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Scientific Contribution

Deafness, genetics and dysgenics

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Abstract. It has been argued by some authors that our reaction to deaf parents who choose deafness for their children ought to be compassion, not condemnation. Although I agree with the reasoning proposed I suggest that this practice could be regarded as unethical. In this article, I shall use the term "dysgenic" as a culturally imposed genetic selection not to achieve any improvement of the human person but to select genetic traits that are commonly accepted as a disabling condition by the majority of the social matrix; in short as a handicap. As in eugenics, dysgenics can be achieved in a positive and a negative way. Positive dysgenics intends to increase the overall number of people with a particular genetic trait. Marriage between deaf people or conceiving deaf children through reproductive technology are examples of positive dysgenics. Negative dysgenics can be obtained through careful prenatal or pre-implantation selection and abortion (or discarding) of normal embryos and foetuses. Only deaf children would be allowed to live. If dysgenics is seen as a programmed genetic intervention that undesirably shapes the human condition – like deliberately creating deaf or dwarf people – the professionals involved in reproductive technologies should answer the question if this should be an accepted ethical practice because the basic human right to an open future is violated.

Key words: deafness, dysgenics, eugenics, genetics, repro-genetics

It has been argued by some authors that deaf parents are making a mistake in choosing deafness for their children (Levy, 2002). Given their own experience of isolation as children, however, it is a mistake which is understandable, and our reaction to them ought to be compassion, not condemnation. I agree with the reasoning at stake but I suggest that this practice could be regarded as unethical.

In fact, it is true that the assumption that deafness is "a disease" is culturally based and disregards the intrinsic value of linguistic minorities, namely deaf culture and its values. Also, it is claimed by deaf associations that deafness is neither a disease nor a disability and that deaf culture should be accepted in a secular pluralistic society (Sacks, 1990). Common practices of auditory (re)habilitation would lead to further discrimination of the culturally deaf. Even some deaf adults feel that auditory (re)habilitation is an inadmissible intrusion within his/her life style. The (re)habilitated patient would be neither a deaf nor a "normal" person. Some deaf people, however, consider themselves a special group with its own identity – Deaf-World (capital letter) – but not an abnormal one (Jacobs, 1989).

It is also commonly accepted that the Deaf-World is a specific community that depends largely on a different language to communicate – sign language. This community has its own customs, beliefs and attitudes. To belong to the Deaf-World one must self identify with the deaf culture and deaf values. Moreover, it is argued that the Deaf-World – as a minority culture – depends largely on parental and societal options to acculturate deaf children in deaf values. In his book "The Mask of Benevolence: Disabling the Deaf Community" Harlan Lane speaks of genocide and ethnocide believing that auditory (re)habilitation would, in the end, overwhelm and destroy deaf culture (Lane, 1992). It is deaf activists' belief that the survival of the Deaf-World might depend on the intentional production

of deaf children. From my point of view this aim could be accomplished by different ways: through abortion of genetically hearing foetuses after prenatal genetic diagnosis (or discarding genetically hearing embryos after pre-implantation genetic diagnosis), through the genetic transfer of the DNA sequences responsible for deafness or by mating of deaf people with exactly the same type of autosomal recessive deafness like DFNB type.

More than discussing the ethical quandaries of auditory (re)habilitation of deaf children, the objective of this paper is to analyse the use of reproductive technologies in ways that are contrary to the fulfilment of the basic human right to an open future.

For a long time now deaf activists, like Harlan Lane (Lane and Grodin, 1997), have spoken in favour of genetic intervention "in order to enhance the possibility that deaf parents will have deaf children" and claim that "...it is unethical for the majority culture to aim to reduce the numbers of children born deaf because measures intended to prevent births within a cultural group constitute genocide...". This possibility, that was only a theoretical one a few years ago, is now put in practice as stated by Spriggs in the paper "A lesbian couple create a child who is deaf like them" (Spriggs, 2002). This practice is ethically problematic because the right of the deaf child to an open future might be at stake. The right to an open future was first proposed by Joel Feinberg referring to the concept of "rights-in-trust", that is rights that are to be "saved for the child until he is an adult". Those rights must be protected in the present to be exercised later in life. This general category of rights holds that parents do not own their children but are only guardians on their behalf. It follows that a child's scope of future choices must be protected (Feinberg, 1980).

For the purpose of this article, I shall use the expression "dysgenic" in a different way than it was previously used. I will not use the concept of dysgenics as a natural genetic deterioration of the human species, the sense proposed by Richard Lynn (Lynn, 1996). Rather, as a culturally imposed genetic selection not to achieve any improvement of the human subject but to select genetic traits that are commonly accepted as a disabling condition by the majority of the social matrix; in short as a handicap. If dysgenics is properly seen as a programmed intervention (genetic and/or reproductive) that shapes the human condition in a controversial way – like deliberately creating deaf or dwarf people – it should be reconsidered by health care professionals.

Deafness and genetics

A large number of articles have been published both in the medical and bioethical literature on the extraordinary development of the genetics of deafness. Physicians as well as geneticists are increasingly aware of the need for curing deafness as a disability and a limiting condition affecting one in every one thousand live births. It has been estimated that half of the cases of profound congenital sensorineural deafness have a genetic aetiology (American College of Medical Genetics, 2002). There are three main patterns of inheritance associated with these conditions: autosomal dominant, autosomal recessive and X-linked recessive. In autosomal dominant deafness a person has one gene for the hearing loss. Therefore, this individual has a 50% chance of passing on the hearing loss to each child. In autosomal recessive deafness there are two copies of the affected gene. When two carriers have a child there is only a 25% chance that the child will receive both genes and have a hearing loss. Nevertheless, when two deaf people (with exactly the same type of autosomal recessive deafness, like DFNB type) have a child he/she will surely be affected. In X-linked recessive deafness the affected gene is on the X chromosome. If the father is affected on his (only) X-chromosome his son will not be affected and his daughter will be an obligate carrier. If the mother is an obligate carrier 50% of her sons will be affected and 50% of her daughters will be obligate carriers.

However, hereditary deafness is extremely heterogeneous with more than 40 genes discovered for non-syndromic dominant deafness and more than 30 for recessive hearing loss (Bitner-Glindzicz, 2002). Recessive genetic deafness usually occurs very early causing severe to profound prelingual hearing loss. Connexin 26 gene mutation is one of the most prevalent forms of congenital sensorineural genetic deafness (Mesolella et al., 2004). Also, Usher syndrome type I, causing profound deafness at birth and leading to a progressive blindness starting in the second decade of life, is a good example of a serious disease that can be detected early by mutation analysis. Moreover, new developments in the genetic field have already allowed the quick screening of known genetic deafness mutations.

Denoyelle et al. (1999) argue for the importance of genetic constitution in prelingual deafness as well as in late-onset deafness of unexplained aetiology. These authors go on concluding that the importance of this finding – that a single gene might be associated to half of all early profound

childhood deafness – brings about new responsibilities to geneticists, particularly to genetic counselling. Indeed it is possible not only to make the prenatal diagnosis of affected embryos and foetuses but also to predict the late onset of deafness.

We often ask if the deaf child has, due to his or her hearing impairment, a normal psychological development. We live in a hearing world and the lack of social integration of deaf children is the basis for the existence of the Deaf-World. The Deaf-World is a community that shares common ideals about the meaning of good life. Moreover, it is asserted today that deafness, *per se*, is not associated with a decreased response rate in non-verbal intelligence tests and other cognitive functions (Moores, 1987). From a physiological perspective, however, deafness is always the result of some kind of pathology of the auditory pathway with characteristic histological and cytological changes. Congenital deafness occurs in approximately 1 in 1000 live births and 50 percent of these cases are hereditary. As previously stated, there are at least 30 genes responsible for non-syndromic recessive deafness, that is for a deafness with no other associated clinical features. Late-onset hearing loss is a major public health concern; genetic deafness may be accountable for progressive hearing loss in adulthood (Morell et al., 1998). From the medical point of view adult and childhood deafness is always a disease and should be treated accordingly.

Keats and Berlin argue that 77% of genetic deafness is autosomal recessive, 22% is autosomal dominant and the remainder is mitochondrial or X-linked (Keats and Berlin, 1999). These authors go on further claiming that there are obvious examples of interaction of genes and environment like the mtDNA mutation responsible for aminoglycoside induced deafness. The increased knowledge of the genetics of deafness will enable society to provide genetic screening for deafness as a common service (Steel, 1998). When asked for prenatal diagnosis of these gene mutations it should be carefully explained that there is a broad range of variation which regards both the severity and the evolution of deafness. Nevertheless from a genetic perspective the hearing status of the first child is indicative of the hearing potential of the children still to be born. As far as genetic deafness is concerned, and due to the predictive nature of the tests, the abortion of affected foetuses is also ethically disputable. It should be reminded that from a disabilities rights perspective the logical consequence of the Human Genome analysis would be the correction, through gene therapy, of the defective genes detected, not the abortion of affected foetuses (Parens and Asch, 1999). Indeed, from this perspective abortion is ethically disputable because it expresses discriminatory attitudes towards de handicapped people and raises the myth of the perfect child.

The central question remains unanswered: is there a clear distinction between the social construction of deafness as a disability and deafness as a variation of normality? In a pluralistic society a consensus is not expected over this issue. Although there seems to be an apparent contradiction between these two perspectives, the main point is that for the time being there is no definitive answer with regard to the best way to rehabilitate a particular deaf child. Therefore, for the time being, communitarian values may be acceptable and deaf parents are entitled to the rearing of the child within the Deaf-World. If, in the near future – as expected – the cochlear implantation technology will provide all deaf children, whatever the hearing status of the family, the capacity to develop acceptable communicative skills, then, but only then, will auditory rehabilitation be an ethical imperative for all deaf children. In short, if the parents are deaf and belong to the Deaf-World, the open future of the deaf child might be developed within Deaf values. For this community deafness is just a variation of normality. With the expected development of auditory rehabilitation technology it will not be possible to defend this perspective anymore and deafness will increasingly be considered as a disability and hearing a sense instrumental to accomplish an open future.

Indeed, it is true that the Deaf-World is a linguistic minority and that it can also be considered a cultural minority due to the existence of particular cultural and familial bonds between deaf people. It is also true that members of that community share a common view of the good life at least with regard to specific aspects of social relationships, namely the use of sign language (Tucker, 1998). What is not true, however, is that children of any age should be referred to as Deaf (capital letter). There is no such thing as a birth right to be deaf. To belong to the Deaf-World parents must decide that this option is in the best interests of the child. In the past, when no auditory (re)habilitation was available, there was simply no choice but to be acculturated in deaf values, namely to learn sign language. Today, recent developments in cochlear implantation technology allow parents to decide for auditory (re)habilitation and therefore a child might still be ''deaf'' from a biomedical perspective but socially he

becomes a hearing person, therefore not "Deaf" (although at the level of a hard of hearing person revalidated with a hearing aid). Nevertheless, deaf communities claim that oral communication, when acquired by the deaf child, is purely mechanic and artificial, with all the limitations associated with it. Also, it is argued that deafness is not a handicap, but a different cultural and linguistic identity.

In this vein, the Deaf-World can, and I feel that it will, go a step further; that is to deliberately create deaf children (it is possible for a long time now through the mating of parents with the same recessive deafness). This purpose can be achieved by different ways: (a) the first one can be accomplished through the genetic selection of embryos for *in vitro* fertilisation and embryo transfer (IVF), after pre-implantation genetic diagnosis for deafness; (b) the second one through the help of a sperm donor (as suggested by Spriggs); (c) the third one through selective abortion of foetuses with a normal genetic endowment (after prenatal genetic diagnosis, only foetuses with deaf genes would survive); and finally (d) through gene therapy: the use of genetic technology to transfer a gene sequence knowingly associated to deafness. If this technology is used on a preembryo, before the primitive streak appearance, germ-line gene therapy might be at stake. It follows that genes associated with deafness would be present not only in the prospective child but also in his or her progeny. This would be in clear contradiction to the right to inherit a genetic endowment that has not been artificially manipulated. Indeed, the Convention on Human Rights and Biomedicine determines that "An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants" (Council of Europe, 1996).

Dysgenics and reproduction

Over the last century, the development of medicine and the global improvement of social and economic conditions have contributed to the overall increase of genetic diseases, diseases and disabilities that the process of natural selection would have eventually discarded. At the same time, however, societal trends reduced the number of disabled people trough genetic selection believing that this practice would, in the end, contribute to a shared agreement of the common good. β-Thalassemia programmes in Mediterranean countries (prenatal and postnatal genetic screening) and phenylketonuria as well as cystic fibrosis neonatal screening in most western countries are a few examples of socially determined practices ethically accepted by the population (Weatherall, 1994). Screening can be performed in families where a particular genetic trait is very common or, in alternative, it might be cost-effective from a social policy perspective to screen the entire population at risk.

Strictly speaking, public policy on genetic screening programmes in most western countries is not eugenic (Kevles, 1996). Social trends do not aim at ensuring an absolute decrease of recessive traits in the population nor to reduce the reproductive capacity of handicapped people (Lappé, 1998). The decision to procreate or not after a positive result is left to the decision-making capacity of the couple. It should be reminded that the introduction of simple routine DNA mutations tests can provide knowledge for deaf people regarding the aetiology of their deafness. This enables deaf couples, including lesbians to have a deaf child although the outcome of such occasional mating in autosomal recessive deafness is just one in every four neonates.

Indeed, one of the aims of genetic programmes is to enhance couple's reproductive autonomy. Those programmes are characterised by the conceptual framework of non-directive counselling. For many years now, surveys (Wertz and Fletcher, 1988) were paradigmatic in the conclusion that clinical geneticists believe that ethics and genetics – sometimes referred to as GenEthics (Suzuki and Knudtson, 1991) – should respect human rights, namely the couple's right to choose. It follows that the counsellor's task is to inform the genetic risk of a particular couple insofar as these risks are concerned. Non-directiveness is achieved by letting the couple decide what is in their best interest. Those informed choices – the concept of free and informed consent – are the proper foundation of good clinical practice in a secular pluralistic society. Genetic choices are private and personal ones by their very nature and neutrality in counselling is usually achieved. The ethical dilemmas involved in genetic counselling are similar in most western countries. There is a widespread consensus about most goals of genetic intervention. In the future controversial indications – such as dysgenic selection – must be properly addressed by genetic counsellors as well as by professional associations. When faced with such an ethical dilemma – namely the active use of reproductive technology to give birth to a handicapped baby – the counsellor may

feel that an injustice is done to the affected newborn. These consequences should be at least considered in the counselling process. As stated by Murray (Murray, 1998), "some counselors feel that the counselor may be justified in not honouring the principle of nondirectiveness because the net reproductive effect is likely to produce more harm than benefit".

But, couples still have a wide range of decision-making capacity as far as reproductive choices are concerned because respect for personal autonomy is an accepted principle of social and biomedical ethics (Wachbroit and Wasserman, 2003). In western societies, genetic diagnosis is usually offered when couples are in a well known genetic risk group. Societal trends, however, are willing to offer genetic services to all couples. As suggested by Thomas Murray "The more one sees women and men on a shared path to flourishing, the more important it appears to empower women with control over their own fertility" (Murray, 2005). However, the assessment of a particular couple's intention to procreate is in clear contradiction with the practice of non-directive counselling (Committee of Ministers, 1990).

In short, any interference in natural reproduction is regarded as unethical unless valid consent is obtained. As an example, although the risk of occurrence of a deaf child in natural reproduction is highly variable, ranging from 100% to almost zero, couples should be allowed to have a deaf child if it is the consequence of their own actions. For instance, if two deaf people have the same autosomal recessive type (like DFNB1), only deaf children will be born. However, this situation is clearly different, both from a social and a professional ethics perspective, from the direct intervention of medicine and repro-genetics to deliberately create a deaf child. The question then is how to balance reproductive autonomy with dysgenic practices.

However, not all dysgenic practices are unethical. As in eugenics, dysgenics can be achieved in a negative and a positive way. Negative dysgenics can be obtained through careful prenatal or preimplantation selection and abortion (or discarding) of normal embryos and foetuses. Only deaf children would be allowed to live. This dysgenic practice could be regarded as unethical because individual rights – namely the right to an open future – are at stake (the ethics of abortion needs a different conceptual framework). Positive dysgenics intends to increase the overall number of people with a particular genetic trait. Marriages between deaf people or conceiving deaf children through reproductive technology are examples of positive dysgenics. Only the latter could be regarded as unethical, not marriage in itself. Indeed, for some deaf parents the hypothesis of having a deaf child is very high. In such a circumstance, one expects that this child is cared for and loved like any other one. For many couples having a handicapped child is better than having no child at all. Nevertheless, in this circumstance the intention is probably to have "a child" not a "handicapped child", which is morally different.

It follows that professions involved in reproduction and counselling should reconsider the ethics of dysgenic practices. By a large majority (14/02) the Danish Council of Ethics determined in an opinion over sperm selection that "the possibility of pre-determining the child's other attributes…should only exist when done to create a certain resemblance with the social father" (The Danish Council of Ethics, 2002). One might conclude, therefore, that this council would oppose sperm selection to deliberately create a deaf child.

The right to self-determination with regard to reproductive choices should be balanced with the vested interests of the future child. Childhood in a broad sense should be regarded much more as a stage than as a status. It follows that the rights of the prospective child should be regarded in this dynamic perspective so that society fully understands its *parens patriae* role. The state is the last resort of the child, not only because it has the duty to protect his/her rights but also because children represent the future of humanity. As suggested by Wellman, whatever the philosophical nature of rights there is some consensus that "rights are ascribed to and possessed by each individual or entity in a group separately rather than collectively. Whereas the many benefits and harms to various affected parties of any action are summed together in the act's total utility, each individual person has his or her own right that demands respect independently of the rights or welfare of any other individuals" (Wellman, 1998). This consensual approach is the distillation of many different views of moral, legal and political rights, namely the understanding of rights as valid claims on others, rights as determinants of proper distribution of freedom, rights as the protection of interests or even as the protection of the individual against state action or intrusion. Moreover, whatever the class of rights invoked there is a broad consensus that human rights are the most fundamental one's, namely when they are the only way to protect individual freedom. In this vein, the right of a child to an open future (Davis, 1997) and

therefore his/her best interests overwhelm the also important right of his parents – but hierarchically inferior – to reproductive autonomy.

It is this author's belief that there is a difference between valuing the Deaf-World – as a cultural minority (Wever, 2002) – and allowing that the rights of a particular child will be overwhelmed by one's own culture. Indeed, it is usually considered, as stated in the Convention on the Rights of the Child, that "In all actions concerning children...the best interests of the child shall be a primary consideration." (United Nations, 1989). Best interest is more than merely allowing a child to survive or to give him shelter, food and clothing. It is to actively allow that he becomes a full member of society, that he will be an autonomous person that can engage in social relationship. With regard to the best interests of the child Mary Warnock states quite clearly that "We are too liable to suppose that what is in our own interests is in the child's. The case of the artificial family is a particular serious indication of this. For there can be no doubt that what people who want children want is their own satisfaction, not that more elevated thing "the good of the child". They may come to want that when they have a child; they may not. But the fact that they want a child does not by any means entail that they will in future consult his interests, and certainly it could not entail that they consulted those interests before he was born" (Warnock, 1992).

Conclusion

Genetics and assisted reproduction are facing new challenges in the coming years. Prospective parents are willing to use these technologies not for legitimate purposes, ethically grounded in presumed consent, but also to shape the human condition in ways substantially different from the values embraced by the overall community. When a person has never been competent – as a deaf child – Tristram Engelhardt's contention is that "guardians may be in authority to choose particular understandings of an individual's best interests in terms of the values embraced by the community within which the ward lives and to which, it can often be presumed, the ward will or would subscribe" (Engelhardt, 1986). Therefore, as this argument goes, choices by parents in terms of the best interests of a deaf child are allowed within a range of expected benefits to the child. Benefits as a prudent and reasonable person would choose. It follows that choices that are not reasonable and that clearly affect the "open future" of any child should not be accepted.

The example of deafness is instrumental insofar as it paves the way to the misuse of these technologies to deliberately create a particular class of people. If this should be the case the concept of non-directiveness in counselling needs to be reconsidered or at least revisited. Even enhancement genetic engineering (of specific human traits like intelligence or memory) is ethically problematic because there is no agreement on which values are universally acceptable. Society can only hope that the Human Genome Project's endeavour in finding the genetic basis of human diseases, like deafness, will not be used in a perverted way, a dysgenic way, to select the human traits – traits universally considered as disabilities and handicaps – that it intended to prevent.

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