CHAPITRE 6. HEARING THE IMPLANT DEBATE: THERAPY OR CULTURAL ALIENATION?

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HEARING THE IMPLANT DEBATE: THERAPY OR CULTURAL ALIENATION?

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1. ENABLING THE DEAF TO HEAR

Contemporary neuroscience has developed several devices and techniques to restore or improve our mental capabilities and performances. Transcranial magnetic stimulation, cranial electrotherapy stimulation, deep brain stimulation, brain prosthesis, neural prosthesis or brain-computer interfaces can be mentioned in this context. Each of them has its domain of application and raises technical, medical and sometimes ethical problems. It is precisely one particular ethical
issue that I want to examine in this paper, related to a neural prosthesis: cochlear implants. These implants are offered to deaf people, especially deaf children, in order to give them the ability to hear. It is a very positive medical intervention, an example of the potential of modern technology when we are the victim of a disability: it prevents the disability becoming a handicap, that is, according to the World Health Organization (WHO), an inability to accomplish something one might want to do, that most others around one are able to accomplish. More broadly, concerning the possibilities of nanotechnology to improve our well-being, in 2004 Philipp Bond said: “Nanotechnology offers the potential for improving people’s standard of living, healthcare, and nutrition; reducing or even eliminating pollution through clean production technologies; repairing existing environmental damage; feeding the world’s hungry; enabling the blind to see and the deaf to hear; eradicating diseases and offering protection against harmful bacteria and viruses; and even extending the length and the quality of life through the repair or replacement of failing organs”.¹ Who could object against these possibilities and in particular to the cure of deafness in children?

Curing diseases and providing remedies for disabilities is good, and parents have a special duty concerning the well-being of their children. Julian Savulescu and Guy Kahane claim even that they must obey a moral principle of procreative beneficence that makes heavy demands on them: “If parents could increase the prospects of future children’s lives by selecting children who are far more intelligent, empathetic or healthier than existing people, then the principle of procreative beneficence instructs parents to select such future children”.² This principle is not accepted by everybody, and many people, even if they think that they have a moral duty of beneficence when procreating children, would have objections either against the selection of better children or the use of certain means for the good of their children. In most western countries, embryo selection is forbidden or restricted; if it were freely allowed, it could even have a paradoxical consequence, as the two authors acknowledge: “In comparison to such possible future persons, most existing persons may count as suffering from disability.” Enhancement by way of selection could shift the threshold of normality. But if enhancement is hotly debated, cure is not. And cochlear implants are a cure for deafness, an impairment and a disability.

Nevertheless, not every­one agrees, as Tsjalling Swierstra and Arie Rip observe: “Such views and criteria [Bond’s view] can be unproblematic, when all participants agree that health, absence of hunger, economic growth, and cheaper products are desirable and that hunger, sickness, and poverty are not. In the case of cochlear implants, however, the promise of allowing the deaf to hear again was contested by the deaf community, with its own culture, and now officially recognized language”.

For some people – especially the deaf community – deafness is neither a disability nor a handicap, but a culture, and some take strong measures to keep this culture alive: they do not only refuse to treat deafness in children, but also ask for preimplantation genetic diagnoses (PGD), aiming at embryo selection in favour of the birth of deaf children, that is, at children designed to belong to the culture of their parents. As Savulescu and Kahane observe: “According to a recent survey, deliberate selection of children with conditions such as deafness […] is not uncommon: 5% of 190 of PGD clinics surveyed in the US have allowed parents to select embryos with conditions commonly taken to be disabilities”. But is it not morally repugnant to create deliberately deaf children, that is, “diminished” children? If human enhancement is morally wrong for some, human un-enhancement must be for all.

2. THE ARGUMENTS AGAINST CULTURAL ALIENATION

However, the case is not so simple. As John Robertson says: “The ethical issue is whether having a deaf instead of a hearing child would have hurt that child. A similar issue has arisen in a widely publicized case of a deaf lesbian couple choosing a deaf sperm-donor in order to increase the chances of having a deaf child. Given the deaf parents’ strong commitment to the well-being of their child and the rich culture now available to deaf people, many bioethicists analysing this case find the deaf parents’ choice to be acceptable (Davis, Fletcher,
Levy). Others, however, strongly disagree (Anstey). From the point of view of their well-being and of their belonging to a rich culture, deaf children are not in a worse position than many (and maybe all) normal children; therefore, why condemn the choice of their parents not to have a hearing child or not to give them a cochlear implant?

It could be difficult to argue that the life of a deaf child would be better than the life of a hearing one – for that, we should be convinced by some argument that a deaf culture is superior than a hearing culture; but it is not preposterous to claim that both lives are simply different and on the same footing, because a deaf child will acquire capacities not available to normal people: “There are relevant cases, such as deafness or Asperger’s syndrome, where it is plausible to hold that genomic variations do generate valuable life options that are not available to other individuals, since the existence of the condition typically correlates with the development of capacities not possessed by species-typical individuals.” In a time of cultural pluralism, and even of cultural relativism, it is the conclusion we ought to come to.

Deafness is nevertheless an impairment, that is a physiological disorder or injury (WHO); how could an impairment count as a cultural trait or as something with a positive value? Of course, deafness is a kind of impairment, but it does not mean that it is a disability, because disability is not an absolute natural condition: it also depends on the environmental and social resources available. Society can change a disability into a “normal” condition, different from normal normality, but not worse. Society should also fight against bias and prejudices, which constitute the main part of the problems of deaf people, as Carol Thomas notes: “The social model asserts that “disability” is not caused by impairment but by the social barriers (structural and attitudinal) that people with impairments (physical, intellectual and sensory) come up against in every arena. The social model views disabled people as socially oppressed”.

Well-being (or beneficence) is not the only reason to approve the choice of deaf parents to have deaf children. Autonomy (especially procreative autonomy)

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5 J. Robertson, Extending Preimplantation Genetic Diagnosis: The Ethical Debate, p. 470.
7 C. Thomas, Disability: Getting it ‘right’, p. 15.
is another powerful reason, as Patrick Lin and Fritz Allhof remind us: “If human enhancement can be ultimately defended, then un-enhancements may seem to be morally permissible as well, if individual autonomy is the most important value to consider in the debate. There are already medical cases in which individuals want to amputate a healthy limb from their bodies; parents want to stunt the growth of their bedridden child to keep her portable and easier to care for; and deaf parents who specifically want a deaf baby in selecting embryos for in vitro fertilization”. As we have just seen above, speaking of “un-enhancement” is even a mistake from a well-being point of view. This last point is important, because we could rightly have objections against giving full predominance to autonomy. Lin and Allhof mention apotemnophilia, that is the amputation of a healthy limb, in their passage; it is a surgical operation that is not easily reconciled with well-being, and that could, with good reason, be identified as a mental disease; therefore, as something that could impair autonomy and be cured by psychiatrists rather than surgeons. There is nothing similar with deaf parents; of course, they must make choices that are in the best interests of their children, but as we have seen, it is not clear that they act against their interests if they decide that their children will not be given cochlear implants or that they will be born deaf.

Finally, there is the non-identity problem: “We understand that the identity of each person who ever comes into existence – the coming into existence, that is, of any one particular person in place of a ‘nonidentical’ other – depends, among other things, on just who the genetic parents of that person happen to be. As Parfit observes, the woman who wonders who she would have been had her ‘parents married other people’ ignores the answer, which is “no one”’. In the same manner, if another embryo is implanted, the human being who will be born will not be the same person. Therefore, not to choose a deaf embryo means that another child will come into existence, and that the deaf child will remain in nothingness for eternity. But as David Shaw observes: “It is better to be born deaf than never to be born”. This means that we cannot harm a child in choosing that he will be a deaf one – we even benefit him – because if we had not chosen deafness, this deaf child would never have been born.

Nevertheless, that is not quite the situation. David Shaw claims that deaf parents are not asking themselves whether they were morally allowed to put into

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10 M. Roberts, The Nonidentity Problem.
11 D. Shaw, Deaf by Design: Disability and Impartiality, p. 413.
life a disabled embryo whose life is worth living (but with a disability) instead of replacing it by another one with hearing capabilities; they have chosen to have a disabled child (through PGD and/or in denying them a cochlear implant): the deaf culture proponent’s “strategy seems to consist in saying ‘Here is a situation where $X$ exists [= a deaf child], and $X$ is not quite 99% perfect. Does this mean that the creators of $X$ should have created $Y$ [= a hearing child] instead?’ This is a straw man: what we need, and get in the case of the deaf children, is: ‘Here is a situation where $X$ exists, and is missing something very important’”.\(^{12}\) A deaf child is born with an impairment we could have prevented, and are still able to prevent with the aid of an implant; therefore we are morally required to choose to prevent it.

This objection underlines the weakness of the non-identity argument. From an ontological point of view, it presupposes that embryos are waiting in limbo and that if we give one embryo the possibility of coming into existence, and if that existence is worth living – if that individual does not suffer dreadful diseases or impairments – we give a benefit that cannot harm. This reasoning is flawed: embryos do not wait in what Alex Mauron has named a Platonist boarding hall\(^{13}\). From an ethical point of view, the problem cannot be framed in that manner either, as David Shaw has just shown: deaf parents voluntarily bring into existence an impaired child and/or voluntarily deny that child a remedy for the condition. As a result, the child is missing something very important, as a consequence of the voluntary action of the parents. Such an attitude is harming for the child.

**3. THE ARGUMENTS IN FAVOUR OF THERAPY**

Consequently, we ought to return to the question of autonomy and particularly of well-being. The upshot of the preceding arguments was that well-being tips the balance in favour of choosing to have a deaf child, belonging to a rich culture. But as we can see when we speak of harm, some authors disagree: it is not so clear that deafness will not constitute a true handicap, with the consequence that the well-being of deaf people will not be as good as the well-being of hearing people. As say Savulescu and Kahane: “Some people in the deaf community claim that deafness does not reduce well-being because signing is a unique form of communication that offers access to a unique culture that can only be fully experienced by the deaf. For these claims to have the relevant force, it is not

\(^{12}\) D. Shaw, Deaf by Design: Disability and Impartiality, p. 409.
\(^{13}\) Personal communication.
enough for it to be true that deafness has some benefits. It must also be true that these benefits clearly outweigh the costs of deafness”.

And the result of the weighing seems to be against the proponents of deaf culture, because normal human functioning, that is health, is incompatible with deafness. Health has to be defined as normal functioning: “Health care has normal functioning as its goal: it concentrates on a specific class of obvious disadvantages and tries to eliminate them”, says Normal Daniels, and deafness is obviously a disadvantage. Therefore, deafness is an authentic handicap and a harm, if we follow the definition given by Shlomit Harrosh: a harm is “a state in which we are worse off than we were or could have been relative to the potential of our species to live a fully human life”. In deafness, we are deprived of an element of human physical integrity, therefore we are worse off. It is, in consequence, immoral to impose it on children or voluntarily not to remedy it.

Moreover, the choice of deaf parents to have a deaf child could not be as truly autonomous as they think. Such parents are unable to be impartial and therefore autonomous in their procreative decisions concerning the condition of their child, because they lack the necessary knowledge to make an informed decision, says David Shaw: “The couple have decided to deprive their children of something of which they have next to no experience. In this particular case, the couple’s disability precludes them from knowing what their children’s lives would be like if they could hear: this alone ought to disqualify them from choosing such a life for their child. […] The fact that they are deaf, though, appears to blind them to the fact that deafness is also a harm to be avoided if possible. […] They are incapable of impartiality about hearing versus deafness, because they have only experienced the negative (deaf) perspective”.

Even independently of the lack of autonomy argument – an argument notably difficult to assess – we nevertheless ought to conclude, that “in the context of procreative choices what matters is not whether particular disabled people have had good lives, but whether parents can reasonably believe that a child with deafness or some other condition is likely to have a better life than a child without

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15 Just Health Care, p. 46.
17 D. Shaw, Deaf by Design: Disability and Impartiality, p. 411.
As deafness is sub-optimal for normal human functioning, to be deaf is to have a worse life, even in a rich culture with caring parents.

But again, it is not so simple: the same authors, Savulescu and Kahane, underline that well-being is context dependent: “There is no context-independent answer to the question whether we should select hearing rather than deaf children”, and it is of no importance for well-being to label a condition “health” or “disease”: “What determines whether there are moral reasons for or against selecting a child with a congenital condition such as deafness is factual information about the expected well-being of such a child, when compared to other possible children, not whether the resulting child could be described as disabled or normal according to some possible definition. According to the Principle of Beneficence it is sufficient that a condition is likely, in our world, to make for a life with somewhat smaller prospects of well-being to give parents reasons not to select this condition”. And if in our world, the result of the weighing is not in favour of deafness, life conditions could be re-arranged to fit deafness.

4. BEYOND WELL-BEING

Life conditions could be re-arranged, but should they? And if they are, will the gain for deaf people be worth not the financial cost for society, but the loss of hearing ability for deaf children? It is important to try to answer this question, if we want to depart from the circle of social conditioning and coercion. Deaf parents call upon their culture to coerce their children to be deaf; normal parents call upon their culture to coerce children of deaf parents to be in a hearing condition. In both cases, children are the victims of social pressures. Parents too are victims, in a state of limited autonomy.

To answer this question, I think that we must widen the scope of the discussion and instead of limiting the inquiry to considerations of cost/benefit maximization in terms of well-being, as the principle of beneficence urges, and to assessment of autonomy, we should contemplate the topic of human

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flourishing, as the concept of “a fully human life” used by Harrosh and the topic of the belonging to a rich culture invite us to do. Another reason to leave this narrow approach is the fact that if harming a person is always bad for that person, it is not always a wrong. As the same author acknowledges: “The harms of [deafness] having been identified, the question now is whether they are justified or involve wrongdoing”.  

But what criterion do we have to ascertain which harms are wrongs? A theory of rights can do that, but it only puts the problem one step back, because we must have another criterion to establish the list of rights we can legitimately claim. In the literature, when this question is asked, two criteria are invoked: basic needs and opportunities of choice.  

Human beings have basic needs, whose satisfaction is crucial for the chance to live a (good) life, and they must have (rich) opportunities to be able to make significant choices, expressing the person they are and want to be. Rights are claims that can be invoked when these important elements of our lives, that is basic prospects in human flourishing, are in jeopardy.

When we consider human flourishing, we consider a bundle of features that characterizes the species, but not individuals as such. It is the same with health, as we have seen, but health is only one feature of human flourishing. The features of human flourishing are achievements, and not capacities. Of course, to be able to achieve something, one must possess the capacity to achieve it (it is this capacity that rights protect). If one is deprived of one sense, such as hearing, one is deprived of one capacity and of the achievements that depend on it; therefore one’s flourishing will be diminished and one’s life will not be completely human, in a sense. In a rich and developed society, citizens are endowed with rights that oblige society to try to remedy this lack of opportunities: cochlear implants have exactly this goal, and consequently deaf children have the positive right to be implanted. The wishes of their parents cannot supersede this right.

The case is even stronger with PGD: to intentionally destroy the capacity of hearing in an already born child would be a crime, even if it is made with the best intentions. Of course, embryos are not persons and we can treat them differently, but to knowingly choose an embryo that will be prevented from leading a full human life is a moral wrong.

As we have seen, the reply of deaf parents is that their deaf children will inhabit a rich culture with its own language, signing, preventing the impairment

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21 H. Harrosh, Identifying Harms, p. 5.
of deafness from becoming a disability and a handicap; therefore, their deafness is neither a harm nor a wrong. We must allow that modern societies offer their denizens possibilities that go well beyond our natural possibilities, and that sometimes they can largely compensate for natural impairments. But here the case for deafness is not very bright, even if deaf children will not be deprived of this cardinal mean of communication: language. For sure, in an era of MP3 and cell phones, to be deaf is a true disability and constitutes a serious hurdle for communication with the majority of the population. It can be lowered in a rich deaf culture, but certainly not fully compensated.

Moreover to speak of deaf culture is not without difficulties. A culture can be defined by its content, and in this sense, deaf culture is a true culture; but a culture, especially in a liberal tradition, is still something we can enter or leave; it is an object of choice. But in voluntarily having a deaf child, we prevent that child from leaving that culture, because deafness is almost definitive (the cochlear implant must be inserted at an early age to be effective). As Vardit Ravitsky says: “Parents should enjoy the liberty to determine the content and the aims of children’s education […] as long as these choices do not create adults who are ‘trapped’ within their own cultures”. Creating deaf children is no more permissible than intentionally raising one’s children in illiteracy, because both will prevent them integrating with other cultures.

For those not yet convinced, I will propose a fictitious story (usually arguments are preceded by such stories; I will finish with it: I prefer to end with our intuitions rather than to begin with them, in so thorny a topic). Subsequent to some nuclear or chemical accident, the human species has become genetically deaf. Fortunately, due to the enduring existence of deaf people in humanity, all human beings have learned signing and are now living in a rich culture, even if nobody is now able to appreciate Mozart or the Beatles, and if the cell phone industry has been obliged to reconvert. One day, because of some genetic mutation or virus infection, some people have “recovered” hearing. Their number has grown and they now constitute a community with its own proper sub-culture. Unfortunately, due to social pressure (to be successful in a deaf culture, one must master signing, every other language being almost useless), their hearing children make no effort to internalize their hearing culture. To remedy it and to foster their own culture, the leaders of their community ask for a genetic modification in their children whose effect will be to render them blind. The reason is that if they are blind, they will not be able to learn signing and will be obliged to use vocal language. Do you think that their demand is morally correct or that their children will be wronged in being blinded?

23 V. Ravitsky, Genetics and Education: The Ethics of Shaping Human Identity, p. 315.
As I have said, this story is not an argument, but it can reinforce the ones we already have.

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