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<https://doi.org/10.1057/s41599-021-00795-w>

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Genome editing and ‘disenhancement’: Considerations on issues of non-identity and genetic pluralism

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In the decade prior to CRISPR-Cas9, Michael Parker criticised Julian Savulescu’s Procreative Beneficence (PB) Principle by arguing against the confidence to know what’s best in terms of genetic traits for our offspring. One important outcome of this criticism was a greater moral acceptance of deaf people genetically selecting deaf children. Although this outcome may have been morally controversial in an impersonal harm context, in such genetic selection (PGD) cases, a deaf child is not harmed in person-affecting terms because no other life is available to that child. We highlight that the person-affecting versus impersonal harm distinction is still held by many as making a significant moral difference to their overall argument (i.e. Savulescu, Parker, Boardman, De Miguel Beriain) and so for the purposes of this paper, we will assume it makes ‘some difference’ (even if only at the level of the message it sends out). Insofar as one considers the presence person-affecting harm to be morally important (and to whatever extent), the impersonal harm context in which the Parker-Savulescu debate arose thereby blunts an arguably even more radical outcome—that of genetically engineering, or gene editing, deafness into pre-existing embryos of future children. Now, the potential of CRISPR-Cas9 has revitalised such debates by reframing impersonal and person-affecting benefits/harms in the context of such disputes on the harm or not of a (chosen) disability. Replacing the genetic selection context with a genome editing context, we argue that Parker’s argument should also deem it morally acceptable for people who are deaf to genetically edit embryos to become children who are also deaf. Felicity Boardman’s recent comments suggest a similar radical potential as Parker’s, with the radicalness also blunted by an impersonal context (a context that Boardman, at least, sees as significant). We conclude that the genome editing reframing will push such arguments beyond what were originally intended, and this will create a more radical message that may help further define the relationship between new genomic technologies and disability.

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Introduction

Julian Savulescu's Principle of Procreative Beneficence (2001) had been one of the most discussed and criticised bioethical principles over the last 20 years (more recent versions can be seen in Savulescu and Kahane, 2009 and Savulescu and Kahane et al., 2017). To briefly recap, the principle applies to the moral decisions of prospective parents in the context of in vitro fertilisation (IVF) procedures. It states that:

couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information (2001, p. 415).

Specifically, we should use pre-implantation genetic diagnosis (PGD) for the purposes of selecting the embryo with the genetic traits considered to be conducive to the best life for the future child. Although many genetic influences that can adversely affect the subsequent child may only be of a weak probabilistic relationship (especially when both disease *and non-disease* genes are targeted), there is a choice that is faced by the prospective parents: take their chances with the prospective life of the future child or pick the best set of genetic traits (i.e. embryo) that can be picked with the available knowledge. Michael Parker (2007) has criticised the confidence involved in knowing what is best (or even *better*) in terms of genetic traits for our offspring. One important outcome of this criticism is a greater moral acceptance of people who are deaf genetically selecting to have a deaf child. Although this outcome may have been morally controversial in an impersonal harm context, in such genetic selection (PGD) cases, a deaf child is not harmed in person-affecting terms because no other life is available to that child. We highlight that the person-affecting versus impersonal harm distinction is still held by many as making a significant moral difference to their overall argument (i.e. Savulescu, Parker, Boardman) and so for the purposes of this paper, we will assume it makes 'some difference' (even if only at the level of the message it sends out). Insofar as one considers the presence of person-affecting harm to be morally important (to whatever degree), we argue that the impersonal harm context in which the Parker–Savulescu debate arose thereby blunts an arguably even more radical outcome (or expressed message)—that of genetically engineering, or gene editing, deafness into pre-existing embryos of future children. We outline how the potential of CRISPR-Cas9 has revitalised such debates (Boardman, 2020a, 2020b; De Miguel Beriain, 2020), with a reframing of impersonal benefits/harms of genetic selection (PDG) as person-affecting benefits/harms of gene editing (GE), particularly in the context of (chosen) disability. The move from PGD and selection to genome editing reframes the message from one of removing or keeping (future) people with disfavoured traits to one of removing or keeping disfavoured traits from (future) people. If a trait was argued to be favoured, rather than disfavoured, there should be no problem to move from keeping such a trait to creating this trait where it would otherwise not exist—even if the otherwise same future person would exist. Accordingly, we revisit the Parker–Savulescu debate and replace the genetic selection context with a genome editing context. With this 'genome editing reframing', we argue that Parker's argument is committed to also deem it morally acceptable for people who are deaf to genetically edit embryos to become children who are also deaf, even if the numerically identical future person would have been naturally hearing. We argue that Felicity Boardman's recent comments (2020a, 2020b) suggest a similar radical potential as Parker's, with the radicalness also blunted by an impersonal context (a context that Boardman, at least, sees as significant). We conclude that the genome editing reframing will push such arguments beyond what were originally intended and this will create a more radical

message that may help further define the relationship between new genomic technologies and disability. Our purpose is not to criticise or defend any such 'radicalised' argument, but to argue that those who make them will have to also defend their genome edited reframed and radicalised versions too.

A pluralistic sphere of genetic traits

Parker's overall doubt over the confidence to know 'what's *best*' is the result of a combination of four overlapping arguments (2007). First, he holds that the principle of procreative beneficence is *underdetermining* in that it is hubristic to think that we can select for the 'best' life. Parker invites us to consider our own lives and reflect on how difficult it would be in advance to speculate on what it would have taken to make our lives go well. The principle, Parker concedes, may be useful in identifying *some* things in advance, for example, deafness in an embryo suggests deafness in the resulting individual. But, beyond this we get caught in complex and possibly incommensurable assessments of what is 'the best life'. This might be a difficult question if we compare the two lives at the end, but especially so when prediction is used to direct genetic selection decisions.

Secondly, there is also the question of whether it is *always* conducive to the best life for *every* sub-optimal or potential sub-optimal event to be removed from our lives. Indeed, in light of this, Parker notes that even the concept of the best possible child is *paradoxical*. This is so because the "best possible life is not necessarily and indeed could not be one in which all goes well [nor] one lived by a person with no flaws of character, or of biology." (2007, p. 281) A life in which all goes badly is not what Parker is referring to here, but never encountering any problem in life might not be such a good thing either. A life of ups and downs might have good results both on our character and on our appreciation of what we achieve in life. On another level, it would simply not be a human life at all, if everything was perfect about us.

Thirdly, the quest for perfection may also suggest that the pursuit of the 'best possible life' is *self-defeating*. Parker notes that as we cannot be sure that we are living the best life of all possible lives, the pursuit of the 'best possible' life would be bound to lead to be a never-ending quest to pursue the best life at the cost of forever being dissatisfied with the life that is had. In other words, this very quest might be the very thing that stands in the way of the best life (if such a thing exists) and in the way of any kind of good life at all.

In so far as the actual goal is underdetermining (and paradoxical), so too might be a causal relationship between a given trait and its overall contribution to the quality of the resulting life. This is the final criticism, that Savulescu's principle is overly *individualistic*. Parker notes:

just as conceptions of the good vary between individuals, families, communities, etc, so too will legitimate beliefs about what it means to secure the conditions for the good in particular cases, and this implies that procreative beneficence will generate somewhat different obligations in different contexts. (2007, p. 282)

In so far as Savulescu would attempt to come up with a list of the best traits to select for, it is possible he might risk giving too much attention to a list conducive to a particular conception of the 'best' life. However, different social and political contexts may give rise to a multiplicity of legitimate interpretations of such a conception. While Savulescu has responded to each of these criticisms (2007), it is the implications of Parker's argument itself that we wish to concentrate on for the purposes of this paper.

Although these criticisms suggest that there is divergence from Savulescu in terms of what is *best*, Parker does not, of course, think that nothing can be said in favour of selecting embryos conducive to the possibility of a *good* life. For instance, any alternative to the principle of procreative beneficence would not approve the selection of embryos where the lives of the resulting children are foreseen to be intolerable or, at least, beneath some minimum threshold level of welfare. Nevertheless, it must be appreciated just how broad Parker's divergence appears to be. This divergence can be ascertained by measuring how many embryonic traits it would include within, what might be called, a 'pluralistic sphere', where some traits within that sphere cannot be considered as 'best' when compared to other traits also within that sphere. Moreover, it not only covers the possibly hubristic notion of the 'best' possible life, but the minimal interpretation of Savulescu's principle as well, that is, the ability to *rank* traits as 'better' or 'worse' because they are likely to lead to a 'better' or 'worse' life (2007, p. 281). One candidate, Parker suggests, for possible incorporation into this sphere are certain cases of the selection of embryos which have the best chance of developing into a deaf child. Parker applies this to the case of the American couple who effectively selected for a deaf child—Gauvin (2007, p. 279). He poses the question whether there is any moral requirement for this deaf couple (given their context of a vibrant deaf community) to select for a hearing embryo, any more than a deaf one, so long as overall we are above the minimal threshold (2007, p. 283). Hearing is a trait which may be conducive to a good life, but there is no reason to think deafness will automatically exclude this possibility either. We cannot know for sure that the subsequent life will not be a good life worth living. We might subsequently find out that the individual had an extraordinarily rich life full of love, happiness, cultural attainment and personal fulfilment. The person who is deaf might have a far better life than many hearing people. This is not certain of course, but neither is the reverse. The person may have what is seen by many as a biological flaw, but this is exactly what it is to be human. We all are flawed in some ways and at some times. Finally, as the context is literally a deaf community in the real and not metaphorical sense, then deafness 'fits', just as hearing has been more traditionally perceived to fit in communities at large. Indeed, numerous arguments exist that cast doubt on any simple link between human flourishing and lack of a given disability (Schroeder, 2018; Mand et al., 2009; Shakespeare, 2006; Boardman, 2020a, 2020b).

Nevertheless, it is not unproblematic to say that certain genetic or biological traits are thereby not disadvantaging *at all* and merely a case of pluralistic disagreement (Hull, 1998; de Miguel Beriain, 2020). The value of deafness can be linked to the pursuit of some range of opportunities for the good life but hearing can be linked to the pursuit of those and more. In particular, it is held that such a reproductive choice is against the resultant child's right to an open future (Davis, 2001, pp. 49–67). If so, the resulting child would seem to have a trait that, contra Parker, *can* be ranked lower than a genetic ability to hear. This can be so even though this *ex ante* evaluation of a trait, in itself, does not rank deaf peoples' lives lower than hearing people's lives either in moral worth or 'ex post' evaluations of lives lived well. So, one might object that Gauvin's life *is* harmed in some way and, insofar as this still passes the test for Parker, this might be a reason to say 'so much the worse for Parker's test'.

The significance of the selection context

Of course, this conclusion is not straightforward as the debate between Savulescu and Parker is only within in the context of genetic selection (Savulescu, 2001, 2002; Parker, 2005, 2007). To

fix this in the case similar to that of the actual Gauvin case, we can imagine the following routes that the couple desiring a deaf child might have taken had it been possible for them to do so.¹

Gauvin 1: Sharon and Candy go to an IVF clinic and, with the aid of artificial insemination by donor, create a number of embryos. They use PGD to select for an embryo that has the trait for deafness. This embryo turns out to be Gauvin.

Gauvin 2: Sharon is pregnant with an embryo or early-term foetus which has a hearing trait. She goes to a clinic that performs gene editing with CRISPR-Cas9. The embryo or foetus now has a trait for deafness. The embryo or foetus turns out to be Gauvin.

Gauvin 3: Sharon has just given birth to a baby boy that has the hearing trait. The obstetrician performs an immediate and painless surgery on the ear. The newborn is now deaf and is named Gauvin.

It may be said that the case of Gauvin 3 is a clear-cut case of child abuse and medical malpractice—at least, the newborn could be seen as having been harmed. Insofar as this is the case, there would seem a *prima facie* moral (and legal) difference between the traits of deafness and hearing. If the exact same surgery was undertaken with parental consent, but it was to give a deaf newborn the ability to hear, to say it was harmed would be highly controversial. In the case of Gauvin 2, although we would not call it child abuse, we may still say that the child that the embryo or foetus *will become* has been harmed in a manner akin to the Gauvin 3 case. Gauvin 2 will have been retrospectively harmed insofar as he could have been born hearing were it not for the gene editing at the embryonic or foetal stages.² In line with both these cases, it is plausible at least to suggest, along with Feinberg, that Gauvin was harmed because he is 'worse off than he would otherwise have been' (Feinberg, 1992, p. 7). What is not straightforward is to suggest that there is an identifiable (Gauvin 2 or 3) person harmed (or whose situation is worsened by selecting deaf and not hearing traits) in the deaf selection case (Gauvin 1).

It can be argued that it is clearly a wrong to deliberately cause, or carelessly bring about, a deafening of an existing individual just as it would be wrong to deliberately expose a foetus to the risk of prenatal injury where, amongst other things, deafness could result (Feinberg, 1992; Savulescu, 2001; Parker, 2007; Hope and McMillan, 2003). This argument is problematic in the case of selection because no particular person is harmed when a deaf trait is selected because it is also the embryo, or future person that is selected. Selecting a hearing trait would not have been better for that subsequent child, because selecting a hearing trait means that a different child would have been chosen instead. Gauvin was not worse off than he would otherwise have been because otherwise he simply would not have been. The argument from an open future of the child is also problematic for the same reason. The choice is not between the child having a constrained future and a more open one. This particular child was never going to have a more open future. The only alternative would be no future at all. From this child's perspective, if he or she was to later regret what his or her parents did for him, he or she might be misguided to wish things were different. But, from this perspective, as there was no alternative, no better situation was blocked off by the parents. Hence, whatever the selection, it may be a case that contrary to appearance is worse for no-one. Our moral intuitions that suggest the Parker test problematically allows selections that are worse for the subsequent children must face this non-identity problem (Parfit, 1984, pp. 351–379).

This problem, extensively explored by Derek Parfit, arises from the person-affecting intuition that 'what is bad must be bad for

someone' (1984, p. 363). The problem arises when 'the bad' and the 'for someone' do not cohere as they normally seem to (or should) do. Reflecting on Parfit's risky policy example, take our concerns regarding some of our purported duties to future generations. Suppose we carry on depleting our resources, this may appear to be worse for the generations living in the future who will one day have to live with the after-effects of our depletion policies. However, if we were to change our policies, and adopt a more conservationist route, it would not just change the environment for the better. Such changes in lifestyle would likely lead to different behaviours and societal patterns than would otherwise be. This would likely affect the timing of a given generation's reproductive actions with the result that (over time) there would be entirely different people conceived than would have otherwise been without the policy change. But, if this is so, the future generations that could have lived (badly) under the present depletion behaviour would not exist under the conservationist behaviour. Different people would exist instead. From the perspective of the original future generations, the environmental policy change is not for the better for them, but simply removes them along with their problem. Nevertheless, we are likely to still feel obliged to adopt the conservationist stance because, even though it is not better for someone in particular, it is still better. And depletion is still worse for future generations, even if there is no one in particular that is made worse off than they might have been. The sense that we owe it to future generations to adopt the conservationist stance is explicable not by the notion of person-affecting harm, but by the notion of *impersonal* harm. On the face of it, if we feel that it is a *moral imperative, for the sake of future generations*, that the conservationist stance should be adopted, it may seem that the harm being impersonal rather than person-affecting makes *no* difference.

This is similar to the Gauvin 1 case versus the Gauvin 2 (with qualification) or Gauvin 3 cases. It would seem that, like 2 and 3, Gauvin 1 should be seen as 'harmed' even though he was not harmed in 'normal' sense that it is worse for him (Harris, 1998, p. 107). On the other hand, this does not, in itself, rule out the possibility that person-affecting harm is *worse* than impersonal harm, even if the latter is still considered bad. It merely suggests that, in non-identity situations there can still be posited some form of harm when the notion of person-affecting harm is unavailable. The additional presence of a person-affecting form of harm may still make *some* difference to our moral assessments. In addition, despite the moral intuitions elicited from the future generation case, one can also go further and suggest that harm being person-affecting still makes *all* the difference. According to this view, the positing of impersonal harm in non-identity situations merely has the appearance of the only *real* form of (person-affecting) harm. Therefore, in the non-identity contexts, the presence or not of the person-affecting stipulation could make all the difference, some difference, or no difference in our moral assessments (Parfit, 1984, p. 363).

The (un)importance of context

Rebecca Bennett in her criticism of the procreative beneficence principle suggests it makes 'all the difference' (Bennett, 2009). She suggests that *if* certain procreative choices are not bad for anyone (in the 'person-affecting' sense of harm), they are not moral choices at all, so long as the resulting lives are not so bad that they would be better off dead (Bennett, 2009, p. 269). They are simply different (and importantly sometimes contrary) preferences for different types of worlds. Those who select for an embryo with (future) disabilities, but with a life worth living are making a morally neutral choice even if it was agreed that such disabilities are worse than normal abilities. This seems to be an extreme form

of a person-affecting argument that sees non-person affecting situations as literally not affecting persons in any morally relevant way. Rather, they are simply non-moral expressions of our desires for certain types of situations. This seems implausible. It would undercut our concern for future generations (which she seems to accept) and almost all of our responses to various pre-conception cases akin to Gauvin 1 (which she seems to intend) (Bennett, 2009, pp. 268–269). Suppose a woman, against her doctor's advice, forgoes a treatment that, if taken prior to conception, would enable any future children she has to avoid an incurable disability. She forgoes the treatment because she would prefer not to undergo the temporary side-effects of mild acne. According to Bennett, and 'all the difference' views in general, this woman cannot be morally blamed in any way, even if the disability brings the welfare of the child down to a level just above the point where life would become unworkable. If she prefers to undergo the difficulties of raising a child with disabilities (and no third parties are affected) in order to avoid mild acne and no child is harmed (in Bennett's sense) by her so doing, then this is no different morally than if she did the reverse. Whether we are considering future generations or decisions to implant an embryo with a congenital impairment, it remains the case that "the reason for our intuition is to do with preference rather than morality" (Bennett, 2009, p. 269). The more this all seems implausible, the less it seems that the 'all the difference' view is acceptable.³

At the other end, we could say, along with Parfit, that the stipulation makes 'no difference' (Parfit, 1984, p. 369). We still feel that the woman who conceived a child with a disability in order to avoid acne has acted morally wrong regardless of whether strictly speaking the subsequent child was harmed. And we also feel that we morally owe it to future generations that we leave their world with less damage as opposed to more, regardless of whether it is worse for any particular person in the future. From an impersonal comparative viewpoint, we can readily see that the inhabitants in the conserved world will be better off than the different inhabitants in the depleted world, even if neither is worse or better than they otherwise might be. It seems necessary to adopt such an impersonal view to support our moral concerns for future generations, where no-one is either worse off or better off in person-affecting terms. From this viewpoint, it makes perfect sense to compare one person's situation as against another person's situation and come to a judgement on which situation is better. Using this information *ex ante*, we can decide to choose the better situation than the worst situation, even if, once the choice is made, neither of the resulting person's can be worse off (or better) off than they might have been. We can judge Gauvin's existence insofar as some 'Gauvin' will exist; we can judge the quality of life for future generations insofar as some future generations will exist, even if Gauvin and the future generations are differently composed.

So, we can still make sense of non-identity cases where, it can still be good for 'someone', even if that someone is not the same someone that otherwise might have been. An impersonal comparative principle can be invoked to suggest that although there is no-one who is better off in one situation than in the other, there is still the situation where someone in one position is better off than someone else in a different position (Parfit, 1984, p. 370). The impersonal comparative approach can make coherent some of our response with respect to cases where the usual rules fail to apply (Buchanan et al., 2000, p. 250; McMahan, 2001). *Prima facie*, it appears the 'no difference' view is more acceptable than the 'all the difference' view when it comes to non-identity cases. Nevertheless, even if the absence of a 'victim' does not make person's 'state of harm' (implausibly) morally neutral, where there *is* a presence of a victim, and a more *straightforward* 'grievance', the situation could (arguably) still be seen as worse.

The lack of an identifiable victim, when talking about disadvantage or harm (or the lack of an identifiable beneficiary when talking about advantage or benefit) seems to make *some* moral difference—whatever the exact degree. Importantly for present purposes, Parker and Savulescu adhere to the ‘some difference’ view which rests some moral weight on the presence or absence of an identifiable victim. Unlike the ‘no difference’ view, the explicit allusion to a no-alternative (for Gauvin) context suggests *some* difference between cases such as Gauvin 1 and the others. Parker, for instance, notes that:

“[i]t is important at this stage to point out that, like Parfit and Robertson, Savulescu is not arguing that choosing to have a child other than the one with the best opportunity of the best life is to harm that child. A child who is born deaf is not harmed by his or her parents in cases such as the one above because no alternative, better, life is available to that child” (Parker, 2007, p. 280).

In the case of Gauvin 1, assuming he has a life worth living, there seems no way ‘he’ can be in a worse off position than he can otherwise be. He has to be in the best situation he can be, even if it is a worse situation than someone else *could* have been in. It seems that, insofar as the latter situation may be bad, if there is a victim, than this may make *some* difference—it might make it in *some* way worse. The distinction between selection of embryos and interventions on a given embryo also underlies Savulescu’s Procreative Beneficence and his preference here and elsewhere for the former over the latter (Savulescu, 2001; Savulescu et al., 2006, pp. 162–163). As Savulescu et al. (2006) note, whereas bad consequences (i.e. an increased risk of cancer) arising out of selection are still bad, the equally bad consequences (same cancer risk) arising out of manipulation are (arguably) worse.⁴ It seems plausible to hold that Parker’s criticism of Savulescu (and the Savulescu argument itself) is only intended for this no-alternative context assessable under the ‘some difference’ view (and the aforementioned area of moral persuasion). Assuming that this is so, and Parker, Savulescu and others clearly seem to agree, it suggests that the ‘no alternative context’ has some important influence on our moral assessments in selecting for deafness. But this seems to side-step a more radical conclusion. Whatever Parker’s own intentions regarding the no-alternative context, the issue seemed to be whether this harm of deafness exists at all. For, simply, if he is right in relation to his scepticism over what is best (or better), then even the very notion of ‘harm of being deaf’ should be treated with a similar scepticism. For the *more* that Parker is successful in the pluralistic sphere (or reasonable disagreement) argument over what is best, the *less* it should matter whether we retain the underlying no-alternative selection context and replace it with, for instance, a genome editing context.⁵

The significance of a genome editing context

The gene editing route can be distinguished from genetic selection in that the former is, roughly, making particular genetic changes to the given embryo and the latter is the selection of different embryos entirely. Some, such as Ranisch (2020), would view the distinction (specifically attributing additional moral weight to person-affecting considerations) to raise as many counter-intuitive implications as it would resolve. Others, such as Boardman (2020a), sees the reframing of the impersonal genetic selection (PGD) context as a person-affecting gene editing context to be deeply significant—at least in the message it seems to portray. She notes that through:

“preservation of the life of the embryo (that would otherwise be disabled), and eradication only of the disabling trait, germline genome editing indeed appears to neatly

sidestep one of the most critical social and ethical concerns levelled at current methods of genetic disease amelioration: that the disabling trait is considered more significant than the life of the embryo or foetus” (Boardman, 2020a, 2020b, p. 125).

While otherwise in disagreement with Boardman, Iñigo de Miguel Beriain (2020) agrees that:

“unlike preimplantation genetic diagnosis (PGD), [germline gene editing] does not send the message that not living at all is preferable to living with a concrete genetic trait that determines a concrete condition because the use of PGD tools results in the unavoidable process of destroying embryos with traits that will trigger concrete pathologies [...]. In contrast, GGE does not result in the destruction of embryos, but instead alters the expression of such traits, to avoid disease occurrence. This process creates a totally different scenario, resulting in this intervention, sending an alternative and totally different message that living without the condition is better than living with it, which appears to be an acceptable conclusion for everyone. Thus, GGE appears to be a perfectly acceptable and necessary method for addressing the issues posed by disabling genetic diseases when identified in in vitro embryos” (p. 241).

The significance of this sidestepping—separating the identifiable embryo that can be intervened upon in person-affecting gene editing from the (dis)abling traits that can be added or removed—can be translated to the above Savulescu–Parker debate. The notion of genome editing may have appeal (in terms of clarification at least) in the current context for two reasons. Firstly, it seems to anchor the assessment of whether certain traits can be ranked as better or worse than each other by exploring what should be its full logical conclusions—that bringing about deafness, as a neutral trait, should not be regarded differently than bringing about hearing. If we really cannot say what is best, then it would seem particularly irrelevant whether we select for deafness in Gauvin 1 *or* edit deafness into Gauvin 2. In so far as arguments for curing deafness in infants are reasonable (other things being equal⁶), then it should be as reasonable to ‘cure’ hearing (other things being equal). Secondly, as also noted by Boardman (2020b), the gene editing route could, in theory at least, importantly change a discussion normally perceived as recommending the controversial removal of disabled people to a less controversial discussion about removing disability from people’s lives.⁷ Suppose that instead of the selection of Gauvin 1, genome editing was performed either in vitro or in utero (Gauvin 2 context). This primary difference between genetic selection and gene editing would be that in the former, no actual alterations are made to the genetic material of any embryo, but some embryos are chosen and others are not. In genome editing, there is a case of alterations being made to the genetic material of the embryo or foetus, and (putting extremely important practicalities aside) in theory, no embryo *necessitates* being rejected. Martin Harvey (2004) argues that, although the genetic augmentation route does not offer a hard and fast distinction from selection in terms of actually being a case of harming the resulting child, it offers a certain context where the ‘no (person-affecting) harm’ issue fails to apply. In theory “the non-identity does not arise for, unlike the IVF example, the *one and the same* foetus is disenanced” (Harvey, 2004, p. 127 [italics in original]). Of course, the word ‘disenanced’ is assuming that editing in deafness (or editing out hearing) is a form of disenancement (as opposed to *differently enhanced*)—something that may be argued to be begging the question by Parker’s argument. Importantly, as the child can exist without being deaf unlike in the selection scenario where he/she

cannot, this raises the stakes for those begging this very question—that is, those who would argue that deafness and hearing are entirely neutral traits. On the face of it, the person-affecting framing of genome editing (and the separation of the disabling trait from the rest of the pre-person) may make it easier to remove deafness, rather than removing deaf people—and harder to engineer deafness to an otherwise hearing pre-person. Those who argue, as Parker’s reframed argument seems to, that traits such as deafness is as neutral as hearing must defend this bolder, more radical genome editing path (for instance, those who consider disabilities as constitutive of their identities). For instance, Felicity Boardman (2020a, 2020b) highlights the use of the term ‘Deaf gain’ to describe cognitive to cultural benefits from ‘Deaf ways of being in the world’, drawing “attention to the possibility of disability being an enriching experience, both at the individual and societal level” (p. 246). Like Parker, the more Boardman accepts this, the less it should matter whether or not there is the reframing of the impersonal genetic selection (PGD) context as a person-affecting gene editing context.

The scope of a pluralistic sphere of genetic traits

How far this would apply to other disabilities (or different abilities depending on your viewpoint) is an open question—although it may appear more open for some disabilities than for others. Even where something may be accepted to be a harm to some degree, the issue of minor or major harm is relative. For some individuals, deafness is a greater harm than for other individuals. It is highly likely that deafness is a greater harm for a future musician than for a future painter. It is even conceivable that visual perception of a painter might be enhanced if the painter is deaf. But what about a blind musician? Would blindness enhance his musical ability? It is certainly possible, if not likely. Is the implication of this that blind parents who love music and who are excellent musicians, decide to opt for a blind child? Do they have the right to genetically select a blind embryo? If so, do they also have the moral right to ask for a gene editing intervention that would make sure that their child is born blind?

Where is the line? Is the selection of deafness morally justified and the selection of blindness not? This can indeed be argued, because blindness disables us to perform more activities that are important for an average human than does deafness. But again, in the example we have given, deafness might be perceived as a greater harm than blindness. What about parents with Down’s syndrome who wish to have a child with the same condition? What about a Paralympics champion who is a basketball star in a wheelchair who wishes to have a child without legs? We can go on with multifarious examples, but we will not be able to draw a line which disability consists a major harm, which a minor harm, which no harm and which an advantage. The reason for this is that the issue of harm in this sense is determined by each specific individual, that is, this type of harm is relative—in keeping with Parker’s more radical interpretations. In this article we do not address this broader sense of diverse disabilities beyond deafness—except to say that the aforementioned arguments should continue to apply to each—with it being an open question as to how many, if any, will pass the genome editing reframing test.

Conclusions

This implication from the change in context from ‘no-alternative’ to ‘alternative’ is curtailed by the context that Savulescu and Parker, and more recently that Boardman and De Miguel Beriain, emphasise is important. But, insofar as Parker’s (and Boardman’s) argument goes, this emphasis should not be necessary. If the ‘pluralistic sphere’ argument is sound, and we cannot say what is best (or better) when ranking deafness and hearing in

certain cases, then there should be no morally significant difference in this argument whether the context is selection or gene editing. If choice of ‘what is best’ in terms of genetic traits are underdetermining, paradoxical, self-defeating, and overly individualistic, then surely they still are, whether they are considered as inseparable from a given embryo or whether they can be introduced or not into a given embryo. Although none of this should make any difference to the ‘no difference’ views, insofar as it may to the ‘some difference’ and ‘all the difference’ views it has some clarificatory purpose in assessing the criticism over ‘what is best’ in its own right. Insofar as the argument against Savulescu was against a ranking of genetic traits as better or worse than each other (i.e. deafness versus hearing) in terms of realising the best life, it would be interesting to see if, in the context of genome editing, Parker’s (‘some difference’) argument still stands. If not, then he might be coming closer to Savulescu’s stance. However, if the genome editing context of a (genome edited, person-affecting) Gauvin 2 scenario contains *both* hearing and deafness as incommensurable alternatives, Parker’s (and Boardman’s) arguments would seem even more radical, particularly in the message it expresses. It would also be radical in terms of how we use concepts such as harming, disenchanting, or disability when we are comparing the ability to hear and deafness. We conclude that the person-affecting versus impersonal harm distinction has allowed these more radical conclusions to be obscured behind a ‘some difference’ view (even if only at the level of the message it sends out). Insofar as this is more widely the case, the genome editing reframing will cast a sharper light on some of the arguments in favour of selecting for disabilities (or against selecting out disabilities) and will create a new message of *genuinely* creating disability that may become part of the future relationship between new genomic technologies and disability.

Received: 3 December 2020; Accepted: 26 April 2021;
Published online: 13 May 2021

Notes

- 1 To be precise, these would be Gauvin-like routes but not the route that was actually taken with Gauvin. His conception was due to a deaf friend who acted as a donor rather than an ‘official’ route (Mundy, 2002). Had their request been accepted by IVF clinics, they would have been able to select for Gauvin in the assisted reproduction contexts that are of relevance here.
- 2 It is important that this point does not rely on, what Jeff McMahan (2005, p. 87) calls, a mistaken view ‘untutored in metaphysics’. For instance, McMahan notes that, although numerically the one and same individual may exist, due to the identity-determining effects of radical genetic alteration, there would really be a different individual as a result of a procedure similar to that outlined for Gauvin 2. Nevertheless, not all genetic interventions need be identity determining in a complete sense (outside of the future child being deaf just as in Gauvin 3). One could stipulate that the intervention is localised to ‘switching-off’ the genetic basis for hearing while leaving all else unaltered. In any case, one could qualify the Gauvin 2 case to be temporally timed as whatever point that McMahan would suggest that there to be some basis to suggest that a ‘same person with genetic alteration’ has occurred rather than a ‘different person effectively selected for, via genetic alteration’.
- 3 One of the reviewers of the paper acutely observed that Bennett’s arguments being arguably counter-intuitive is not a sufficient argument in itself—as our intuitions must be rational and logically justified for this to have any weight. Nevertheless, reducing the welfare of future individuals (be it future generations widely understood, or a future child from PGD) to barely above a threshold below which they would be better off dead should generally raise a moral red flag, certainly in the context of practice and policy on assisted reproduction and environmental conservation. Of course, Bennett’s argument might ultimately be argued to be rational and logically justified, but this is an argument that needs a strong defense for it to be acceptable to the ethical context or morality encountered by prospective parents, environmental policy makers, assisted reproductive ethical guidelines and so on. To some degree, we are relying on common sense morality to do some of the work, especially where it would be beyond the scope of this paper to elaborate on the appropriateness of ethical theories, such as that of Bennett.

- 4 Hope and McMillan (2003, p. 2164) concur and note, in the context of a choice between deafening a 'hearing' embryo or selecting a 'deaf' embryo, that a particularly important distinction exists between such cases. For the non-identity problem renders it unclear that "doctors have the right to override parental choice when no-one is harmed by that choice." The implication, of course, is that, in the case of deafening an embryo or foetus, doctors may have the right to over-ride the parent's request where there is an identifiable someone (see also Glover, 2006).
- 5 Alternatively, it would reduce the moral difference between Parfit's 'no difference' view and Savulescu and Parker's 'some difference' views with similar implications.
- 6 That is, 'transition costs'—where the experience of losing an ability (or gain one) may be worse than never having (or getting) it.
- 7 I emphasize 'less controversial' rather than 'uncontroversial' for, as Boardman notes, this essentially is to beg the question. See also Buchanan et al. (2000, p. 275).

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Competing interests

The authors declare no competing interests.

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