Embryology and Fertilization Authority (HFEA) for around 50 conditions, including cystic fibrosis, familial hypercholesterolemia, blood disorders such as thalassemia and hemophilia, muscular dystrophy, deafness, achondroplasia, Down syndrome, Huntington's Chorea, X-linked mental retardation and other X-linked disorders, and so forth.[7]

In spring 2008, the debate on choosing children with a "disability" surfaced again in the United Kingdom on Clause 14(4) (9) of the draft Human Fertilization and Embryology Bill, which stated that "embryos" known to have a genetic abnormality "with a significant risk of transmitting a serious mental or physical disability, serious illness, or any other serious medical condition . . . must not be preferred to those that are not known to have such an abnormality."[8] A petition was filed to drop the clause 14(4) (9) of the HFE bill, and was rejected on August 20, 2008, on the ground that "[i]t is in the best interests of the child not to prefer embryos that have a significant risk of developing a serious medical condition."[9] The still ongoing debate revolves around the interpretation of the clause and its relevance for the deafness case, because, according to one interpretation, it could imply that a deaf couple undergoing PGD would not be able to choose embryos carrying a gene associated with a genetic hearing impairment.

The Impairment–Disability Distinction

Do we need to define "deafness" as a disability to argue that it is morally wrong to choose deaf children with PGD? And do different definitions imply different normative judgments about the ethical acceptability of parental choices regarding genetic traits?

I will try to provide an answer to the first question and make some suggestions relevant to the second one.

There are several notions of disability: a purely medical definition such as the one given by the World Health Organization (WHO),[10] a purely social definition such as the one formulated by Michael Oliver,[11] and a "harmed-condition" account of disability by John Harris.[12] In this paper I do not want to argue in favor of a particular notion of disability, but I will take for granted a particular notion and then shift the discussion to the level of "impairment." As also Jonathan Glover has recently argued in his book *Choosing Children. Genes, Disability and Design*, it is time to abandon the "unfruitful" disability debate.[13]

On the one hand, "disability" is defined as the possible functional consequence of impairment (e.g., inability to hear certain sounds or inability to speak clearly).[14] This definition is close to the commonsense notion of disability and impairment. In what follows I adopt a more philosophically elaborated one, namely, the definition given by Oliver, the main theorist of the social model of disability, which does not refer explicitly to any notion of "normality."

On the other hand, the 2001 revision of the WHO's International Classification of Functioning, Disability and Health defines "impairment" as "an abnormality of a structure or function of the body" that can be congenital (present at birth) or acquired, through disease or trauma.

According to the definition by Oliver, impairment is "lacking part or all of a limb, or having a defective limb, organ or mechanism of the body" whereas "disability" is defined as "the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities."[15] Therefore, impairment has to do exclusively with the body; disability also necessarily involves other factors.

As defined by Oliver, impairments often result in disabilities, but need not. A disability is inherently relational: being disabled is being unable to do something, to perform some significant range of tasks or functions that individuals in some reference groups (e.g., adults) are ordinarily able to do.

How do these notions of "disability" and "impairment" relate to the deafness case? Being deaf in a deaf community is not a disability understood in these terms, but is still an impairment. In other words, one can have a physical impairment without being disabled, for example, a person in a wheelchair living in a town devoid of architectonic barriers. For this reason someone's ethnicity (e.g., being Black) is not a disability under a social constructivist approach, precisely because all its disadvantages are socially imposed.

In what follows I argue on the basis of Oliver's definition and contend that it is still possible to claim that choosing deafness with PGD is morally wrong.

Deafness as a "Variation"?

Empirical research suggests that deaf people often have a degree of preference for a deaf child, and a rather smaller number would consider acting on their preference with the use of selective techniques.[16] It turns out that such parents do not view certain genetic conditions as disabilities, but as a passport to enter into a rich, shared culture. They see being deaf as defining their cultural identity and sign language as a sophisticated, unique form of communication. Parents contend that not hearing is just a form of human variation, as being Black or gay, and that one that has given rise to a culture of its own, with members who want to see their community continuing into the future.[17]

Darshak M. Sanghavi, a pediatric cardiologist at the University of Massachusetts Medical School, wrote in favor of their reproductive freedom:

> Controlling a child's genetic makeup, even to preserve what some would consider a disease, is the latest tactic of parents in an increasingly globalized society where identity seems besieged and in need of aggressive preservation. Traditionally, cultures were perpetuated through assortative mating, with intermarriage among the like-minded and the like appearing. . . . Viewed in this context, the use of PGD to select for deafness may be merely another ritual to ensure that one's children *carry on a cultural bloodline*. (italics mine)[18]

According to deaf parents, deafness is a condition that opens up as many and as valuable options as it closes down. In this sense, they argue, deafness is analogous to "Blackness," as both minorities suffer socially imposed disadvantages because of their condition. The analogy goes on to say that, as deaf people, also Black people, on average, do worse than their White (hearing) peers, but (according to the parents) due to social discrimination, not to their skin color (hearing defect).

But is it plausible to claim that not hearing is just a variation as being Black or gay? I contend that it is not, on the ground that deafness (and not Blackness) is an impairment that limits a broad array of different life plans, independently of the societal context.

Let us, then, imagine how Oliver's definitions would be applied if we were in a very advanced and nondiscriminatory society. Of course, it is true that different shades of disability could go with certain impairment, depending on the social context, but the hearing impairment would still be limiting the person in some activities even in the most advanced societies, whereas the social constraints imposed on other kinds of minorities (e.g., Black or gay) would vanish because they are completely socially determined. Thus, under Oliver's account, being deaf would still be an impairment in any kind of society, because of the underlying asymmetry of this trait.

Therefore, even accepting a social constructivist model of disability and defining deafness as an impairment that does not necessarily go with a disability, the question remains whether it is morally wrong to choose children with a physical impairment.

Let us elaborate a bit more on this and think of two groups of people in an ideal society with no societal barriers toward deaf people: the only differences between the two groups would be that one group can hear and the other cannot and that one communicates with sign language and the other with a verbal, spoken language. Notwithstanding what the prospective parents assert on this point, the relationship between the two groups would still be asymmetrical, because hearing people could be part of the "shared and rich" deaf culture by learning how to communicate with sign language, but not vice versa.[19] Of course, to this it can be objected that being born genetically deaf is not the same thing as learning to be deaf and learning the sign language. I can concede this point, together with the point that the deaf culture may have its compensations that hearing people cannot fully experience, but the fundamental point here is that deaf parents do not need to choose to exclude their children from the hearing world in order to include them in theirs (however, imperfectly include them, as parents may counterargue), because both worlds and languages are open to their children: both the hearing and the not hearing worlds, both the verbal and the nonverbal languages.

Sanghavi also wrote that "[t]he small number of PGD centers selecting for mutations doesn't bother me greatly. After all, even natural reproduction is an error-prone process. . . . I've learned to respect a family's judgment. Many parents share a touching faith that having children similar to them will strengthen family and social bonds. . . . But it's not for me to say."[20]

While conceding that parents have good intentions concerning the future of their children, is it tenable to claim an equivalence between natural reproduction being an "error-prone process" and deliberately choosing to have a deaf child with PGD? And, if it is not for Sanghavi or for the discretion of individual practitioners to decide (and I agree with him on this point), does it follow that it is for nobody to decide? In other words, is there still ground to argue that parental reproductive freedom should be regulated?

It is now time to go back to the question posed by John Harris:

> Some apparently decent deaf people do in fact wish their children to be deaf like them and resist therapies to improve the hearing of their children. They suggest that there is a distinctive deaf culture which is in some senses better than that available to those with hearing. Perhaps the test here is whether or not we would feel a deaf parent justified in *deliberately* taking steps to ensure that any future child would be conceived with deafness genetically guaranteed in order to ensure that it had secured to it the benefits of deaf culture. (italics mine)[21]

Because this thought experiment by Harris has become reality in some PGD centers in the United States, I will attempt to answer this question on the basis of three main arguments.

Why It Is Morally Wrong to Choose Deafness with PGD

Framing the issue in terms of justice toward the future children avoids not only the thorny discussion of what a disability is but also the related and somewhat underlying discussion of the treatment–enhancement distinction. Such a distinction has been strongly criticized[22] and forces us to treat relevantly similar cases in dissimilar ways, by making some "morally arbitrary" ad hoc assumptions. As Buchanan and coauthors also argue, such a distinction should not play a moral role, because it is useless in helping us to draw both an obligatory/nonobligatory boundary and a permissible/impermissible boundary.[23]

In our society, there is a presumption in favor of not interfering with parents' decisions, and they are allowed a big degree of discretion in choosing what is good for their children (e.g., education, religion).[24] Some scholars argue that, indeed, it should not be so (and parents should be licensed by the state, as it is required from people applying for an adoption).[25] More recently, other scholars have made the less extreme case for compulsory parental education.[26]

Reproductive freedom is one of the fundamental rights of the person and finds its justification (at least in part) in the democratic presumption.[27] According to this principle, citizens should be free to live according to their own values, and the state should not interfere with their freedom unless there is a direct danger to other citizens or to society in general. To note, it is not sufficient that other people disagree with the choices of a person or find her values "fastidious" or "disgusting" for a limitation to freedom; otherwise all our fundamental freedoms of speech, expression, religion, sex, and reproduction would vanish together with the very concept of democracy.

This said, I believe that in case of parents choosing deaf children with PGD, the condition of a "direct danger to other citizens" (i.e., future children) is satisfied, and the state (through some authority such as HFEA in the United Kingdom) could, and indeed should, interfere with the parental reproductive freedom. The direct danger to the children would be the restriction of a broad array of possible, future life plans due to deafness. The extensive character of the hindrance makes the case for the limitation of the democratic presumption and therefore of the reproductive freedom, whereas it does not make the case (other arguments would be needed to support such a claim) for limiting parental freedom in more general terms.

Along lines of reasoning similar to those by Buchanan and coauthors, I believe that a certain degree of neutrality must be expected from parents toward different conceptions of the good for their children.[28] Parents, *qua persons*, can, of course, have a particular conception of the good and lead their lives according to it (which brings us back to the democratic presumption), but parents, *qua parents*, should maintain a certain degree of neutrality toward different conceptions of the "good" for their children. In other words, parents should not be allowed to make their children suitable for only one particular conception of a good life that the parents happen to have, such as the conception of the rich and shared culture of the deaf community. Any intervention that would greatly restrict this range of choices, as a hearing impairment would do, would be unjust to the child.

Finally, the notion of "self-determination" is one of the values that determines the moral importance of reproductive freedom (together with individual well-being, equality of expectations, and opportunities[29]). *Self-determination* can be understood as the interest in making significant decisions about one's own life for oneself, according to one's own values and conception of a good life. John Rawls has characterized this interest as based on people's capacity to form, revise over time, and pursue a plan of life and conception of the good.[30] This said, the impact of peoples' actions on others (i.e., future children) must be understood as a competing moral consideration that can, and must, place a limit on self-determination and, therefore, on reproductive freedom. Shaping the nature of children is not primarily a matter of individual self-determination but as well, and more importantly, the determination of another.

To note, I am not questioning here the motivations of the parents reported and interpreted by Sanghavi.[31] Such parents may all have good intentions—and thinking to choose "the best" for their children—when choosing to have a deaf child, but considerations of justice suggest to us that parents should not maintain their currently accorded discretion toward such broad scope capabilities such as hearing, because this means to determine the lives of others.

Of course, I am aware that an important problem of threshold is looming in the background here, namely: Where should the threshold be set, and when could reproductive freedom be limited, on the basis of justice considerations and the limitation of a reasonable array of different life plans?

The discussion of where to put the bar would lead us to the above mentioned debate on compulsory parental education and parental licensing, which I can only hint at in this paper. Nevertheless, I believe that the deafness case is not a borderline case and that it can be successfully argued in favor of limiting parental reproductive freedom.

The Social Construction of Impairment

So far, my arguments were based on the definition of disability and impairment given by Michael Oliver.

Some scholars, such as Philippe Cole, could object on the basis of the more radical claim that impairment also is socially constructed.[32] Cole argues that disability arises always in a particular social context and that the "social structure + impairment" cause the disability. So far, I could agree with him. But then he goes too far, as he wants to take one of the two factors (namely, impairment) out of the causal relationship that gives rise to disability, and leave all the blame on the social structure. To claim this he stretches his arguments to the point of writing: "Certainly, the disability is the product of the interaction between bodily impairment and social context, but it is the social context that gives the action or ability its form and context."[33]

In the end, Cole concludes that "it is the political idea of disability that determines what counts as bodily impairment," because persons wearing glasses (as do Cole, long-sighted, and myself, short-sighted) to correct some minor eyesight defect have an "eyesight that is impaired to some extent" (at least he concedes this point!) but we "would not want to describe them as bodily impaired."

Why not? We could reply (and Philippe Cole would probably object something along these lines) that it is so because there exists something so simple and readily available as wearing glasses to correct the minor eyesight defect, and there is no need to use the power of thought to correct it. So, from one point of view, we (people wearing glasses) are "impaired," but from another (and the only one relevant, according to Cole), we are not. Who chooses the relevant point of view, or what makes it relevant? Indeed, Cole proceeds and spells out the reasons why this is so, namely, that from a "purely philosophical approach": "There is no good reason why a defect in eyesight should not count as bodily impairment, but politically, there are very good reasons why it should not count."[34] These "very good reasons" are taken for granted to a good extent.

I would like to remark on two points touched upon by Cole that are useful for the discussion of the deafness case. The first revolves around the issue of the normativity of definitions. Cole aims at defining "deafness" or "blindness" as "something less than an impairment," as a "mere inability," with the purpose of deriving a normative judgment about the permissibility of making some kinds of parental choices or of society adopting certain kinds of policies. But the derivation of ethical prescriptions from a definition cannot be taken as straightforward, as it would need to be justified and argued for. As a consequence, we can decide to accept Cole's point that under some circumstances deafness is not an impairment, but from such a definition no ethical judgment of PGD screening permissibility would be automatically derived.

This brings us to my second and more general remark, namely, that I do not think it is necessary to define "deafness" as disability or impairment or inability to infer some kind of ethical judgment on the parental choices. We can still reason on a case-by-case basis, even if some kind of broader, normative definition that could be applied to different cases (e.g., blindness, deafness, dwarfism) would be useful. But, to repeat, it is not necessary to possess such a kind of normative definition to claim that choosing deafness with PGD is morally wrong.

Indeed, it can still be argued that it is wrong to choose deafness with PGD even if it is not an impairment on the ground that there is an underlying asymmetry and that not hearing is a broad limitation of the future child's life plans (as I did in the previous paragraph) or on the basis of other arguments (e.g., an "impersonal concept of 'harm'" as developed, among others, by Buchanan and coauthors to deal with "non-identity" problems such as this one[35]).

As for the consequences of my line of thought concerning parental freedom in molding the nature of their children, I cannot dwell on them here, but I will at least mention this issue in the concluding paragraph.

Conclusions

In this paper I focused on the existing case of parents choosing to bring deaf children into the world with PGD screening.

The discussion concerning the moral acceptability of choosing deafness with PGD has been traditionally framed in terms of disability and of the treatment–enhancement distinction, without reaching any satisfying conclusion on either side of the debate. I here abandoned such a loaded perspective, shifting the debate from the issue of disability to the more objective and less controversial issue of impairment.

I took for granted the definitions of "disability" and "impairment" given by the social constructivist scholar Michael Oliver and showed that it is still possible to claim that choosing deafness with PGD is morally wrong, without contending that deafness is a disability.

I framed the issue in terms of justice toward the future children, as I argued that choosing deafness with PGD is unjust toward them because it is a broad limitation to a "reasonable array of different life plans." I also supported my view in terms of the balance between self-determination of parents within their sphere or reproductive freedom and their determination of future children.

As defined by Oliver, deafness remains an impairment, even if in some societies, and in deaf communities, it may not count as a disability. Parents who choose to impose on their children their idiosyncratic vision of the good, in terms of the richness of the deaf culture, are acting unjustly toward the future child, who should have a sufficiently large array of opportunities to decide on her own what is good for her later in life. Moreover, the advantages of being part of a deaf community are asymmetric, as also a hearing person could learn the sign language and be part of it (even if only "imperfectly," if we concede this point to the deaf parents).

To those scholars, like Philippe Cole, who view "impairment" as socially constructed, I replied that we could abandon the quest for a normative definition valid for several traits (e.g., deafness, dwarfism, blindness) and reason on a case-by-case basis. In other words, we can decide to call deafness just "deafness": Is it or is it not "not being able to hear"? If we agree on this, then we should agree that it is a limitation on the future of the child, and not a minor one, as it is a general hindrance for a vast array of plans of life. It is obviously not the same thing as "being Black/White/boy/girl," contrary to what the parents assert, as being deaf is an asymmetrical condition in respect to hearing, and even the most advanced and nondiscriminatory societal context would not abolish the limitations of this trait.

What are the consequences of my claim? Should parental reproductive freedom in terms of PGD choices be regulated from a legal point of view?

What about parental discretion for other kinds of choices? Where should the threshold be put, if we decide that one has to be put (as I argued)? And who decides?

I cannot here respond fairly to these complex questions and will only suggest two possible directions to elaborate in the future.

For what concerns regulation, the issue here is subtle and manifold: As Sanghavi has rightly noticed, in the past people were mating the "alike" (physically and mentally) to have children like them. I believe this kind of reproductive freedom should not be constrained, as we do not want to live in a paternalistic society where deaf couples are discouraged from having children for the "good" of future generation or for improving the gene pool, as was done with forced sterilization back in the old eugenic times. Somehow different is the case of the lesbian couple who seeked a deaf donor to have a very high probability (although not a certainty, because of the heterogeneity of the trait) to have a deaf child, as Candace and Sharon McCullough did. Can this still be considered a kind of assortative mating? I doubt it.

The case is even more straightforward for those parents who choose PGD to be "sure" (medical errors not considered) to have a deaf child. Unlike Sanghavi, I do think that there is a morally relevant difference between the natural errors of reproduction and the intentional choice to have a deaf child. This morally relevant difference makes the case for the justified natural assortative mating, but it does not make it for cases of PGD screening for deafness or of couples soliciting a deaf donor.

Who would be entitled to limit parental reproductive freedom? Sanghavi does not feel entitled to choose, and I agree with him on this point. Such a decision should not rest on the shoulders (and discretion!) of individual practitioners. Exactly for this reason the U.S. system of having unregulated PGD clinics and complete nondirectiveness in genetic counseling should be modified. Other countries have developed different institutions to regulate such issues, as the HFEA in the United Kingdom.

As for the consequences of a consistent application of this line of thought, I am willing to accept them. This is to say that, in a different paper, I would argue in favor of further limitations on parental discretion concerning other kinds of interventions (not necessarily genetic) that could limit a reasonable array of different life plans of the future children.

Decisions in terms of education (e.g., parents belonging to the Amish community requesting to withdraw their children from school at 14 years, 2 years before the normal age limit for compulsory education[36]), religion (e.g., should parents be allowed to impose compulsory Catholic education on their children, as is still common practice in Italy?), and healthcare (e.g., Jehovah's Witnesses opposing blood transfusions) could fall within those that need to be regulated.

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