



Is it morally justified to create disabled designer babies?

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Abstract

This research paper explores the question—whether it is morally permissible for an auditory impaired parent to create an auditory impaired offspring? It makes an epistemological inquiry into the experiences of persons with auditory impairments to make an informed decision on the question at stake. There is a general attitudinal bias against the disability. On the contrary, arguments have been raised that a parent with auditory impairment may have a moral right and a liberty to have a specially designed deaf baby. It is argued that a deaf parent's desire to have a deaf child, stems from their need to relate linguistically and culturally with the child. It is also in the best interest of the child and the parent. Such arguments seem grossly misguided and are often countered with arguments of 'open future,' and the costs of disability. This research paper seeks to inquire into the epistemic challenges in examining the validity and the soundness of these arguments. It engages into the arguments and counter arguments with respect to whether auditory impairment is a disadvantageous condition to find that deafness does involve an element of harm though it is not only and only harm. It argues against the proposition that laws permitting abortion in case of foetal anomaly are eugenic. It uses Kantian theory to delve into the moral permissibility of the use of genetic engineering for the creation of impairment and enhancement. In the light of moral, ethical and jurisprudential considerations it finds that it is morally impermissible to use genetic interventions to create impairments or enhancements, as it strikes at the humanity in the 'designer babies' and uses them as a means for the satisfaction of desires.

Keywords Kant and designer babies · Auditory impairment · Designer babies · Genetic technologies · Morality of impairments and enhancements

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1 Introduction

'A' is a deaf¹ person in the Deaf² world. She has been to the University meant for deaf students and has been enculturated in the Deaf world. In this world she faces no communication barriers with her friends or her environment. She appreciates her life which she considers, a gift of the enabling environment she has been in, so much so that she intends to have a child enculturated in her own environment. She has learnt that modern genetic technologies can be used to ensure the birth of a deaf child. She harbours dreams of enjoying the company of a deaf child with whom she can relate, being in the same likeness. To her deafness is not a disabling condition, but something that has been the cause for her exposure to a wonderful Deaf culture. Her hearing friend finds this idea bizarre. 'A' points out that she should have the liberty and the autonomy, just like others, to decide the traits of her child and plan the nurturing of the child, in a way she thinks would be in the best interest of the child.

Writings like these have ignited philosophical deliberations on the appropriateness of the use of technology to create impairments and enhancements. Epistemological inquiry into the experiences of persons with auditory impairments to make an informed decision is fraught with uncertainties. Deaf persons fully enculturated into the Deaf world may not perceive the impairment in any way disabling. They may even consider it enabling.³ There are numerous instances of successful stories of persons with disabilities. The stories highlight the determination and the grit with which the disability was dealt with. They speak of how a disabling experience was converted to an enabling experience. So much so that proponents of Deaf culture⁴ often object to any implants to facilitate hearing as it is not only invasive, but it also threatens Deaf culture.⁵ Disability scholars claim that disability is not an impairment as understood by the medical world. Rather it is socially constructed. They claim that it is 'mere-different' condition.

But such testimony often invites criticism. It gets rejected as it is grounded on adaptive preference.⁶ Disability pride comes from not the impairment but the

¹ Following the standard convention used in research on this subject, the word 'deaf' in the lower case refers to the pathological condition of being hearing impaired of whatever percentage. 'Deaf' in the capitalised word refers to the cultural context of deaf persons. In addition to the condition of being 'deaf' it refers to a multitude of other characteristics that encompasses the 'cultural outlook' of deaf people.

² A culture that has sign language as the primary language of communication and includes other inclusive values and ways of life, giving a feeling of belongingness to deaf persons.

³ 'American Deaf Culture' (*Minnesota Hands & Voice*). <https://www.mnhandsandvoices.org/resources-information/american-deaf-culture>. Accessed 3 July 2021.

⁴ Doubts have been raised on whether the Deaf community has a separate cultural identity. See Carol Padden and Tom Humphries, *Inside Deaf Culture* (Harvard University Press 2006) 3–10.

⁵ Bonnie Poitras Tucker, 'Deaf Culture, Cochlear Implants, and Elective Disability' (1998) 28(4) *Hastings Centre Report* 6.

⁶ Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford University Press 2007); Ariel Glucklich, *Sacred Pain: Hurting the Body for the Sake of the Soul* (Oxford University Press 2003).

successful response to overcome the impairment.⁷ Disabled persons feel that such testimony based on their experience should be respected.

But the traditional⁸ understanding of disability is yet to change.⁹ Disability is seen as by nature detrimental.¹⁰ It evokes sympathy and pity for the impaired person. A hearing impairment of whatever degree is considered as a ‘harm’. Consequently, any epistemic inquiry on the morality of using gene technology to create a deaf child, influenced by the traditional notions, fights the proposal for genetic intervention for the creation of a deaf child. The conflicting notions of ‘deafness as pathological condition’ and ‘deafness as a social construct’ gives rise to competing claims. This research makes an evaluative judgement of these competing arguments on the touchstone of morality using Kantian theory as a tool.

This research focuses on impairments that do not necessarily require medical attention and can be managed by changes in the social environment of the person. Auditory impairments, achondroplasia¹¹ are some such impairments.

In Section 2, I engage with the debate on whether disability is a ‘mere-different’ condition, or a detrimental health condition and I am going to defend the idea that disability does involve some element of harm, though it is not only and only harm. My argument in support of this is three pronged. Absence of hearing does constitute harm as per Bentham’s ‘pleasures of the sense’ and ‘pains of privation’. In relation to well-being, I argue that disability is not a neutral element, but an active element that combines with other factors to yield an adverse or a beneficial result. Drawing empirically from the data provided by various bodies, with respect to status of disabled persons in society, it has been seen to affect adversely. So, in relation to well-being, disability does constitute harm. I conduct a thought experiment to show that disability in respect to person-to-person communication may not evidence harm, but in the interaction between the person and his environment it does present some harm.

⁷ Sara Goering, ‘Rethinking Disability: The Social Model of Disability and Chronic Disease’ (2015) 8(2) *Current Reviews in Musculoskeletal Medicine* 134, 134–138.

⁸ The traditional understanding of disability can be traced back to the idea that a disabled body is a consequence of past sins that one must endure as repentance. See Pauline A Otieno, ‘Biblical and Theological Perspectives on Disability: Implications on the Rights of Persons with Disability in Kenya’ (2009) 29(4) *Disability Studies Quarterly*; Andrew Wilson, ‘Barriers and Enablers Provided by Hindu Beliefs and Practices for People with Disabilities in India’ (2019) 6(2) *Christian Journal of Global Health* 12. A disabled body was always seen as a burden. In 1880, the Second International Congress on Education of the Deaf held in Milan, Italy, passed a resolution stating the primacy of oral communication over sign language. It stated that oral speech was the only way of complete communication. This view dominated the field for almost 80 years until around 1960 when the focus was shifted to societal response towards disabled persons. Donald F Moores, ‘Partners in Progress: The 21st International Congress on Education of the Deaf and the Repudiation of the 1880 Congress of Milan’ (2010) 155(3) *American Annals of the Deaf* 309.

⁹ Mary Johnson, ‘Before Its Time: Public Perception of Disability Rights, the Americans with Disabilities Act, and the Future of Access and Accommodation’ (2007) 23 *Washington University Journal of Law and Policy* 121; William Draper, *Workplace Discrimination and the Perception of Disability* (DPhil Thesis, Virginia Commonwealth University 2012); Moores, ‘Partners in Progress’ (n 8).

¹⁰ Elizabeth Barnes, *The Minority Body: A Theory of Disability* (Oxford University Press 2016) 89.

¹¹ A form of short limbed dwarfism.

In Section 3, I examine the concepts of health, eugenics and genetic engineering to explore two main questions. Whether genetic technology can be used for the creation of ‘deafness’ and whether it is justified to use genetic technologies to detect and remove foetal impairments. I examine the counterarguments that use of genetic engineering to detect foetal anomalies and aborting them, are eugenic practices designed to put an end to the Deaf community that is of distinct linguistic and cultural significance. I argue that since disability constitutes harm, society would be perfectly justified in enacting laws introducing measures to control. Yet laws merely permit and do not mandate abortion. Hence, I argue against the argument raised by disability scholars that laws that permit abortions in case of foetal anomaly are eugenic.

In Section 4, I examine the grounds raised for the quest for a deaf child. Applying Kantian theory, I argue that the autonomy argument, fuelled by a desire to have a disabled child, depicts a heteronomous condition. Decisions aren’t autonomous when they are governed by desires. I also argue that in the quest for a deaf child, the humanity of the child is at stake. When someone is used as a means to an end, he is relegated to mere instrumental value. I contend that it would be morally impermissible to permit creation of disability for the sake of keeping alive diversity in the society for the reason that morality cannot base itself on empirical considerations. The deontological account of morality that Kant presents, endorses moral worthiness of actions that are good in itself. I argue that since disability involves some element of harm, it would be morally impermissible to create deaf designer babies.

2 Is auditory impairment a disadvantageous condition? What constitutes harm?

It is necessary to evaluate what may be considered as harm or a ‘bad-difference.’ What is seen as harm may vary from person to person. It may also vary with the context. The question at hand, in the context of this research, is whether ‘loss of hearing’ constitutes harm? If there is a highest standard of human existence, is it an existence without impairment? I argue that disabilities that arise as a result of social construct, can to that extent be construed as a ‘mere-difference’. But otherwise, impairment is in a limited sense ‘harm’ or a ‘bad-difference’. I use Jeremy Bentham’s pleasure of the sense and pain of privation as a framework, use data with respect to well-being, and examine the limitations arising out of disabilities to support the claim that auditory impairment involves ‘harm’, but it is not only and only harm.

The traditional view¹² seems to be that an impairment is always a harm. ‘Disability’ has been seen as a ‘defect’, a condition that is ‘abnormal’, that evoked sympathetic response from members of the society. Not necessarily because of societal prejudices that regard impaired persons as burdens. Neither is it because of ostracism or lack of accommodation of the special needs of the disabled. It is considered

¹² Melinda Rosenberg, ‘Harm, Liberty, and Disability’ (2009) 29(3) *Disability Studies Quarterly*; Elizabeth Barnes, ‘Disability, Minority and Difference’ (2009) 26(4) *Journal of Applied Philosophy* 337.

to be of harm, independent of the above considerations. Since the able-bodied members of the society enjoy the privileges of a mentally and a physically fit body, they perceive the absence of any of these faculties as an impairment. Since majority of the members are fit, any deviation from the standard is considered as a disability. So, if a normal functioning eye can see, then blindness is a disability. If normal function of the ear is to hear, then deafness is a disability.

It may be interesting to note here that ‘normal functioning’ is judged in reference to what most members of the society depict as a characteristic. So, if most members of the society are able to hear and see, then not being able to do so is considered to be a ‘disability.’

The Medical Model of Disability refers this limitation in the use of physical, mental, or sensory function, that an impaired person experiences. The root cause of disability is the limitation. It proceeds to rectify the disadvantageous condition, using medical procedures even in cases where the impairment is not painful. This requires persons with impairment to incur expenditures on costly medical procedures and equipment. This ‘disability mindset’ led to ‘disabled’ persons being treated as burdens, to society and their families, as they always needed special care, and help for the conduct of their regular routine. Added to their predicament, they faced social stigma, social exclusion, missed out on social opportunities, and were relegated to the background. All in all, it was considered to be a disadvantageous condition and thereby a harm. This ensured proper treatment of the disability.¹³

Earlier philosophers held ground for centuries, understanding impairment as intrinsically bad. The idealisation of existence without impairments influenced earlier policies and laws. It blinded decision-making and reforms for upliftment. Laws to root out disability were passed.¹⁴ The majority of the societal members being able-bodied, it was considered normal. The ableist society therefore worked towards setting right the impairment. But there is nothing to suggest that this is the only correct view.

As opposed to the traditional view, the Social Model perceives disability as an outcome of social barriers. In the 1960s, disability scholarship overturned the traditional view, to assert that it is not the problem with the impaired person, rather the society that viewed disability as a defect and did not make provisions for the differential needs.¹⁵ Known as the ‘Social Model’ of disability, it viewed disability not as an impairment, but as an outcome of how society is organised. The root cause of disability are the societal barriers. In fact, it is the outcome of social barriers. It is a consequence of the lack of fit between the person and his social environment.¹⁶ If society accommodates the needs of the persons with impairments, then they could

¹³ Simo Vehmas and Tom Shakespeare, ‘Disability, Harm, and the Origins of Limited Opportunities’ (2014) 23 *Cambridge Quarterly of Healthcare Ethics* 41.

¹⁴ The Law for the Prevention of Genetically Diseased Offspring 1933 was passed by Nazi Germany to eliminate ‘life unworthy of life’.

¹⁵ Colin Barnes and Geof Mercer, *Exploring Disability: A Sociological Introduction* (2nd edn, Polity 2010) 25; Union of the Physically Impaired Against Segregation and Disability Alliance, *Fundamental Principles of Disability* (1976) 3.

¹⁶ Goering, ‘Rethinking Disability’ (n 7) 134–138.

lead independent autonomous lives. Disability arises out of discriminatory treatment meted out to persons with impairments.¹⁷ So instead of perceiving the impairment in a negative view of ‘can’t(s)’ and ‘inability’ of the disabled person, it pointed towards the ‘inability’ of the social and political processes, to accommodate the differential needs of the disabled person, thus resulting in creation of dependency.¹⁸ It begged to view persons with impairment as merely different, and not as carrying an abnormal condition. Being different, their differential needs needed to be provided for. So, this view considered ‘disability’ as a mere different condition and therefore not a harm *per se*.

Both the accounts of disability yield opposite results. Despite this development in disability scholarship, the prevalent general perception of disability maintained the traditional outlook.¹⁹ Deafness is perceived as an undesirable condition. Regardless of social model viewpoint, of acceptance of disability as a difference, it is still seen as troublesome.²⁰ It is considered to create a negative impact on wellbeing.²¹

First, I enlist the help of Bentham in examining whether deafness is a harm. The list of pleasures and pains offer a conceptual framework that steers clear of societal perspectives and focuses on the core characteristic of disability. Since ‘deafness’ is in relation to the ‘sense’, Bentham’s account of ‘pleasures of sense and the pains of privation’ can inform our understanding of whether ‘deafness’ constitutes harm. Bentham in his explication of the pleasures of the sense, lists *inter alia* the ‘simple pleasures of the ear, independent of association’. Apart from the pleasures of the sense, he lists able body, good health, the pleasure of imagination, all play an important role in the well-being and in the making of a fruitful life. Amongst the pains, he lists the pain of privation.²² So, the absence of any of these faculties causes pain. It is the absence of, or deprivation of, the enjoyment and full realisation of the bodily potential, that causes pain. The absence of a pleasure that was never enjoyed, is grounded in the idea of the pleasure, an expectation not fulfilled, but known to have the potential of causing happiness in case the deprivation didn’t exist. Another case is of the deprivation of a pleasure that was enjoyed and now severed, the memory of the pleasure which is no more available.

Consider the case of persons who are deaf since birth, and have never known the pleasure of the auditory sense. Would they perceive their state as a disadvantageous condition? One may argue that they are not really in the disadvantage, since they do not know what they miss and have no knowledge of the existence of a sense of

¹⁷ Anna Lawson and Angharad E Beckett, ‘The Social and Human Rights Models of Disability: Towards a Complementarity Thesis’, (2021) 25(2) *The International Journal of Human Rights* 348.

¹⁸ Michael Oliver, *The Politics of Disablement* (Palgrave Macmillan 1990) 78. Oliver first coined the phrase ‘Social Model of Disability’.

¹⁹ Moores, ‘Partners in Progress’ (n 8) 309.

²⁰ Barnes, *The Minority Body* (n 10) 54–89.

²¹ Hannah Tough, Johannes Siegrist, and Christine Fekete, ‘Social Relationships, Mental Health and Wellbeing in Physical Disability: A Systematic Review’ (2017) 17(1) *BMC Public Health* 414.

²² Jeremy Bentham, *An Introduction to the Principles of Morals and Legislation* (first published 1789, Clarendon Press 1907) 33. Bentham lists pleasures and pains. Interestingly he states that pleasure is the only good and pain the only evil. 102.

hearing. Yet it is very unlikely that this would happen. The real world is inhabited by deaf, Deaf, and hearing people. In their dealings with other members of the society, they would know that they are deprived of the sense that would have helped in the experience of the auditory pleasures. Unlike others they are not able to experience the sounds, that others can. The absence of the sense of hearing, is therefore a disadvantageous condition.

Another instance may be of a person who has experienced auditory capabilities and is now deprived of the same; encounters pain for the reason that such will not be experienced again, causes a sense of deprivation and pain. So, whether an instance of ‘absence’ or of ‘privation’ in either case, it is a harm.

Secondly, disability scholars²³ have also attempted to measure the ‘harm’ component from the standpoint of well-being. Disability to a certain extent detracts from norms of human flourishing.²⁴ The traditional view that dominates is that disability is a ‘harm’. It is intrinsically bad and a cost on a person’s well-being. It is bad not just because of societal attitudes and treatment of impaired persons as burdens. Even if the society would be the opposite—fully accepting the impaired person and accommodating the needs, yet it is a ‘bad-difference’.²⁵ In fact, ‘bad-difference’ is the default view as it relates to the frustration of desires.

This traditional view has faced opposition on the face of innumerable instances of flourishing lives of people with impairments. These instances provide testimony to the contrary. Their impairments had a major role to play in their flourishing. So perceived, disability is a neutral condition in relation to well-being.²⁶ There are numerous factors that combine to affect the well-being of a person.

Few instances of flourishing lives cannot be used to generalize to the conclusion that disability is a completely neutral condition in relation to well-being. No one claims that a certain disability is uniformly harmful.²⁷ Neither can it be claimed that a certain disability is uniformly beneficial. Disabled persons across the globe are a vulnerable group requiring support.²⁸ Data reveals that they lag in education, employments and are hugely dependent on others for support. So, in the determination of well-being, disability is a factor that may adversely or favourably interact

²³ Stephen M Campbell and Joseph A Stramondo, ‘The Complicated Relationship of Disability and Well-Being’ (2017) 27(2) *Kennedy Institute of Ethics Journal* 151; Lois M Verbrugge, Joseto M Reoma, and Ann L Gruber-Baldini, ‘Short-Term Dynamics of Disability and Well-Being’ (1994) 35(2) *Journal of Health and Social Behaviour* 97; John Harris, ‘Is There a Coherent Social Conception of Disability?’ (2000) 26(2) *Journal of Medical Ethics* 95.

²⁴ Refer Aristotle’s ‘objective list’ view of well-being. Roger Crisp, ‘Well-Being’ (*Stanford Encyclopedia of Philosophy*, 6 November 2001). <https://plato.stanford.edu/entries/well-being/>. Accessed 18 September 2021.

²⁵ Barnes, *The Minority Body* (n 10) 55.

²⁶ *Ibid.* 54.

²⁷ Brigham A Fordham, ‘Disability and Designer Babies’ (2011) 45(4) *Valparaiso University Law Review* 1473, 1477.

²⁸ United Nations Department of Economic and Social Affairs: Disability, *Factsheet on Persons with Disabilities*. <https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html>. Accessed 18 September 2021; United Nations Department of Economic and Social Affairs: Sustainable Development, *Transforming Our World: The 2030 Agenda for Sustainable Development*. <https://sdgs.un.org/2030agenda>. Accessed 18 September 2021.

with the other factors promoting well-being. In most cases, it has adversely impacted well-being.

Thirdly, senses are the tools that help us perceive the world around us. Minus one of the senses, the knowledge of the world would be to that extent restricted. Hearing helps in interacting with and communicating with the world.

Consider the case of deaf children born in a Deaf community, a community that consists of signing deaf members where the sense of hearing is unknown. Their interactions with the world will not be inhibited, as the people in this world are all akin to them. The condition of being deaf in such a world is perfectly normal. They perceive the world with four senses just like all other members of that world. There is no disability. There is no harm. All knowledge gained through sensory experiences is all that can be known with the use of four senses, the fifth being completely absent thereby unknown.²⁹ So the second objection, that the perception of the world would be limited, fails as the perception of the world to the extent possible, would be otherwise complete with the other senses. Further in conforming, supporting society gaining knowledge would be in conjunction and hence very fruitful. In this society, a person would be alerted of danger, only through his sight or smell, in the absence of hearing.

Consider this—in a world of the Deaf what would a hearing person be like? What rules would govern the processing of data in such a world? Being born in the Deaf community, he would certainly inculcate all the social and cultural values of the Deaf world. He may be for the sake of ease referred to as a hearing-Deaf person. Would his capacity for hearing be understood as a capacity? A capacity that enables him to hear. Would he be considered a supernatural person with the divine ability to hear birds, the tides, and the wind? More likely that such a person, even though hearing, would not know communication by the use of language as there would not be any developed speaking language in such a society. Yet he would have the capacity to communicate through signs about his ability to hear. His sense of hearing will alert him of impending danger, even before he sees it, and in possessing this capacity he would be having an advantaged position in that society.

Now consider this—supposing this hearing-Deaf person visits a world of hearing people. He would find himself crippled in not being able to communicate with the hearing world. He would need to learn the language of the hearing community. So is the case of every new-born child, who needs to learn the signing or talking language of communication.

This thought experiment has one result—in the context of communication ‘deafness’ *per se* is not a harm. It is a harm/incapacity when there is a communication gap on account of parties speaking different languages. A hearing person who does not know sign language, finds himself handicapped amongst the members of a Deaf

²⁹ Like in the electromagnetic spectrum of light, the infrared and ultraviolet waves are not visible, similarly in sound, the infrasound and ultrasound are outside the human hearing range. Hence, dog whistles are not heard.

community.³⁰ Similarly a deaf person who does not know the language of the hearing, finds himself handicapped, amongst members of the hearing community.

Disability is therefore not just a natural consequence of a pathological condition, but also a cultural construction. Viewed in the cultural context, from the *perspective of communication*, it may simply suggest that it is a ‘mere-difference’, and not a ‘harm’.³¹ Being deaf is similar to having a minority body. So, disabilities that are a product of social constructs can be better managed with addressing traditional mindsets, reducing dependency by empowering and making structural adjustments. It also proves that the idealisation of existence without impairment as the best form of existence is an erroneous social construct. Breaking free of the construct results in accepting that auditory impairment is just a ‘mere-difference’³² form of existence and not necessarily a ‘bad-difference’³³ form.

But as discussed above, the sense of hearing, does not merely aid in a person-to-person communication process. It establishes a communication between the person and his environment. Hearing the sound of a horn from the rear, and its intensity, alerts one to the direction and the proximity of the vehicle even before it is seen. It alerts us of dangers around us much before we can see them. Merely addressing communication problems, is not enough. There is an element of ‘harm’ involved in the lack of connect with the environment. Also, it has been seen that in the measurement of well-being disabled persons stand low not merely because of how society treats them but also because it is in a restricted sense, a harm. Harm, as in the case of an auditory impairment, may mean the absence of the sense of hearing that is an ‘intrinsic good’ leading to ‘frustration of desires’.³⁴ But disability isn’t just an accumulation of losses or the lack of intrinsic goods. There are other intrinsic goods that are disability specific. So, deafness can be construed as involving ‘harm’ without being only and only ‘harm’.³⁵

3 On health, eugenics, and engineering designer babies

Having classified disability as involving some element of harm, it is necessary to deal with the issues arising out of using medical procedures to rectify the disability. Disability scholars who perceive being deaf as possessing a different body or a

³⁰ The standpoint leads to the question whether Deaf people constitute a linguistic minority or a disabled group. See Jan Branson and Don Miller, *Damned for their Difference: The Cultural Construction of Deaf People as Disabled* (Gallaudet University Press 2002).

³¹ Emphasis added.

³² This view asserts that an impaired body is merely different from the able body. Being disabled is having a minority body very similar to being gay. It does not make lives worse. Or, as Barnes suggests, it is even like being male. Women have the capacity to grow a child within their bodies and give birth, which men can’t. This is not perceived as a bad difference. Barnes, *The Minority Body* (n 10) 57–58.

³³ A term used by Barnes as contradistinguished from ‘mere-difference’. *Ibid.* 55.

³⁴ *Ibid.* 56–59.

³⁵ Elizabeth Barnes, ‘Valuing Disability, Causing Disability’ (2014) 125(1) *Ethics* 88, 90.

minority body, harbour apprehensions³⁶ that the ableist society, that views deafness as an adverse health condition, will make efforts for the removal of the health condition, and in so doing wipe out disability completely. Hence raising the query.

Are laws allowing abortions in case of foetal anomalies eugenic in nature? Are we, by enacting laws permitting abortions in cases of foetal anomalies, targeting to reduce the number of Deaf births³⁷ and thereby extinguish the deaf community from the face of the earth? I argue that since deafness does involve an element of harm, it is justified that laws be enacted to curb it and even root it out. I place the subject in jurisprudential context of liberty to examine this question and argue that it is not eugenic and that such laws do not target the extinguishment of 'Deaf' community, for the reason that the laws do not make abortion mandatory in cases of detected foetal anomalies.

While scientific developments and new technologies have always assisted in making lives easier and healthier, there has always been a threat and a fear that these may be misused. In the context of this research, a discussion on 'health', and 'healthcare systems' is essential to place it in proper perspective.

Norman Daniels in his book, *Just Health: Meeting Health Needs Fairly*, explains health to mean the absence of significant mental or physical pathology that hinder 'normal functioning'.³⁸ He believes that health is a contributing factor in availing a wide range of opportunities that are open. This idea of health put forth by Daniels is a reflection of what societal mindsets held through centuries. Health was deemed equivalent to an existence without impairments. The idea that a 'normal functioning' body is the only correct way for the body to be, is so deeply ingrained in human consciousness that it ignores other possible ways of efficient functioning. Healthcare systems try to set right the disability. They are aimed at restoring the normal functioning of the body. Healthcare insurance provides support for the necessary expenditures incurred for undergoing medical procedures.

Satz argues that this belief, and the resultant design of healthcare and healthcare systems, promotes 'negative eugenics'.³⁹ It ignores the possibility of existence of alternate ways of human functioning. It gives a blind eye to functional outcomes. For instance, it promotes medical procedures for rectification of the impairment and offers insurance but does not extend insurance benefits to a person who chooses a wheelchair instead of costly invasive medical procedures. The laws and institutions tacitly support the traditional medical model, with no support to the alternative methods.⁴⁰ Persons with impairments opt for the painful and often ineffective medical procedures, as the normal functioning body is accepted and idealized as the only correct position. The medical field works on the assumption that the degree of

³⁶ Harlan Lane, 'Ethnicity, Ethics, and the Deaf-World' (2005) 10(3) *The Journal of Deaf Studies and Deaf Education* 291.

³⁷ *Ibid.* 303.

³⁸ Norman Daniels, *Just Health: Meeting Health Needs Fairly* (Cambridge University Press 2007) 2.

³⁹ Ani Satz, 'Healthcare as Eugenics' in I Glen Cohen et al., (eds), *Disability, Health, Law and Bioethics* (Cambridge University Press 2020) 20–21.

⁴⁰ *Ibid.* Satz supports this stand as insurance companies also support medical treatments instead of providing funds for hearing aids or wheelchairs and the State has made no efforts to help with either.

impairment is inversely proportional to the quality of life. Systems are so designed that they focus on early detection and treatment instead of focusing on cultural or communication issues. Disability has no nature. But the common perception of impairment as a ‘bad-difference’ fails to value the atypical methods of functioning. It skews social and legal support mechanisms. If the principle underlying this health policy continues, ‘individuals with disability may not be born’.⁴¹ Those who exist would be treated to inefficient health care procedures.

But Satz’s objections and apprehensions about extinguishment of disability, seem far-fetched in that abortion laws do not mandate a prohibition on the birth of disabled children.

In 1883, Francis Galton initiated a movement for improving the human stock.⁴² Influenced by Darwin’s theory of natural selection, he coined the term ‘eugenics’ to describe the selection of heritable traits to improve the future generations of humans. Strategising for creating better humans were found in the works of Plato (378 BC) and Tomasso Campanella (1623).⁴³ In 1865, Gregor Mendel discovered the basic laws of heredity.⁴⁴ Darwin argued that humans could steer their future evolution.⁴⁵ The terms ‘positive eugenics’ and ‘negative eugenics’ came into existence. ‘Positive eugenics’ meant the increased reproduction of genetically fit families and ‘negative eugenics’ meant the decreased reproduction of genetically unfit families.⁴⁶

The fourth industrial revolution has set up a storm in the physical, digital, and the biological world.⁴⁷ The Human Genome Project aimed at mapping the genetic information of human cells to enable the identification of disease-causing genes.⁴⁸ Through the past decade there has been considerable discussion and excitement about the capacity of genetic technology to produce ‘designer babies’. The ability to edit the biological world promises giant leaps in medicine, biotechnology, and allied sciences.⁴⁹ In 2015, Chinese researchers became the first to publish a scientific paper on how the DNA of human embryos can be altered.⁵⁰ In 2018, the world’s first gene edited babies took birth.⁵¹ It

⁴¹ Ibid. 21.

⁴² Philip K Wilson, ‘eugenics’ (*Encyclopedia Britannica*). <https://www.britannica.com/science/eugenics-genetics>. Accessed 3 July 2021.

⁴³ Ibid.

⁴⁴ Ibid.

⁴⁵ Ibid.

⁴⁶ Daniel Wikler, ‘Can We Learn from Eugenics?’ (1999) 25(2) *Journal of Medical Ethics* 183, 184.

⁴⁷ Klaus Schwab, *The Fourth Industrial Revolution* (World Economic Forum 2016) 19–27.

⁴⁸ ‘What is the Human Genome Project?’ (*National Human Genome Research Institute*, 28 October 2018). <https://www.genome.gov/human-genome-project/What>. Accessed 18 September 2021.

⁴⁹ F Ann Ran et al., ‘Genome Engineering Using the CRISPR-Cas9 System’ (2013) 8(11) *Nature Protocols* 2281.

⁵⁰ David Cyranoski and Sara Reardon, ‘Chinese Scientists Genetically Modify Human Embryos’ (*Nature*, 22 April 2015). <https://www.nature.com/articles/nature.2015.17378>. Accessed 2 July 2021.

⁵¹ It is claimed that twin girls Lulu and Nana, were born in 2018. He Jiankui used the gene editing tool CRISPR to edit DNA embryos to make them HIV resistant. This got mired in controversy, as humankind was yet to decide on whether it can drive its own evolution and whether technology can be used to interfere with humanity’s shared gene pool. The work was deemed ‘irresponsible’ and invited immense condemnation from scientists world over. Even China condemned it saying it was against ethics. He claimed they were healthy babies. He later presented his work at The Second International Human Genome

generated huge controversy⁵² and was criticised as being ‘criminally reckless’.⁵³ In 2019, the World Health Organization (WHO) issued a statement and advised regulatory and ethics authorities to refrain from issuing approvals to such research.⁵⁴ Later the WHO created a registry for the recording of all human gene editing research.⁵⁵

The Nazi Germany Holocaust⁵⁶ dealings put eugenics in a bad light, when eugenic practices were employed to cleanse the world of communities who were considered inferior. It became synonymous with racism, criminality,⁵⁷ violation of reproductive freedoms,⁵⁸ class bias, etc.⁵⁹

Later societal mindsets indicated similar tendencies, albeit in the individual sphere, that disfavoured disabled lives as being of poor value.⁶⁰ This was also manifested in the desire of individuals to have healthy babies. Laws and institutions reflected the same mindset.⁶¹ So much so that the general population, driven by the traditional notions of disability, believed that carriers of genetic heritable diseases

Footnote 51 (continued)

Editing Summit held in Hong Kong on 27 November 2018, after this matter came to light when MIT Technology Review published an article, Antonio Regalado, ‘Years Before CRISPR Babies, This Man was the First to Edit Human Embryos’ (*MIT Technology Review*, 11 December 2018). <https://www.technologyreview.com/2018/12/11/138290/years-before-crispr-babies-this-man-was-the-first-to-edit-human-embryos/>. Accessed 18 September 2021.

⁵² David Cyranoski, ‘The CRISPR-baby Scandal: What’s Next for Human Gene-editing’ (*Nature*, 26 February 2019). <https://www.nature.com/articles/d41586-019-00673-1>. Accessed 4 July 2021.

⁵³ Christina Farr, ‘Experiments to Gene-edit Babies are ‘Criminally Reckless,’ Says Stanford Bio-ethicist’ (*CNBC*, 26 November 2018). <https://www.cnn.com/2018/11/26/chinese-crispr-baby-gene-editing-criminally-reckless-bio-ethicist.html>. Accessed 18 September 2021.

⁵⁴ ‘Statement on Governance and Oversight of Human Genome Editing’ (*World Health Organisation*, 26 July 2019). <https://www.who.int/news/item/26-07-2019-statement-on-governance-and-oversight-of-human-genome-editing>. Accessed 18 September 2021.

⁵⁵ Kate Kelland, ‘WHO Panel Calls for Registry of All Human Gene Editing Research’ (*Reuters*, 20 March 2019). <https://www.reuters.com/article/us-health-who-gene-editing/who-panel-calls-for-registry-of-all-human-gene-editing-research-idUSKCN1R02IC>. Accessed 18 September 2021.

⁵⁶ State sponsored systematic persecution of the Jews and Gypsies, among other communities.

⁵⁷ Allen Buchanan et al., *From Chance to Choice: Genetics & Justice* (Cambridge University Press 2000) 37.

⁵⁸ Forced sterilisation of around 4,00,000 people was carried out, of which 2000-4000 were sterilised on account of hereditary deafness. See Benoit Massin, ‘Crying Hands: Eugenics and Deaf People in Nazi Germany (Review)’ (2001) 75(1) *Bulletin of the History of Medicine* 165, 166.

⁵⁹ Daniel Wikler, ‘Eugenic Values’ (1998) 11(3-4) *Science in Context* 455, 457.

⁶⁰ The UN Committee of the Rights of Persons with Disabilities expressed concern over societal perceptions about disabled life being of poor value. Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland* (CRPD/C/GBR/CO/1, 2017) [12]; Tiny Tim in Charles Dickens’ *A Christmas Carol* portrays that disabled people deserve pity; Also see Colin Barnes, *Disabling Imagery and the Media: An Exploration of the Principles for Media Representations of Disabled People* (The British Council of Organisations of Disabled People and Ryburn Publishing 1992).

⁶¹ David Ruebain, ‘What is Prejudice as it Relates to Disability Anti-Discrimination Law?’ (*Disability Rights Education & Defense Fund*). <https://dredf.org/news/publications/disability-rights-law-and-policy/what-is-prejudice-as-it-relates-to-disability-anti-discrimination-law/>. Accessed 18 September 2021; Gerard Quinn et al., *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (United Nations 2002); Compulsory steri-

should be restricted from having children.⁶² While eugenic practices are still prevalent, decision making has shifted to individuals and families.

Almost all countries⁶³ have laws that allow screening of fetuses for genetic disorders and aborting them in cases of detected anomalies. There are some international principles that apply to the subject.⁶⁴ Studies reveal that parents prefer to abort a child, if screening shows that the child was deaf.⁶⁵ Another study conducted revealed the factors that should be taken into consideration while devising law and policy on the subject. The key considerations it highlighted were the destruction of embryos, the impairment or the disease that was to be eliminated, the trait that was to be selected, the bigger repercussions of the technological intervention and the future that people contemplate.⁶⁶ Another research conducted on the attitudes of deaf, Deaf, hard of hearing, and hearing people on gene editing, revealed that culturally Deaf persons harboured apprehensions about genetic testing being detrimental

Footnote 61 (continued)

lisation laws; Colette Leung, 'Race Betterment Foundation' (*eugenics archives*, 27 April 2015). <https://eugenicsarchive.ca/discover/tree/553e95f955b4ad0326000001>. Accessed 18 September 2021; Immigration laws of the US to check the dilution of American stock; *Buck v Bell* 274 US 200, 207 (where Justice Holmes opined that 'three generations of imbeciles are enough').

⁶² Dorothy Wertz collected data from 37 countries. The desire for healthy babies was the same across nations. China was more agreeable to State involvement in decision-making. Andy Coghlan, 'Perfect People's Republic' (*New Scientist*, 23 October 1998). <https://www.newscientist.com/article/mg16021572-800-perfect-peoples-republic/>. Accessed 18 September 2021.

⁶³ 80 out of 158 (51%) countries permit abortions in case of adverse foetal conditions. Antonella Lavelanet et al., 'Global Abortion Policies Database: A Descriptive Analysis of the Legal Categories of Lawful Abortion' (2018) 18(1) *BMC International Health and Human Rights* 44, 48. Examples of these laws include The Abortion Act 1967, 1967 c. 87 (UK), and the Medical Termination of Pregnancy Act 1971, Act No. 34 of 1971 (India); The UN Committee of the Rights of Persons with Disabilities stated that 'Women's rights to reproductive and sexual autonomy should be respected without legalizing selective abortion on the ground of fetal deficiency'. Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland* (n 60) [13]; Physical and mental abnormalities are considered as Ground E grounds for abortion. Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales, *Royal College of Obstetricians and Gynaecologists* (May 2010), 3–4. <https://www.rcog.org.uk/globalassets/documents/guidelines/terminationpregnancyreport18may2010.pdf>. Accessed 23 September 2021; See Chitra Subramaniam, 'India's New Abortion Law is Progressive and has a Human Face' (*Observer Research Foundation*, 7 March 2020). <https://www.orfonline.org/expert-speak/india-new-abortion-law-progressive-human-face-62023/>. Accessed 18 September 2021.

⁶⁴ For more reading see Stephen P Marks, 'Tying Prometheus Down: The International Law of Human Genetic Manipulation' (2002) 3(1) *Chicago Journal of International Law* 115; Rumiana Yotova, 'Regulating Genome Editing under International Human Rights Law' (2020) 69(3) *British Institute of International and Comparative Law Quarterly* 653; Melanie Hess, 'A Call for an International Governance Framework for Human Germline Gene Editing' (2020) 95(3) *Notre Dame Law Review* 1369.

⁶⁵ Jyotsna Agnihotri Gupta, 'Exploring Indian Women's Reproductive Decision-making Regarding Prenatal Testing' (2010) 12(2) *Culture, Health & Sexuality* 191, 195; Neetu Chandra, 'Would-be Parents Opt for Abortion of 'Deaf' Fetuses, Says Study' (*India Today*, 18 February 2013). <https://www.india-today.in/india/north/story/abortion-of-deaf-fetuses-on-rise-sir-ganga-ram-hospital-154253-2013-02-18>. Accessed 18 September 2021.

⁶⁶ Andrea L Kalfoglou et al., 'Opinions About New Reproductive Genetic Technologies: Hopes and Fears for Our Genetic Future' (2005) 83(6) *Fertility and Sterility* 1612.

to the interests of their community.⁶⁷ They were of the opinion that they would not consider abortion if it is a hearing foetus, and that abortion of a hearing foetus should be made punishable. Hearing subjects preferred hearing children, as against Deaf who exhibited no preference. Hearing subjects were of the opinion that choice should be given for abortion if the foetus has a hearing impairment, whereas Deaf people thought it should be illegal to abort a deaf foetus. Abortion of hearing foetuses should be illegal.

Reproductive genetic technologies (RGTs), simply put, are technologies that help in designing desired babies with or without certain traits.

RGTs have been categorized as either technologies that result in “genetic additions, deletions, or modifications that alter an embryo’s DNA” or processes—including selective abortion to eliminate fetuses with unwanted traits or preimplantation genetic diagnosis (PGD)—used to select or alter traits without directly manipulating DNA.⁶⁸

DNA is the storehouse of genetic information for the organism. It may be described as a unique⁶⁹ code that is specific to the person and determines the characteristics, traits etc. While no two persons’ DNA can be the same, they are common to the extent of 99.5%.⁷⁰ Yet the miniscule difference of 0.5% that is found contributes significantly to the variation between individuals. Preimplantation genetic diagnosis is used to diagnose genetic defects within embryos. Once detected, RGTs may be used to rectify the defects.⁷¹ Classifying RGTs broadly under two categories, Professor Kirsten Rabe Smolensky refers to these as ‘direct’ and ‘indirect’ respectively.⁷² Gene editing technologies that allow ‘direct’ ‘genetic manipulation’ have evoked interest and widespread deliberations.

One technique in particular that has garnered interest is CRISPR/Cas9. It works using a pair of molecular scissors to cut off the unwanted part of the DNA precisely and replace it with a desired substitute. It is claimed that the principle underlying this technique is borrowed from nature.⁷³ While this technique has huge potential in terms of prevention of serious ailments, it also lays unrestrained power in the hands of the user for using it for non-therapeutic purposes as well. This includes

⁶⁷ S J Stern et al., ‘Attitudes of Deaf and Hard of Hearing Subjects Towards Genetic Testing and Prenatal Diagnosis of Hearing Loss’ (2002) 39(6) *Journal of Medical Genetics* 449.

⁶⁸ Shawna Benston, ‘CRISPR, A Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability’ (2016) 5(1) *Laws* 5, 6.

⁶⁹ John A Robertson, ‘Extending Preimplantation Genetic Diagnosis: The Ethical Debate: Ethical Issues in New Uses of Preimplantation Genetic Diagnosis’ (2003) 18(3) *Human Reproduction* 465. Preimplantation genetic diagnosis is a process to screen embryos for potential diseases.

⁷⁰ ‘How is the Completed Human Genome Sequence Being Used?’ (*Your Genome*). <https://www.yourgenome.org/stories/how-is-the-completed-human-genome-sequence-being-used>. Accessed 20 September 2021.

⁷¹ For more reading see JPM Geraedts and GMWR De Wert, ‘Preimplantation Genetic Diagnosis’ (2009) 76(4) *Clinical Genetics* 315.

⁷² Kirsten Rabe Smolensky, ‘Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions’ (2008) 60(2) *Hastings Law Journal* 299.

⁷³ Benston, ‘CRISPR, a Crossroads in Genetic Intervention’ (n 68) 6.

trait selection and gene manipulation. To what extent can gene editing be permitted? Issues have been raised concerning the identity, diversity and the role of genetic technology in creating designer babies.⁷⁴ While ‘tailor-made’ babies to suit the fancies of commissioning parents may soon be a reality, it remains to be seen, to what extent the implementation of such fancies will have the approval of the law.

Since deafness is detrimental to a certain extent to the health and well-being of a person, the aid of genetic technology cannot be called for the creation of deafness. The key stakeholders apart from the society are the Deaf parents, hearing parents, future child⁷⁵. The concern is with respect to selection or manipulation of a gene in favour of creating deafness or removing deafness. The competing and the conflicting claims that can be deduced are Deaf parents demanding similar liberty as the hearing parent to choose traits. Note that a key stakeholder, the future child, is not involved in the decision-making process.⁷⁶ Presently parental liberty to use genetic technology have been restricted by barring sex selections and permitted for detection of foetal anomalies. Curbing parental liberty to protect the interest of future children may be jurisprudentially impossible, except where it is to protect a State recognised interest of the society in ensuring public health with reduced impairments. The availability of technology for the screening of foetuses for anomalies and abortion laws allowing termination are factors that allow parents to choose termination of pregnancy, without compelling them to do so. Parents who choose to abort a foetus are exercising their personal choice. By aborting a foetus that carries impairment, they are not making moral judgements about the disability.⁷⁷ Hence, to say that abortion laws are eugenic in nature, would be incorrect.

4 On the morality of designing impaired babies or creating enhancements

Some questions that philosophers⁷⁸ have been trying to grapple with are—whether it is morally permissible for a parent to use genetic technology for the creation of impairment in an offspring? Whether it is morally permissible for a parent to use genetic technology for the creation of enhancements?

Most disability scholars try to espouse the cause of the impaired.⁷⁹ They claim that disability is not necessarily harmful, grossly negative or something to be pitied

⁷⁴ Nancy Pham, ‘Choice v. Chance: The Constitutional Case for Regulating Human Germline Genetic Modification’ (2006) 34(1) *Hastings Constitutional Law Quarterly* 133.

⁷⁵ Not a legal person at this juncture.

⁷⁶ Whether a future child would have a right to sue parents for choosing or creating disablement considering laws that support compensation for injuries caused to the foetus before birth remains to be seen but it is not a subject matter for the present study.

⁷⁷ John Gillott, ‘Screening for Disability: A Eugenic Pursuit?’ (2001) 27 *Journal of Medical Ethics* 21.

⁷⁸ Michael J Sandel, *The Case Against Perfection: Ethics in the Age of Genetic Engineering* (Harvard University Press 2007); Elizabeth Barnes, *The Minority Body* (n 10).

⁷⁹ Teresa Blankmeyer Burke, *Quest for a Deaf Child: Ethics and Genetics* (DPhil Thesis, The University of New Mexico 2011). See also Oliver Feeney and Vojin Rakić, ‘Genome Editing and ‘Disenhancement’: Considerations on Issues of Non-identity and Genetic Pluralism’ (2021) 8 *Humanities and Social Sciences Communications*.

and cured, as the proponents of ‘bad-difference’ view claim. It is just another example of diversity amongst societal members. It puts the person in a distinctly dissimilar situation but not in an exclusively worse off situation. Such diversity should be valued and respected.

The opponents of ‘mere-difference’ view are appalled at the contention.⁸⁰ They believe that disability scholars will next argue for a ‘right to disability’⁸¹ leading to a quest for a disabled child or may even argue that hearing impairment be left untreated. If the ‘mere-difference’ view is accepted, then disability cannot be removed. Since disability scholars consider impairment as a ‘mere-difference’, does it follow that it is permissible to intervene in the genetic composition of a person and edit it in favour of creating disability, or that it is wrong to treat impairments by medical procedures?

Burke, a member of the signing Deaf community, in her thesis titled *Quest for a Deaf Child: Ethics and Genetics*, states that deaf people often desire to have deaf children.⁸² They often harbour a ‘deep longing to have a child who can be an integral part of their linguistic and cultural community’.⁸³ Burke lists some of the benefits that are associated with being deaf.⁸⁴ Within the Deaf world, the deaf person is normal, not different; being deaf gives membership to the Deaf community (with whom they connect at the social and at the emotional level) that is a small minority community within a larger community, yet a transnational one. It enhances opportunities. Burke also perceives other benefits in keeping diversity alive. She asserts that it enriches human experience by exposure to varied languages and cultures.⁸⁵ The presence of Deaf community encourages human compassion⁸⁶ and presents more opportunities for demonstration of magnanimity and generosity. It further keeps the beauty of sign language alive. Burke states the aesthetic appeal of ‘form and motion’ in the sign language is an intrinsic good that is beautiful and needs to be cherished.⁸⁷ Burke refers to William May in Michael Sandel’s work stating that deafness can be a gift. In accepting and in being ‘open to the unbidden’,⁸⁸ there is benefit in willing

⁸⁰ Allen Buchanan et al., ‘From Chance to Choice’ (n 57); John Harris, ‘One Principle and Three Fallacies of Disability Studies’ (2001) 27(6) *Journal of Medical Ethics* 383; Jeff McMahan, ‘Causing Disabled People to Exist and Causing People to be Disabled’ (2005) 116(1) *Ethics* 77; Guy Kahane, ‘Non-identity, Self-defeat, and Attitudes to Future Children’ (2009) 145(2) *Philosophical Studies* 193; Peter Singer, ‘Ethics and Disability: A Response to Koch’ (2005) 16(2) *Journal of Disability Policy Studies* 130.

⁸¹ The author raises an interesting philosophical debate on a ‘right to disability’ for consideration. Benston, ‘CRISPR, a Crossroads in Genetic Intervention’ (n 68).

⁸² Burke, *Quest for a Deaf Child* (n 79) vii.

⁸³ *Ibid.*

⁸⁴ *Ibid.* 163–168.

⁸⁵ *Ibid.* 166.

⁸⁶ *Ibid.* 166.

⁸⁷ *Ibid.* 166–67.

⁸⁸ William May as cited in Michael J Sandel, *The Case Against Perfection* (n 78) 45–46.

to ‘relinquish mastery and control’.⁸⁹ Burke further states that whether one participates in a ‘genetic lottery,’⁹⁰ or buys deaf genes at the ‘genetic supermarket,’⁹¹ the outcome isn’t markedly different. The set of characteristics that children acquire combined with life experiences, shape their future.⁹² Thus, they may encounter an unaccommodating society, or may even benefit from the varied support schemes of the State and flourish. She adds that the prevalent notion amongst deaf persons is—instead of asking what one loses out of being deaf it would do well to ask what does one gain out of it. Seeing these benefits and having a neutral outlook towards impairment, deaf people have no qualms or apprehensions about having deaf children. Burke claims that it is morally justifiable to select deaf genes to design a child who can be a part and parcel of a community they cherish.

In the following paragraphs these arguments are verified on the touchstone of the Kantian⁹³ theory of morality. I especially choose the Kantian theory as it is central to all⁹⁴ deontological theories and scores over consequentialist theories that base their decisions of moral worthiness of actions on the consequences of the act. Deontological theories focus on the action itself. Can a hearing-impaired parent make a valid moral claim for using genetic intervention for the creation of a hearing-impaired child?

As stated in the above paragraph, the justifications are:

- i. desire to have a child who can belong to and participate in the cultural community of the Deaf world, and
- ii. desire to share what they cherish, and
- iii. numerous opportunities are available for deaf children, and
- iv. it maintains diversity in the society.

⁸⁹ Burke, *Quest for a Deaf Child* (n 79) 167.

⁹⁰ John Rawls, *A Theory of Justice* (Harvard University Press) 107-108. Knowing fully well that in the natural state there is always inequality, Rawls proposes liberty and equality on the minimax principle, to bring about justice in the society. Though we complain that nature is never just, we have built our understanding and our laws to suit that difference. Our equality laws have grounding in the fact that race, sex, gender, impairment are not choice domains. Designer babies/CRISPR babies challenge that notion. They project a world where some traits would be naturally considered superior and thereby all babies could have them and this would be demeaning to the others. For it would not be just about removing impairments, it would be indirectly derogating the moral status of the living with those not so preferred characteristics. For more reading see Kelly Dhru, ‘Rawlsian Questions about CRISPR Gene Editing’ (*Bill of Health*, 23 August 2016). <https://blog.petrieflom.law.harvard.edu/2016/08/23/rawlsian-questions-about-crispr-gene-editing/>. Accessed 25 June 2021.

⁹¹ Colin Gavaghan, *Defending the Genetic Supermarket* (Routledge 2006) i. The author refers to the works of Robert Nozick where he speculated about prospective parents able to shop the characteristics of their child from a genetic supermarket.

⁹² Burke, *Quest for a Deaf Child* (n 79) 167.

⁹³ Immanuel Kant makes a case for a moral theory in his writings titled *Groundwork of the Metaphysics of Morals* (1785), *Critique of Practical Reason* (also known as the Second Critique; 1788), and the *Metaphysics of Morals* (1797).

⁹⁴ Larry Alexander and Michael Moore, ‘Deontological Ethics’ (*Stanford Encyclopedia of Philosophy*, 21 November 2007). <https://plato.stanford.edu/entries/ethics-deontological/#DeoTheKan>. Accessed 20 September 2021.

Kant suggests that for an action to be morally right, it should be unconditionally good in itself.⁹⁵ If an action is good by virtue of another then it is conditional to the other. The action should have moral worth independent of any other consideration. Kant believes that what is of utmost importance is the ‘good will’ or the ‘motive’ that propels the action. Consequences of an action do not endorse the morality of an action. Consequences may be good or bad, but they do not help in deciding the moral worthiness of the act. If the reason for the action is a higher moral law propelled by duty it is morally upright. So, it is the motives and not the consequences that matter.

A preliminary glance into the first argument, (i) desire to have a child who can belong to and participate in the cultural community of the Deaf world, seems justified where deaf parents are concerned. Hearing persons may not really be in a position to sit on judgement over the longing that deaf parents experience. The privilege of being a member of the Deaf cultural community and the feeling of belongingness that it provides is a rich experience that is not found amidst the hearing world. In fact, from the narrative experiences of deaf persons it can be gathered that they face social apathy as they are perceived to be burdens,⁹⁶ pity and objects of charity⁹⁷ at not being able to be independent and requiring help.⁹⁸ As against that, what the Deaf world offers is confidence, independence, and the strength to fight their impairment and perceive it as a mere-difference. That’s empowering.

These arguments, that seem right at the first glance, on a closer look fail the duty requirement that Kant provides. It yields contra results on the duty-inclination parameter. Kant requires an examination of the motive. If the action is driven by a motive of duty the action is morally worthy. If it is driven by inclination then the action is not morally worthy.⁹⁹ The underlying reason this argument presents is that being deaf, they yearn for a deaf child who can belong to their own linguistic and cultural community. Denuding it off the emotional attributes, it points to a self-interest, a want, a desire, to have a child, bearing certain attributes (here deafness), so as to fit in one’s own cultural community that consists of deaf persons. This argument stems from human inclination.¹⁰⁰ It stems from a selfish interest of wanting a child akin to their (parents) characteristics. It arises from a biological conditioning of the mind. Basing actions on desires strips it of its moral essence.

⁹⁵ Immanuel Kant, *Fundamental Principles of the Metaphysics of Morals* (Thomas Kingsmill Abbott tr, first published 1785, Dover Publications 2005) 29.

⁹⁶ Luke Staniland, *Public Perceptions of Disabled People: Evidence from the British Social Attitudes Survey 2009* (Office for Disability Issues, HM Government 2010) 24–34.

⁹⁷ United Nations Department of Economic and Social Affairs: Disability, *Disability and the Media*. <https://www.un.org/development/desa/disabilities/resources/disability-and-the-media.html>. Accessed 20 September 2021.

⁹⁸ Gerard Quinn et al., *Human Rights and Disability* (n 61) 33–35; Naveli Sharma, Virendra Pratap Yadav, and Aashima Sharma, ‘Attitudes and Empathy of Youth Towards Physically Disabled Persons’ (2021) 7(8) *Heliyon*.

⁹⁹ Robert Johnson and Adam Cureton, ‘Kant’s Moral Philosophy’ (*Stanford Encyclopedia of Philosophy*, 7 July 2016). <https://plato.stanford.edu/entries/kant-moral/>. Accessed 30 June 2021.

¹⁰⁰ For more reading on inclination, see Tamar Schapiro, ‘The Nature of Inclination’ (2009) 119(2) *Ethics* 229.

Would the argument be morally worthy if it were to focus on the child rather than on the desire of the parent? Suppose we twist the argument to—it would be in the best interest of the child to belong to the community his parents belong to and therefore share the same attributes as the parents. The answer would still be a no because from a prudential viewpoint, it would still lack the grounding in duty. Such an argument would still stem from a natural inclination of humans to be close to members of their community. It rests on an assumption that the child would be a member of the Deaf community only and will not move out, and so being deaf would be good for him. It snatches the child's autonomy and decides on his behalf.

The second argument—(ii) deaf parents desire to share what they cherish—also stems from an emotional need to share emotions with like persons. It is the natural tendency of human beings to share their feelings. Actions arising from inclinations lack moral worthiness. It is also not an autonomous decision. A decision is heteronomous when it is driven by something apart from the subject itself. Acting autonomously, according to Kant, is acting as per a law that I give to myself.¹⁰¹ A Deaf parent's desire to have a deaf child, to share what they cherish, is propelled by their experience of deafness. The motive for the decision can be traced back to their bodily and sensory experience of being deaf. Like an action of drinking water is propelled by the need to quench thirst and as such is not an autonomous action. If the motive of an action can be traced back to a requirement that is an outcome of being a human being with sensory needs, actions propelled out of such motives aren't autonomous. It's rather a dictate of my human nature.

The third argument—(iii) numerous opportunities are available for deaf children—is primarily utilitarian in nature. Burke lists the benefits that are available to deaf persons.¹⁰² Educational support and other disability benefits under social security or other schemes are available for persons with varied degrees of impairments. But to argue that the child will be benefited under all these schemes were he to be deaf is like doing one thing for the sake of another. As human beings we do that often. In this case deafness is merely instrumental to have access to opportunities. It is to say—be deaf or you forgo all benefits. It is a sort of instrumental reasoning that states that if you want to avail of all the opportunities then have a deaf child. Kant would reject the moral worthiness of this decision as being heteronomous in nature. Creating a deaf child for the sake of access to opportunities and concessions is using the impairment to avail benefits and this makes it morally wrong.

The fourth argument raised is—(iv) it keeps alive diversity in the society. '[W]e learn what it is to be human when we look at different modalities, whether it is writing, or signing, or speaking. And so, to eradicate a thriving, flourishing, signing deaf community seems just, on the face of it, wrong to me'.¹⁰³ This is a utilitarian

¹⁰¹ Michael J Sandel, *Justice: What's the Right Thing to Do?* (Penguin 2010) 197; Kant, *Fundamental Principles of the Metaphysics of Morals* (n 95) 27.

¹⁰² Burke, *Quest for a Deaf Child* (n 79) 167.

¹⁰³ This extract is from an interview of Teresa Blankmeyer Burke from a podcast episode of *Let's Make the Future*. 'Deafness and Genetic Engineering' (*Let's Make the Future*, 7 September 2018). <https://letsmakethefuture.com/2018/09/07/lmtf-podcast-episode-20-deafness-and-genetic-engineering/>. Accessed 24 June 2021.

argument. It indicates the usefulness of preserving the Deaf community. Arguments based on the principle of utility tend to measure the total outcome of an action or decision in terms of contributing towards maximising happiness. If it maximizes happiness and minimises pain, the action has a good tendency.

There are a few strands in this argument that need examining. The argument has merit in that diversity must be protected. This is generally applied to preserving diverse culture, diversity in language, biodiversity, and such others. The human mind profoundly develops when it is applied to diverse cultures, experiences and it helps shape not just humans but also knowledge.¹⁰⁴ An important part of human flourishing is the application to the senses of all possible variations the world can offer.

The Deaf community offers an experience of an inclusive society, bound by common issues, providing support to its members, empathising with each other, and bearing a distinct language. Members of the community find this beautiful and enriching. It is not something to be thrown away. It should be cherished and preserved. So, it points to a common good as an outcome.

There are diverse opinions on whether the Deaf community offers a culture distinct and separate from the rest of the society that they are in.¹⁰⁵ While trying to eradicate the impairment, spreading awareness and supporting deaf persons, we have arrived at a stage where rich cultural diversity that it presents is valued.¹⁰⁶ While most members of the Deaf community perceive it as a distinct culture,¹⁰⁷ others have pointed out¹⁰⁸ that there is not much beyond a distinct language that one may refer to. Even assuming that the Deaf community offers a culture that has a distinct standing of its own and that exposure to a distinct culture helps in the development of knowledge in many ways. Would it be morally right to conclude that we should let the deaf community grow numerically, so that the others have a chance to perceive a culture rich on its own?

If there is an element of ‘harm’ that an impaired person is faced with,¹⁰⁹ there is a cost. The cost is the pain of the deaf person. At his cost the society continues to perceive and know about the Deaf culture. Therefore, creation of deaf persons for the sake of continuing a community of Deaf so that others in the world are kept abreast

¹⁰⁴ Denise C Park and Chih-Mao Huang, ‘Culture Wires the Brain: A Cognitive Neuroscience Perspective’ (2010) 5(4) *Perspectives on Psychological Science* 391; Massachusetts Institute of Technology, ‘Culture Influences Brain Function, Study Shows’ (*Science Daily*, 13 January 2008). www.sciencedaily.com/releases/2008/01/080111102934.htm. Accessed 20 September 2021. This study found that patterns of usage of the brain varied from culture to culture.

¹⁰⁵ See Padden and Humphries, *Inside Deaf Culture* (n 4).

¹⁰⁶ Marion Andrea Schmidt, *Eradicating Deafness? Genetics, Pathology and Diversity in Twentieth-Century America* (Manchester University Press 2020).

¹⁰⁷ Kathleen Brockway, *Baltimore’s Deaf Heritage* (Arcadia Publishing 2014); Clifton F Carbin and Dorothy L Smith, *Deaf Heritage in Canada: A Distinctive, Diverse, and Enduring Culture* (McGraw-Hill Ryerson 1996); Kaehee M Christensen and Gilbert L, *Deaf Plus: A Multicultural Perspective* (DawnSign Press 2000).

¹⁰⁸ Megan A Jones, ‘Deafness as Culture: A Psychosocial Perspective’ (2002) 22 (2) *Disability Studies Quarterly* 51. Jones refers to authors perceiving deafness as an impairment in the Deaf Culture Debate.

¹⁰⁹ Barnes, ‘Valuing Disability, Causing Disability’ (n 35).

of a diversity, is an argument that has absolutely no moral standing. Consequences do not decide the moral worthiness of an action. The fact that it serves greater good, does not make the decision right. Morality cannot base itself on such empirical considerations of the ‘greatest happiness of the greatest number’.¹¹⁰

While it is essential that cultural diversity be protected, it should not be at their cost. They are individuals worthy of respect. Kant states, ‘act that you use humanity, whether in your own person or in the person of any other, always at the same time as an end, never merely as a means’.¹¹¹ It is immoral to use persons as instruments for the attainment of other things. In so doing we devalue humans to mere things. Deaf persons being persons, have intrinsic value that must be respected. Any preservation of culture cannot be at the cost of their humanity. Similarly, the protection of Deaf culture cannot be at the cost deaf persons.

As seen in the previous section, laws permitting abortions in case of foetal anomalies are not designed to be eugenic, neither are the oppositions to the creation of impaired babies eugenic. Though a beautiful world has been created by and for the Deaf community, it would be fallacious to say that for its continued existence, we need to permit the creation of impaired persons. It is the culture that has been built to serve and support the deaf persons and not vice versa. The values stay on as the ‘jewel shining for its own sake’¹¹² and not because of the gold ring that embeds it.

So, creating impairments, in my view, fails to pass the Kantian test of morality. We now consider the case for enhancements.¹¹³ If genetic technology could help to enhance hearing, beyond the range of what humans can hear, would it be morally permissible to employ the same?

Enhancements here refer not to the welfarist model of enhancements.¹¹⁴ ‘Enhancement’ here means alteration in the genetic composition to improve the performance. Any modification done to the genetic composition that helps in the improvement of the functional or aesthetic appearance would be included within the meaning of the term ‘enhancement’. So, enhancements could be with respect to genetic technological intervention aimed at a fairer skin, better height, shape of physical features, etc. that are purely cosmetic and appealing to the aesthetic sense. It could be purely functional as changes that are aimed at enhancement of strength, vision, hearing capacities that help in better functioning. To illustrate, enhancing hearing capacity to be able to hear dog whistles as well or improving athletic performance.

¹¹⁰ John Stuart Mill, *Utilitarianism* (first published 1863, The Floating Press 2009) 8, 14. See also Bentham, *An Introduction to the Principles of Morals and Legislation* (n 22) 1–7.

¹¹¹ Kant, *Fundamental Principles of the Metaphysics of Morals* (n 95) 16.

¹¹² Kant, *Fundamental Principles of the Metaphysics of Morals* (n 95) 5.

¹¹³ For more reading on enhancements see Alexander Harding, ‘Rehabilitation or Enhancement? FDA & The Gene Therapies of Tomorrow’ (2020) 33(2) *Harvard Journal of Law and Technology* 639.

¹¹⁴ Walter Veit, ‘Procreative Beneficence and Genetic Enhancement’ (2018) 32(1) *KRITERION-Journal of Philosophy* 75.

Causing enhancements has been endorsed¹¹⁵ as well as met with much criticism.¹¹⁶ This section discusses the autonomy argument as against the instrumental use that cases of enhancements endorse and the argument that humans should not meddle with nature. That the ‘openness to the unbidden’ teaches humility and is of immense value. I argue that the autonomy argument does not pass the Kantian test. A person is not acting autonomously while his actions are governed by his desires. The humanity in the child is sacrificed when he becomes the instrument to fulfil another’s desires. I deviate from the ‘power in the openness to the unbidden’ argument and argue that there is nothing wrong about using genetic technology to the extent it allows us to improve ourselves. But using genetic technology to create enhancements in future children robs them of their humanity.

If causing impairment is wrong because it causes ‘harm’, causing improvements must be good as it would be beneficial. *Prima facie* causing enhancements seems unproblematic. If genetic technology is freely available, parents would have the option to use it for the creation of enhancements, unless prohibited by law. Libertarians argue that human-beings have the autonomy to decide how they want their offspring to be. They shape the lives of their children with respect to the child’s upbringing as well that includes schooling, language, etc.

But causing foetal enhancements cannot be equated with shaping lives of children after birth. Extreme cases of parental involvement in shaping the child’s future whether after or before birth, relegates him to mere instrumental value.

Enhancements may be of two kinds—cosmetic enhancements and functional enhancements. Consider the case of cosmetic enhancements. Parents could choose the colour of the skin, hair, or the colour of the eyes, based on the socially praised standards of beauty. Consider the case of functional enhancements. Parents could choose taller, stronger genes as traits. It is the desire to have a child with specific traits that governs this choice. Kant would say, acting as per dictates of social conventions or desires is not autonomous action.

There are other questions that do not squarely require an examination of the moral basis, but nevertheless require considerable thought. Laws lay down that a person cannot be discriminated based on his caste, sex, race, nationality etc. as these are not for him to choose. He is simply born into them. Laws try to artificially set right the natural inequalities. If inequalities are not natural in the first place what would be the justification for having a law to force equality? Can a parent be sued for having introduced a trait that has a negative consequence on their well-being?

But there are deeper problems associated with it that raises questions on the morality of the action. As Sandel points out, (1) Children are not instruments to satisfy our desires, and (2) there is some power in the ‘openness for the unbidden’.¹¹⁷

The first argument is similar to why causing impairment is wrong. When parents fulfil their dreams through their children, children are reduced to mere instrumental

¹¹⁵ Richard A Posner, ‘In Defense of Prometheus: Some Ethical, Economic, and Regulatory Issues of Sports Doping’ (2008) 57 *Duke Law Journal* 1725.

¹¹⁶ Sandel, *The Case Against Perfection* (n 78) 45–46.

¹¹⁷ May as cited in Sandel, *The Case Against Perfection* (n 78) 45–46.

value. The second argument reinforces the power of nature and human vulnerability to that power. It keeps us humble and restrained. Children are the gifts of nature. We know the nature of the gift only when we have them. Sandel points out at a problem in the hubris of man to obtain mastery over birth which is natural process.¹¹⁸ In so doing, the humility that we carry in knowing the strength of nature and our own vulnerability to it is robbed. But scientific inquiry particularly in medical science, is directed towards the improvement of human health. The pursuit of knowledge is also to find ways of making our lives better. The spirit of inquiry that humans possess leads them to fascinating insights into improving human stock. It would be wrong to give up on them for the sake of the humility, that an ‘openness to the unbidden’ would teach us. And there would still be much left to the unbidden.

Thus, causing enhancements also does not stand the test. Actions dictated by desires are not autonomous and in causing enhancements uses children as tools. Like we choose the features of a car, or a piece of furniture to see if it matches the decor; we do not want children to be so designed to match the tastes and the traits of the society, the parents, or the family. Converting them into tailored products of certain physical attributes and with certain extra powers and strengths, denudes them of their autonomy to make them instruments of their parents. That’s where it is morally questionable.

5 On responsible use of eugenics: Balancing of conflicting interests

Parents have a time-honoured right to raise their child as they deem fit.¹¹⁹ They have the first right¹²⁰ to decide on the child’s upbringing, education,¹²¹ the language and the medium of learning *inter alia*. It is largely also determined by the place of his birth and the status of the family to which he is born.¹²² The natural lottery that a child may win or lose. But those are circumstances beyond human control. It can be mitigated to a certain extent, but not completely. Parents have a primary responsibility for the upbringing of their child.¹²³ The underlying assumption is that parents are naturally inclined to further the best interests of the child. It has been the convention that parents have always exercised their liberty right to decide on the child’s

¹¹⁸ Sandel, *The Case Against Perfection* (n 78) 61; Posner opposes Sandel with a libertarian argument in Posner, ‘In Defense of Prometheus’ (n 115).

¹¹⁹ William J Brennan, Stephen L Sepinuck, and Mary Pat Treuhart, *The Conscience of the Court: Selected Opinions of Justice William J. Brennan, Jr. on Freedom and Equality* (Southern Illinois University Press 1999) 41; *Federal Communications Commission v Pacifica Foundation* 438 US 726 (1978).

¹²⁰ A common law liberty-right protected from state interference. E.g., It’s the fundamental duty of parents to send their child to school in India. The Constitution of India art 51A(k).

¹²¹ Erik M Zimmerman, ‘Defending the Parental Right to Direct Education: *Meyer and Pierce* as Bulwarks Against State Indoctrination’ (2005) 17 *Regent University Law Review* 311; *Wisconsin v Yoder* 406 US 205 (1972) on the kind of education; *Prince v Massachusetts* 321 US 158 (1944) on exposure of children to serious hazards.

¹²² See also Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 UNTS 3 (CRC) art 18, 23.

¹²³ CRC art 18.

upbringing, education, values¹²⁴ that have a bearing on his life; and this has been generally understood as a parental responsibility.

Children have a right to an open future. Would that be a misnomer?¹²⁵ Children are persons on their own, but being minors, they depend on their parents for care.¹²⁶ Yet a complete autonomy of a parent over the child's future cannot be validly read in parental autonomy.¹²⁷ Genetic interventions made before the birth of a child would have an effect on the child's life, and its future descendants. A decision on the physical attributes of the child, say the colour of the skin, eyes, or hair, different from that of the parents, that *prima facie* seem harmless, but combined with societal responses may have long lasting detrimental effects on the well-being of the child. Hence any unnecessary technological intervention except where it is for the health benefit of the child may be seen as a harm.¹²⁸

6 Conclusion

An inquiry into the question of whether disability is a disadvantageous condition has revealed that it constitutes some harm. The 'mere-difference' view does not completely project the condition. It stresses on the social construct and in that context implores a correction of mindsets. But in the personal sphere there remains a cost of disability. It may be in the nature of a faculty not experienced, or a pain felt in the body. To that extent it involves harm. Good health is an optimal condition of living. States follow the traditional model and fund medical procedures for setting right the disability but does not fund for a wheelchair. This objection points out a very nuanced stand imploring for viewing disability not as a pathological condition, but as a condition of a minority body. So instead of rectifying the pathological condition, it would be better to facilitate changes in the environment. Often disability scholars have raised suggestions that instead of rooting out disability it would do well to treat disabled persons as holders of minority body and support their differential requirements. They have raised apprehensions about abortions laws being eugenic. But this research finds that since abortion laws do not make it mandatory to remove foetus—it is not eugenic in nature. It merely permits abortion in parents so choose.

This research paper using Kantian theory has argued that the autonomy claim fails where the basis of the claim lies in a desire. Heteronomous decisions aren't autonomous. For the same reasons it is morally impermissible to create impairments for the sake of keeping the Deaf world continuing. Parents do have a responsibility

¹²⁴ John A Robertson, 'Genetic Selection of Offspring Characteristics' (1996) 76(3) *Boston University Law Review* 421, 480.

¹²⁵ Burke, 'Deafness and Genetic Engineering' (n 103).

¹²⁶ Robertson, 'Genetic Selection of Offspring Characteristics' (n 124) 481.

¹²⁷ State may intervene in cases of harsh punishments to child. *Parents Forum for Meaningful Education v Union of India* AIR 2001 Delhi 212.

¹²⁸ Jason C Glahn, 'I Teach You the Superman: Why Congress Cannot Constitutionally Prohibit Genetic Modification' (2003) 25(2) *Whittier Law Review* 409, 430–34.

for upbringing of their children, but it is far-fetched to argue that it encompasses causing of deafness. The use of genetic technology to modify the genes so as to remove health problems and disabilities have moral justification. But the creation of impairments is not morally supported. Creation of impairments strikes at the humanity in the person and uses him as a tool for the satisfaction of desires. Similarly, the use of genetic intervention to generate enhancements of a cosmetic nature or of a functional nature robs the person of his autonomy. So, neither impairments nor enhancements can stand the test of morality.

Declaration

Conflict of interest The author has no conflicts of interest to declare that are relevant to the content of this article.

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