

Fixing Deafness

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As we exist in a world of ever-increasing technological advances, perhaps it should have been expected that we would reach a point where we would want to repair all broken people and fix all those who deviate from the norm. To be honest, the drive to normalize people to fit with expected archetypes existed far before modern medicine and advanced technologies gave us the means to alter people in the profound ways we now have at our disposal. Modern medicine and technological advances have just given us better tools for the physical “fixing” of those judged to be broken. One important consideration is whether those individuals desire to be fixed in the first place.

In contrast to the drive to “fix” persons with disabilities, representatives from communities of persons with disabilities have come forward in recent years to argue for the cessation of treatments and technologies aimed at fixing those in their groups. The Deaf¹ community is a well-publicized example of such a group, as they advocate for the cessation of certain technologies aimed at fixing deafness, which many Deaf individuals do not consider a disability (Ladd 2003; Lane 2005). One striking feature of the cases involving deaf and Deaf individuals refusing technologies aimed at changing their deafness is the response of incredulity from the hearing community when they learn that there are deaf people who do not want to be “fixed.” Although not all members of the Deaf community are against such treatments and technologies, the Deaf community represents the most publicized and adamant of those who lobby against certain kinds of assistive technologies, as they argue, for example, that cochlear implants forced upon deaf children will result in the genocide of the Deaf culture (Lane 1997).

The model used for delineating “normal” people from persons with disabilities can have a profound impact on decisions regarding the use of assistive technologies on existing deaf people and in the deliberate creation of future deaf people. We will address the current debates over cochlear implants and the use of assistive technologies to genetically select for deafness in potential offspring. We will also discuss whether deafness is necessarily a harm that should be corrected and avoided.

This paper addresses and answers the following two related questions. First, is either

the medical model or the psychosocial model preferable for framing ethical arguments and policy decisions regarding persons with disabilities and deaf people in particular? Second, considering the controversies surrounding genetically selecting for deafness and cochlear implants, should deafness be fixed and prevented whenever possible? In answering the first question, we argue that the psychosocial model is preferable as it considers more than the medical and physical aspects of disability and is thus more “human-centered”. In answering the second question, and working within the framework of the psychosocial model, we argue as follows: (1) deafness isn’t necessarily a bad thing, or a harm, and can be a good thing for individual deaf or Deaf people; (2) deafness should not be fixed without the consent of deaf or Deaf persons, although competent people can decide for themselves or their children to attempt to change their deafness; (3) it is morally permissible for parents to genetically select for deafness; and (4) when choosing cochlear implants for children, it is preferable to have parents understand the controversy surrounding the implants, including issues raised by the Deaf community, before they consent to surgery.

The structure of the paper is as follows. We first consider the terminological and theoretical differences between the medical model and the psychosocial model for viewing persons with disabilities. We argue that working within the psychosocial paradigm provides a preferable lens with which to view and evaluate the use of assistive technologies. Following this is a discussion of deafness and Deaf culture, including variations amongst deaf persons, the distinct causes and co-occurrences² of other physical conditions, the disparities existing between deaf individuals and hearing individuals in general, and the appropriateness of viewing the Deaf culture as worthy of protection or preservation. The third section examines the claims arising from two important moral controversies raised by the Deaf community; namely, the controversy over allowing potential parents to select for genetic deafness and the controversy over cochlear implants and assistive technologies that aim to fix deafness. This section also considers whether deafness is a harm that should always be avoided. The final section summarizes the arguments and contains a brief discussion of autonomy, consent, and choosing for or against deafness, as these relate to the two distinct models for framing disabilities, along with suggestions for policies governing the application of “fixing” technologies on deaf individuals.

The medical model vs. the psychosocial model: Reconceiving persons with disabilities

The paradigm within which we construct the boundaries of “disabilities” that delineate the normal from the disabled has significant consequences for the questions at hand. The two models of disability that we will evaluate here are the medical model, prevalent among physicians and many healthcare providers, and the psychosocial model, prevalent among counselors and psychologists.

Medical models of human beings in general and of persons with disabilities in particular view people as the sum of their parts. Like the Cartesian automaton bodies inhabited

mysteriously by ethereal souls, human bodies are conceived of as machines that can be broken and thus can be fixed, leaving the task of diagnosing and fixing the pieces to medical professionals. And while medical models have been quite successful in framing medical research, in advancing science, and in saving lives, there remains a nagging suspicion that we are more than the mere sum of the parts of our physical bodies. Because a disability, on the medical model, is essentially equivalent to bodily parts that are not functioning “normally,” many disabilities are theoretically “fixable” if it is within the medical practitioners’ abilities to bring the body closer to “normal”. Conceived in this way, “people with disabilities” are viewed as “disabled people,” a nomenclature that focuses on their disabilities first rather than their abilities. In examining cases of deaf individuals, however, a striking factor is the high degree of variation in what counts as “deaf” and variations in the extent of positive and negative consequences of deafness for particular deaf individuals.

Many practitioners in health and health-related fields have long been concerned that medical models are insufficient (Dunn 2005) and do not address the full range of central health problems, like illness, which often includes factors beyond the malfunctioning of body parts. And in those disciplines and amongst practitioners who deal with persons with disabilities, it has long since been decided that addressing disabilities as abnormalities that require fixing is a problematic approach that devalues, oppresses, and potentially harms persons with disabilities (Dunn 2005). This devaluing of individuals with disabilities was a major impetus behind the development of the psychosocial model.

The shift to a less mechanistic view of individuals with disabilities is actually not a recent occurrence. Many in disability studies trace the shift to the seminal work of Beatrice Wright (1960) in *Physical Disability: A Psychological Approach*, which was later expanded and revised (Wright 1983) to *Physical Disability: A Psychosocial Approach*. (Dunn 2005) Fields like disability studies have long been cognizant of the potential harm caused by marginalizing an already vulnerable population and have attempted to correct for this potential harm in several ways, including, as previously mentioned, by restructuring the language used in their research and practice. By restructuring the very language employed, the psychosocial approach claims to view individuals as a whole rather than focusing on their perceived deficiencies. In addition to this linguistic alteration, we argue that two other conceptual shifts made by the psychosocial model are worth discussing in this context – shifting the focus from weaknesses to strengths and shifting the burden of compensating for the disabilities away from the person with disabilities and to the society. Briefly examining each of these conceptual shifts can assist in understanding the differences between medical and psychosocial models of disabilities.

Recognizing the impact of language, several key referential terms were changed in research and practice by proponents of the psychosocial model. The most significant of these seems to be a fairly subtle change – replacing “disabled person” with “person with a disability.” But as previously mentioned, this change nonetheless reflects the move

from placing focus on the disability first (“disabled person”), as would presumably be done in a medical model that focuses on deviations from the norm, to focusing on the individual first (“person with a disability”). Another significant linguistic change was the move from “patient” to “client.” Under a psychosocial model, “patient” has significant negative connotations, such as passivity in persons with disabilities who need to be fixed or acted upon with or without their consent or participation. The prevailing view under the psychosocial model is that individuals with disabilities should take an active role in their therapeutic processes, reflecting a shift towards empowering persons with disabilities. A third lexical change involved the move from “subject” to “participant” in research areas. This change reflects the notion that those who participate in research should not be objectified as entities upon which research is performed, but rather as willing participants in a study.³

A second central conceptual shift focuses on the person as a whole, especially their strengths, rather than focusing merely on the “disability” portion of a person with disabilities. This so-called “constructive message” (Dunn 2005) reflects the move away from fixing the perceived deficiencies and towards emphasizing the strengths and abilities of each person with a disability. Viewing an individual with a disability as a whole requires being cognizant of what he or she can do as opposed to what he or she cannot do and turns out to be far more constructive in addressing the needs of the client. This conceptual shift further emphasizes involving the client in the process of addressing their strengths and needs as the view from the inside of the disability can be far more illuminating and constructive in assisting a client than utilizing only the external view of the counselor or therapist or healthcare provider.

A third conceptual shift involves moving the burden of responsibility from the individual with a disability and towards the society in general, as the psychosocial model locates the perception of “disabled” in the society and not in the individual perceived to be disabled. In other words, the medical model places the locus for change in the individual and views the problem as one that an individual with a disability needs to address and overcome. Arguing as the medical model does that disability is fixable entails that the problem is truly *in* the “disabled person” and changes should occur with them. The difference between models reflects where the burden of change should lie: the medical model places the burden of change on the individual to make corrections and ameliorate his or her conditions and the psychosocial model shifts the burden of change or adaptation to society, arguing that the problem is how society responds to individuals with disabilities. To illustrate, imagine the case of an individual in a wheelchair who cannot reach the light switch in his place of employment. The medical model would say he is too short to reach the switch and so should find a way to adapt if he needs to use the switch, whereas the psychosocial model would say the light switch is inappropriately placed for his height. A further example can be given for a deaf individual who cannot fully participate in a work meeting with a group of people who do not Sign. The medical model would say the deaf individual needs to fix the situation by learning to read lips or by bringing appropriate adaptive technology or an interpreter, whereas the psychosocial

model would place the burden of inclusion on the workplace, thus reversing the burden of adaptation from the person with a disability to the company or organization.

Using the lens of the psychosocial model of disabilities to view deafness leads to a different picture of the concept of “fixing deafness.” Empowering persons with disabilities to emphasize their strengths, putting the person before her or his disabilities, would suggest that the individual should be allowed to make decisions for their own life and treatment, even if those decisions are unpopular, like a Jehovah’s Witness who refuses a blood transfusion, for example. What follows from this is that deaf people should clearly not be acted upon without their consent in utilizing “fixing” technologies on them, assuming they have the competency to consent in general. But what about deaf children? Of course many would hold that the autonomy rights of adults do not extend to putting their children at risk as the state has a significant interest in acting paternalistically towards children and against the wishes of parents if significant harm or death may follow. But much of this turns on whether deafness counts as a significant harm. We will examine this question in the third section as we discuss the controversies surrounding deaf parents selecting for genetically deaf children and the arguments surrounding cochlear implants.

Viewing persons with disabilities through the lens of the medical model, however, needn’t result in undermining the autonomy of a deaf individual to make his or her own choices regarding treatment, but the burden of demonstrating ability will always be on the “disabled” individual on this model. The concept of *ableism* can be helpful in understanding a likely predisposition in viewing persons with disabilities when working with the medical model. Ableism is the discrimination against individuals based upon their perceived deviation from the norm or society’s view of a normalized body and perhaps is best understood as a parallel to racism and sexism (and perhaps “speciesism” (Singer 2001)).⁴ Ableism is typically considered to include problematic discrimination against, and marginalization of, those who deviate from the “able-bodied” norm. It is also linked to the medical model as it fits with the view that disabilities are a kind of brokenness. (Campbell 2008; Silvers et al. 1998; Tong 1999) There is ample discussion in the literature of disability studies demonstrating bias against persons with disabilities attributed to ableist assumptions (Silvers et al. 1998; Nowicki and Sandieson 2002).

In considering the differences between the medical model and the psychosocial model, we argue that examining technological interventions for persons with disabilities within the framework of the psychosocial model is preferable. Working from the medical model is useful in some contexts; however, working *solely* from the medical perspective to address issues of deafness in particular and disabilities in general, without considering the challenges raised by advocates from disability communities against the medical model, is problematic.

Considering deafness: Variations in deafness, disparities, and the Deaf community as a culture

Although searching for “Deaf culture” in the *Philosopher’s Index* yields only 13 results, there is extensive literature on deafness and Deaf culture in the fields of disability studies and deaf studies.⁵ Because Deaf culture has its own language, customs, and rules, advocates from the Deaf community claim that Deaf culture merits protection and consideration as a unique culture that is in danger of extinction (Padden and Humphries 1988; Dolnick 1993; Jones 2002). Further, advocates of Deaf culture argue it meets the requirements set by most social scientists to count as a culture⁶ (Bauman 2005; Lane 2005) and so deserves the same consideration offered any other culture, especially those that are marginalized or stigmatized, assuming that its preservation does not cause significant harm or disadvantage some other culture.⁷ And like other marginalized or stigmatized cultures, there is a fairly significant rift in understanding between mainstream (hearing) culture and Deaf culture (Cohen 1994).

One defining feature of the Deaf community is the historical disparities that exist between deaf individuals and the hearing world. There is evidence of significant disparities in educational achievement, income, and access to certain services between deaf individuals in general and hearing people in general (Padden and Humphries 2005; Ohna 2006; Nowicki and Sandieson 2002). Although such disparities exist between the deaf and the hearing, this cannot in and of itself demonstrate any inferiority on the part of deaf individuals, as we know that similar disparities exist in the U.S. between ethnicities, socioeconomic classes, and sometimes gender, although we certainly do not assume inferiority of the disadvantaged groups. Instead, most would look to ascertain the cause of such disparities, considering their existence to be evidence of injustice or unfairness in some way (Jones 2010). A disadvantaged socioeconomic status, coupled with restricted access to needed services and communication challenges, creates a vicious circle that makes it more challenging for deaf individuals to break the cycle of poverty (WHO 2011).

If we accept that Deaf culture counts as a bona fide culture that has been historically marginalized or stigmatized and that is in danger of extinction, then we may be required to protect its existence, assuming such protection does not cause significant harm that outweighs the potential harm caused by its extinction. We return to this issue in the next section, but we first need to consider the categorization of “deafness.”

Addressing the question whether deafness requires fixing entails examining deafness as a category. To this end, two aspects that are significant to the examination of the moral permissibility of fixing deafness are the extreme variations in what constitutes “deaf” and the variety of causes and co-occurring conditions of deafness. These factors are practically quite important in clinical determinations of suitable recipients of cochlear implants, for example, and so bear consideration in our discussion.

There are many degrees of deafness and the sources of deafness are equally varied, although the main medical distinction is made between congenital (present at birth) and acquired (not present at birth). This distinction can be misleading, however, as some

acquired hearing loss can be caused by genetic factors whereas some cases of congenital deafness can be caused by environmental factors. (In other words, both congenital deafness and acquired deafness can be caused by genetic factors or environmental factors or a combination thereof.) The type, causes, and degree of deafness are relevant in determining candidacy for assistive technologies like cochlear implants. Further, there are often other co-occurring conditions⁸ for deafness in children and adults, such as autism (Szymanski 2012) that complicate the identification and addressing of deafness and fuel the erroneous and dangerous assumption that all deaf people are mentally disabled.

Most audiologists use a four-level scale for identifying the degree of deafness: mild, moderate, severe, and profound. Individuals with mild hearing loss may have some difficulty following conversations, especially in noisy circumstances. Individuals with moderate loss have significant difficulty following the conversation in noisy conditions and can have difficulty following conversations even with technological aids. At the severe level individuals reach a threshold that the general public would consider deaf, however individuals with severe hearing loss may be able to understand conversation if they use amplification and other supports. At the profound level, individuals will not be able to understand spoken conversation even with amplification and amplification may be of no assistance at all for their hearing loss. Profoundly deaf individuals need to rely upon visual communications.

While most studies report that 10 percent of children with congenital deafness are born to deaf or hard of hearing (HoH) parents, this number has been challenged as recent studies report lower numbers closer to five percent (Mitchell 2004). These numbers are significant for many reasons. First, deaf children of deaf parents (deaf-of-deaf) have a higher social standing in the Deaf community, second, deaf parents are less likely to seek implants for their children, and third, the advantages of deafness discussed by the Deaf community are less likely to be known or understood by hearing parents (Hyde 2010).

Space prevents a thorough discussion here of Deaf culture⁹ and the arguments that have been offered for and against its protection from extinction due to the increasing prevalence of cochlear implants at early ages. As we've mentioned, the overwhelming majority (at least 90 percent) of children born deaf are born to hearing parents. In the past, many of these children would learn Sign from an early age, but that number decreases with the number of cochlear implants on small children as most hearing parents will go to great lengths to normalize their deaf children (Crouch 1997). Given the history of discrimination faced by the deaf, the hearing community should not be surprised that they are mistrustful of efforts to fix them. Just as many black Americans are mistrustful of research and healthcare aimed at assisting them, given the long and painful history of egregious discrimination and harm performed "for their own good" (Tuskegee and the cold war radiation experiments spring to mind), members of the Deaf culture shouldn't be derided for wanting to preserve their culture and protect their members from the harm they perceive from the "fixing technologies."

In reflecting on these issues, we are reminded of the famous philosophy of mind article “What is it like to be a bat?” in which Thomas Nagel (1974) argues that the felt experiences of bats, who navigate with senses foreign to us, are impossible for humans to appreciate. We can analogize that the experiences of those in the Deaf community are virtually impossible for those of us who are not deaf to appreciate (and perhaps, conversely, that the qualia experienced by the hearing are similarly inaccessible to the profoundly deaf).

The moral controversies over selecting for genetic deafness and cochlear implants

The philosophical literature on the decision to select for genetic deafness is varied as some argue in favor of such selection (Häyry 2004) while some argue vehemently against it (Shaw 2008). The literature regarding the decision to perform a cochlear implant, on a child in particular, is also varied (Nunes 2001; Sparrow 2005), although it is interesting to note that both those who argue against allowing the genetic selection for deafness (e.g., Shaw 2008) and those who argue strongly for fixing deafness in children and adults through cochlear implants (e.g., Nunes 2001), routinely adopt the language of the medical model rather than the language of the psychosocial model. Indeed, such writers typically use “disabled person” or “handicapped person” rather than “person with a disability” and such writers seem to take it for granted that deafness is a kind of brokenness that should be fixed whenever possible.

“Notwithstanding the existence of a deaf-world, deafness should be considered as a handicap. Therefore, society should provide the means for the fulfillment of a deaf child's specific needs” (Nunes 2001, 337).

“...[W]ealth enables people to make particular lifestyle choices for their children. It seems abhorrent that deafness should be the subject of such a choice...Equally, deafness is like having a broken leg. These metaphors simply serve to illustrate the medical norm that deafness is bad...” (Shaw 2008, 411).

“It is better to be born deaf than never to be born, but an impartial perspective tells us that it is better to bring hearing people into existence than deaf ones, if such a choice is available to us” (Shaw 2008, 413).

In contrast to writers who view persons with disabilities and deaf people through the lens of the medical model, there are others who adopt different approaches. Cooper (2007), for example, evaluates the important related question of whether it can be a good thing to be deaf. Cooper recognizes that how one answers this question has significant impact for deciding the moral implications of practical issues such as cochlear implants for children, genetic selection for deaf fetuses, abortion of deaf fetuses, and whether deafness requires “fixing” in general. We take her to argue that if deafness is a good thing, or at least not a bad thing or “pathological”, then fixing it would seem problematic. She concludes, quite reasonably we argue, that the question of whether deafness is a good thing for an individual is largely situational – i.e., it depends

upon the individual and the circumstances. For some deaf people, deafness is good, whereas for others, it is not. She also rightly notes that she has confined her evaluation of whether deafness can be a good thing to the question of whether deafness can be a good thing for an individual deaf person, rather than whether deafness can be a good thing for other people (both hearing and deaf), the Deaf community, or society in general. But many arguments arising from the Deaf community against the fixing of deafness with technology involve more than determining whether deafness is good for individual deaf persons. These arguments instead rely on claims made on a cultural or societal level, such as the claim of moral wrong caused by the eradication of Deaf culture (Lane 2005), necessitating that a moral analysis of cochlear implants and fixing deafness in general requires considering whether deafness and being Deaf can be a good thing for not only individual deaf people, but for others, for the Deaf community, and for society in general. We will return to evaluating the “good” of deafness for groups shortly.

Cooper defends the view that it is a good thing for some people to be deaf in two ways. First, she evaluates the two most significant ways that deaf people and hearing people differ: qualia and language modalities, and second, she deflates the common view of hearing people that deafness is merely a deficit, an unnatural deviation from the norm of hearing. The latter is accomplished by pointing out that just because a condition or trait is “natural” does not mean it is good for the individual organism that possesses it, and by recognizing that some states that are dysfunctions or deviations from what would naturally occur are good for an individual organism. The former is accomplished through arguing that the lack of some kinds of qualia needn’t be a bad thing (not hearing unpleasant noises or the more extreme case of not smelling in a heavily polluted environment, for example), through noting that some deaf people have been shown to experience qualia that the hearing probably lack, and through examining claims that sign language (or “Sign”) is preferable to other languages. Sustaining a supporting argument from language modalities and the claims about the superiority of Sign, however, is a more arduous task, leading Cooper to conclude that the question of whether Sign is equal to or superior to spoken languages is an open question, thus it neither supports nor detracts from the claim that deafness can be a good thing. She critically evaluates and rejects the seemingly politically correct claim that all languages are equal and instead concludes that the goal of language is communication and that some languages are more effective than others at this. While she neither rejects nor defends the claim made by deaf advocates that Sign is a superior language, she notes that Sign can be learned by the hearing but that some deaf people cannot effectively learn spoken languages.

While we are here giving careful consideration to claims regarding the costs and benefits of deafness, it is important to note that claims like “deafness may be a good thing for some deaf individuals” is often not considered, presumably because it is outside of the realm of claims about deafness deemed plausible, given that most people view deafness as a significant disability that should be avoided or fixed, if possible. For example, in considering the real-life case of a Deaf lesbian couple who chose a deaf sperm donor because he was several generations deaf (i.e., he was the child of deaf

parents who were the children of deaf parents, and so on), Shaw (2008) makes numerous references to deafness as a clear harm and an obvious disability that should be fixed whenever possible and avoided in future people whenever possible.

“And deafness *is* a harm. The simplest impartial perspective will tell anyone that being able to hear and listen to music trumps any possible risk of alienation from a particular community...But the case for avoiding deafness is overwhelming. We have only five senses. If we had none, we could not function in the world. It is clearly best, both partially and impartially, for everyone to have all their senses” (Shaw 2008, 413).

We infer that Shaw considers deafness as an unarguable example of something that requires fixing, if possible, as it is inherently “bad”, much like most ethicists would judge the torture of human beings to be a clear example of a wrong that should be avoided. But not all ethicists share Shaw’s view that deafness is clearly a harm to be avoided. Sparrow offers and evaluates arguments in defense of Deaf culture and against the public funding of cochlear implants, arguing that:

“In the face of such evidence and testimony from those who *experience* deafness, it is problematic for hearing persons to continue to insist that it constitutes a disability to be avoided if at all possible” (2005, 137).

And Fahmy (2011) argues in a similar vein that genetically selecting for deafness isn’t as horrific as the hearing world would have us believe. Her discussion of genetically selecting for deafness hinges on a popular problem considered by many who discuss reproductive rights, known as the “non-identity problem.”

The non-identity problem is of particular interest in a discussion of the moral permissibility of selecting for a genetically deaf child as it points out that the deaf child created as a result of genetic selection is not harmed in any traditional sense as the alternative for that *particular* child is not to exist at all. Most who consider this issue argue that existence is preferable to non-existence, unless the life of the child is so profoundly painful or futile that non-existence is preferable to existence, which is not the case for genetic deafness. Considerable attention has also been paid to the concept of creating a child with a “right to an open future.” As children cannot yet exercise their full moral rights, some argue that a child can nonetheless be harmed when these future rights are curtailed in significant ways, for example, by creating a child with the “disability” of deafness (if indeed deafness is a disability in this sense) as deafness places notable restrictions on the kind of future a child can have, thus limiting their future rights. Fahmy argues that selecting for deafness does not violate a child’s right to an open future on similar grounds to the argument that the deaf child created by selecting for genetic deafness is not harmed by existing.

In considering cochlear implants for young children, however, Fahmy argues that these may be morally required in many situations. While she does not argue that a cochlear

implant at a young age *necessarily* benefits a child, she argues that if it is expected to offer significant benefit, then something like a child's right to an open future would morally require the implant. Thus, the arguments presented by Fahmy conclude that cochlear implants may be morally required if a strong case can be made that the future life of a child will be negatively impacted to a significant extent by the child's deafness. This leads to the somewhat paradoxical conclusion that it is morally permissible for parents to choose to produce a deaf child over a hearing child but not morally permissible for them to choose against "fixing" the deafness once the child is born. While her analysis is compelling, we argue that she does not fully consider the question of deafness as a good thing for individual deaf persons *and* for Deaf culture. If deafness can be a good thing in some circumstances, especially the situation she considers where a deaf couple wants to have a deaf child, factoring in a broader sense of harm and a broader sense of good for an individual in a context, there would still be situations where choosing cochlear implants would be appropriate, but others where they are not. At the very least, factoring in the idea of a fully informed choice, which seems to require some level of understanding of what a person gives up when they receive cochlear implants (the experiences of Deaf culture, amongst other things) requires some familiarity with deafness and Deaf culture before a decision is made.¹⁰

Returning to the issue of whether deafness can be a good thing not only for individual deaf people, but also for others, including the Deaf community and society in general, we argue that it too is situational, just as Cooper argues that it is situational for an individual deaf person. If an individual deaf person takes herself to be so significantly burdened by her deafness that she is not a functioning member of society, whether Deaf culture or the hearing community, then her deafness is an aspect that deserves attention and it is unlikely to be judged a good thing. Conversely, if a deaf individual is empowered rather than hindered by her deafness, then it is difficult to imagine that it isn't a good thing for society. However, in considering the survival of Deaf culture, if it is indeed in jeopardy of extinction from declining numbers, then it might very well be a good thing for Deaf culture if more people were deaf, and so their individual deafness would be a good thing in terms of Deaf culture. Of course the harm caused to individuals and to society by intentionally deafening people would be ruled out, but the cost/benefit analysis for Deaf culture vs. individual deaf people who do not want to remain deaf or those who are on the fence and society as whole is a different story. But then this question simply reduces to the question of whether to allow cochlear implants if we can reasonably expect that it will lead to the demise of Deaf culture. We make two claims regarding this question: (1) restricting a competent deaf individual's ability to choose a cochlear implant is an inappropriate restriction on the individual's autonomy, as is restricting their ability to refuse one, and (2) it is not yet settled that Deaf culture will die as a result of cochlear implants. Regarding parents choosing cochlear implants for their children, we argue that the best course of action is to require that their consent be truly informed in that they are apprised of the details of Deaf culture and Sign, including the view that many in Deaf culture do not view their deafness as a disability, along with the perspective from the psychosocial model, before they consent.

Reflective of the arguments offered above by Cooper and Fahmy, as well as the psychosocial model of disabilities, we argue that deafness is neither good nor bad in and of itself, but should be judged in context. Note that this would be a strange conclusion to draw using a medical model of disabilities that considers deafness a deviation or a brokenness that is necessarily bad. Regarding the moral permissibility of selecting for genetic deafness and cochlear implants on children, we argue that both are morally permissible but, as mentioned above, individuals must be making a truly informed decision for themselves or their children and should demonstrate at least a rudimentary understanding of the controversies involved before their decisions are enacted. This is especially important for cochlear implants on young children, given the seriousness of the decision and given the scarcity of information many parents report is available, considering the short amount of time they feel they have to make such a decision (Hyde et al. 2010).

Conclusions and suggestions for best practices: Why we should let the Deaf be deaf, if they so choose

Returning to the two framing questions with which we originally began; namely, which model is preferable in dealing with persons with disabilities and whether deafness should be fixed and avoided whenever possible, we argue that the psychosocial model is preferable and that deafness does not *require* fixing, although individual deaf people and parents of deaf children may choose to change their deafness, but should do so only after careful consideration of the issues involved. As all technologies aimed at “fixing” have inherent risks, such technologies should only be employed if the risks are outweighed by the expected benefits. We further argue that selecting for genetic deafness, while potentially problematic on the medical model, is significantly less so, depending upon the circumstances, on the psychosocial model.

Some countries have considerably more “Deaf-friendly” policies than the United States. Sweden, for example, requires families seeking cochlear implant surgery for their children to have established communication via Sign prior to the surgery and Sign is recognized as the official language of the deaf in Sweden (Preisler 2001). Recommendations from researchers and advocacy groups in Australia (Hyde and Power 2006; Deaf Australia 2006) and Canada (CASLPA 2006) argue that deaf or Deaf individuals, or at least educators of deaf individuals, should be involved in implantation teams. The recommendation that parents should consult with a member of the Deaf community prior to consenting to cochlear implant surgery for their children seems warranted, given that real informed consent for a medical procedure requires comprehension of relevant information. As the majority of deaf children are born to hearing parents, they likely have little to no understanding of Deaf culture and its purported benefits and so including some exposure would enhance informed consent.

Another moral concern over cochlear implants involves issues of access and fairness. As noted above, some researchers argue against public funding for cochlear implants and assistive technologies (Sparrow 2005) in an attempt to limit harm to Deaf culture. But such policies could unfairly discriminate against people with disabilities, many of whom are already economically disadvantaged, if they make an informed choice *for*

assistive technologies. Thus, we argue that restricting access to these procedures would harm many already marginalized deaf individuals who may choose the procedure in a fully informed manner, given the economic rift between mainstream hearing society and deaf individuals in general. As the demise of Deaf culture as a result of the increase in cochlear implants is not a given, it seems highly problematic to sacrifice the interests of deaf individuals who meet the standards of informed consent for an unproven harm to Deaf culture.

One might wonder whether the suggestions offered here regarding fixing deafness should be considered for all kinds of interventions aimed at fixing people with disabilities, to which we respond that it depends. Healthcare in the U.S. has shifted towards a patient-centered (or client-centered) model and the suggestion that the autonomy of a person with a disability should be respected is no different from respecting the wishes of patients or clients in general, assuming they are competent to make such choices. Complicating factors arise, however, in the cases of individuals with disabilities, as they are typically judged to be “broken” in a significant way and many are assumed to have mental deficiencies if they have visible physical disabilities, including deafness.¹¹ But deafness seems to be an unusual case as the Deaf community is reasonably construed as an entity in itself that deserves preservation for its uniqueness, given numerous arguments in the literature of disability studies that demonstrate Deaf culture meets the requirements set by most social scientists to count as a culture (Bauman 2005; Lane 2005) and assuming that we should act to preserve cultures, *ceteris paribus*. Further, it is unlikely that other groups of persons with disabilities will come forward to argue against technological interventions to the extent the Deaf community has done, given the uniqueness of Deaf culture as a phenomenon.¹² If this does happen, however, the claims against treatment should be considered on an individual level in the same manner and whether further regulations should occur, like consultation with members of the particular community of persons with disabilities before parents consent to technological interventions on their children, would have to be established in context. And so even though we should not sacrifice the interests of individual deaf people who choose cochlear implants, or parents choosing for their children, we should assist in the preservation of Deaf culture in ways that do not undermine individual autonomy.

In conclusion, we argue that “fixing deafness” in general, as narrowly envisioned by the medical model, is problematic as it entails a deaf person is broken, even if that deaf person does not consider their deafness to be a disability. Deaf individuals and parents of deaf children who decide to “fix” their deafness are better served by considering deafness through the lens of the psychosocial model, as it is less demeaning to persons with disabilities in general, considering that even after cochlear implants, deaf individuals may still need to be judged as deaf since the surgery destroys any residual hearing in place of the implants. (And in some places, like Sweden, for example, children are still considered “deaf” after cochlear implants (Preisler 2001)). The psychosocial model, which is the preferable paradigm for viewing persons with disabilities, allows for consideration of the context and circumstances of individual deaf and Deaf persons, as well as the parents of deaf children and those who wish to

genetically select to produce deaf offspring. But again we are not here arguing that cochlear implants should be viewed like elective cosmetic surgery, as this would be problematic on fairness grounds by making cochlear implants unattainable for those who couldn't afford the price tag. We argue that an additional category be added for cochlear implants that requires at least the imperative to distribute information on deafness and Deaf culture to prospective cochlear implant patients or their parents to allow more informed choices. Of course if the health practitioners involved do this grudgingly, it will defeat the purpose, so perhaps an accessible Deaf resource center would be helpful as well.

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References

Ballin, Albert. 1998. *The Deaf Mute Howls*. Washington, D.C.: Gallaudet University Press, The Gallaudet Classics in Deaf Studies Series, Volume 1. (original publication: 1930. Los Angeles: Grafton Publishing Co.)

Bauman, H-Dirkson L. 2005. "Designing Deaf Babies and the Question of Disability." *Journal of Deaf Studies and Deaf Education* 10.3: 311-315.

CASLPA. 2006. *Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) Position Paper on Cochlear Implants in Children*. http://caslpa.ca/system/files/resources/Cochlear_implants_%20in_children_Oct_2006.pdf (accessed 6.21.14).

- Campbell, Fiona Kumari. 2008. "Refusing Able(ness): A Preliminary Conversation about Ableism." *M/C Journal* 11.3.
- Cohen, Leah Hager. 1994. *Train Go Sorry: Inside a Deaf World*. New York: Houghton Mifflin Harcourt. Kindle edition.
- Cooper, Rachel. 2007. "Can It Be a Good Thing to be Deaf?" *Journal of Medicine and Philosophy* 32: 563–583.
- Crouch, Robert A. 1997. "Letting the Deaf be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually Deaf Children." *The Hastings Center Report* 27.4: 14-21.
- Deaf Australia. 2006. *Deaf Australia Inc. Policy on Cochlear Implants*. http://www.deafau.org.au/info/policy_cochlear.php (accessed 6.21.14).
- Dolnick, Edward. 1993. "Deafness as Culture." *The Atlantic Monthly* September: 37-53.
- Dunn, Dana S. and Timothy R. Elliott. 2005. "Revisiting a Constructive Classic: Wright's *Physical Disability: A Psychosocial Approach*." *Rehabilitation Psychology* 50.2: 183-189.
- Fahmy, Melissa Seymour. 2011. "On the Supposed Moral Harm of Selecting for Deafness." *Bioethics* 25.3: 128–136.
- Häyry, Matti. 2004. "There Is a Difference between Selecting a Deaf Embryo and Deafening a Hearing Child." *Journal of Medical Ethics: The Journal of the Institute of Medical Ethics* 30.5: 510-512.
- Hyde, Merv, Renee Punch, and Linda Komesaroff. 2010. "Coming to a Decision about Cochlear Implantation: Parents Making Choices for Their Deaf Children." *Journal of Deaf Studies and Deaf Education* 15.2: 162-178.
- Hyde, Merv and Des Power. 2006. "Some Ethical Dimensions of Cochlear Implantation for Deaf Children and Their Families." *Journal of Deaf Studies and Deaf Education* 11.1: 102-111.
- Jones, Cynthia. 2010. "Why Should We Eliminate Health Disparities? The Moral Problem of Health Disparities" *American Journal of Public Health* 100.S1: 47-51.
- Jones, Megan. 2002. "Deafness as Culture: A Psychosocial Perspective." *Disability Studies Quarterly* 22.2: 51-60.
- Ladd, Paddy. 2003. *Understanding Deaf Culture: In Search of Deafhood*. Clevedon: Multilingual Matters, Ltd.
- Lane, Harlan and Michael Grodin. 1997. "Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child." *Kennedy Institute of Ethics Journal* 7.3: 231-251.
- Lane, Harlan. 2005. "Ethnicity, Ethics, and the Deaf-World." *Journal of Deaf Studies and Deaf Education* 10.3: 291-310.

- Mitchell, Ross and Michael Karchmer. 2004. "Chasing the Mythical Ten Percent: Parental Hearing Status of Deaf and Hard of Hearing Students in the United States." *Sign Language Studies* 4.2: 138-163.
- Nagel, Thomas. 1974. "What Is It Like to Be a Bat?" *Philosophical Review* 83.4: 435-450.
- Nowicki, Elizabeth and Robert Sandieson. 2002. "A meta-analysis of school-aged children's attitudes towards persons with physical or intellectual disabilities." *International Journal of Disability, Development and Education* 49.3: 243-265.
- Nunes, Rui. 2001. "Ethical dimension of paediatric cochlear implantation." *Theoretical Medicine and Bioethics: Philosophy of Medical Research and Practice* 22.4: 337-349.
- Ohna, Stein Erik. 2006. "Deaf in my own way: Identity, learning and narratives." *Deafness & Education International* 6.1: 20-38
- Padden, Carol and Tom Humphries. 1988. *Deaf in America: Voices from a Culture*. Cambridge: Harvard University Press.
- Padden, Carol and Tom Humphries. 2005. *Inside Deaf Culture*. Cambridge: Harvard University Press.
- Preisler, Gunilla. 2001. *Cochlear Implants in Deaf Children: Report for the Committee on the Rehabilitation and Integration of People with Disabilities*. http://www.coe.int/t/e/social_cohesion/soc-sp/Cochlear_Implants_E.pdf (accessed 6.21.14).
- Shaw, David. 2008. "Deaf by Design: Disability and Impartiality." *Bioethics* 22.8: 407–413.
- Silvers, Anita, David Wasserman, and Mary B. Mahowald. 1998. *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*. Maryland: Rowman & Littlefield.
- Singer, Peter. 2001. *Animal Liberation*. New York: HarperCollins.
- Sparrow, Robert. 2005. "Defending Deaf Culture: The Case of Cochlear Implants." *The Journal of Political Philosophy* 13.2: 135–152.
- Szymanski, Christen, Patrick Brice, Kay Lam, and Sue Hotto. 2012. "Deaf Children with Autism Spectrum Disorders." *Journal of Autism and Developmental Disorders* 42.10: 2027-2037.
- Tong, Rosemary. 1999. "Dealing with Difference Justly: Perspectives on Disability." *Social Theory and Practice* 25.3: 519-530.
- World Health Organization. 2011. *World report on disability*. http://www.who.int/disabilities/world_report/2011/en/ (accessed 4.7.14).
- Wright, Beatrice. 1960. *Physical Disability: A Psychological Approach*. New York: Harper & Row.

Wright, Beatrice. 1983. *Physical Disability: A Psychosocial Approach*. New York: Harper & Row.

¹ It is important to note “deaf” is an audiological term which refers to a significant loss of hearing while “Deaf” refers to a person who identifies culturally with a group of shared history and language (Padden 1988).

² We use the term “co-occurrences” rather than “comorbidities” as the latter suggests the medical model and viewing deafness as an illness.

³ It is interesting to note, although anecdotally, that a recent debate over the wording for a new Medical Humanities minor at our university elicited very negative reactions to the terminology used by the psychosocial model. Namely, the move from “patient” to “client” was viewed by scholars from Philosophy and Modern Languages as adopting a consumer-based view of health and the move from “subject” (which many see as the appropriate way to view people, as opposed to “object”) to “participant” was also viewed as veering away from respect for the individual and towards mere involvement. One explanation might be that the choice of these words in a social science context is not “loaded” in the same way as in the humanities context.

⁴ Traveling to a conference recently, we encountered an excellent example of a kind of ableism in practice. After waiting over an hour for a taxi from the hotel, we were told that the delay was caused by the scarcity of handicapped-accessible vans in the area. Apparently, because one of us is deaf, a handicapped van was required, just to be safe.

⁵ Accessed April 7, 2014.

⁶ Space prevents a thorough discussion of the issues surrounding accepting Deaf culture as a culture on par with others, but we will assume for the sake argument that Deaf culture counts as a bona fide culture worthy of preservation.

⁷ We might not, for example, be required to preserve a unique culture that has as its core the slaughter of some other group.

⁸ See note 2.

⁹ We suggest the Research Guide at Gallaudet University as an excellent starting point (<http://libguides.gallaudet.edu/>; accessed October 10, 2013)

¹⁰ Crouch (1997), for example, offers an excellent discussion of this topic and more general articles like Dolnick (1993) are also helpful for an introduction to deafness and Deaf Culture.

¹¹ One of the authors can relate many first-hand experiences with such prejudices, including the assumptions of many teachers in numerous public school settings where the author’s inability to speak clearly as a result of deafness led the teachers to assume he was mentally deficient, despite evidence to the contrary. Studies of educational achievement levels of deaf children are also not encouraging on this front.

¹² We are grateful to comments received from the 2014 Annual Meeting of the Association for Practical and Professional Ethics, during which it was suggested that autism might present a similar example in that some high-functioning autistic individuals argue that they are not handicapped but rather perceive the world differently than “normal” people and that the stigma attached to their “illness” is thus unjustified (<http://www.autismsupportnetwork.com/news/autism-not-disability-what-do-you-think-2273822>; accessed April 7, 2014). Although this seems to weaken the claim that Deaf culture is unique among “disability” groups, it strengthens the claim that respect for persons with disabilities requires that we do not assume that they are necessarily broken, as the medical model implies.