

Genetic Engineering Option for Persons with Disabilities: To Be or Not To Be

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ABSTRACT

This paper discussed the topic of genetic engineering option for persons with disabilities, to be or not to be. In this paper, the meaning of genetic engineering as a field of biotechnology, which deal with the modification of genes was discussed. The international regulations on genetic engineering on the rights of persons with disabilities were exposed; the issues against genetic engineering for persons with disabilities, which were based on limitation of children's freedom, fears that genetic engineering will lead to eugenics, social inequalities, and possible environmental hazards were pointed out. The discourse highlighted the possible gains or merits of genetic engineering as a treatment option for persons with disabilities, also on children's independence to rebuild their own destinies, among others merits. Possible dangers of genetic engineering to persons with disabilities were discussed and the paper gave recommendations, inters alia, that there should be established regulations and published safety guidelines to reduce the dangers of researches on genetic engineering.

Keywords: Genetic Engineering, Persons with Disabilities, Human Right, Genes, social Discrimination

INTRODUCTION

Contemporary days have observed a universal move in the awareness and management of disability and people with disabilities towards a human rights viewpoint in line with the social model of disability (Oliver and Barnes, 1998). This was in response to the recent shift in the development of genetic technology particularly in the field of modified plantations and food and lately regarding the technology of cloning. The ongoing worldwide argument that interfering with humans through food and genes is an infringement of basic human rights for decent living and a safe existence which is clearly stated in Article (3) of the Universal Declaration of Human Rights (UN, 1948) and the UNESCO's Universal Declaration on the Human Genome and Human Rights (UNESCO, 1997; Degener, 1998). This further necessitated the current draft disability convention which has touched on this issue in its 4th session of the Ad Hoc Committee on the Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (UN ESA, 2004).

The term genetic engineering is a technique, performed by scientists in a laboratory, to change a living organisms' Deoxyribonucleic acid, or DNA. Genetic engineering is defined as an alteration of the traits of the cell of an organism through the direct manipulation of genes. Nature can produce organisms with new gene combinations through sexual reproduction. A black cow for example, bred to a brown cow produce a calf of a completely new colour. However, reproductive mechanisms limit the number of new combinations, that is, cows must breed with other cows (or very near relative). A breeder who wants a purple cow would

be able to breed towards one only if the necessary purple genes are available somewhere in a cow or near relative to cows. Genetic engineering has no such restriction. If purple genes are available anywhere in nature such as in a sea urchin or iris, those genes could be used in attempts to produce purple cows. This unprecedented ability to mix up genes means that genetic engineering can create gene combinations that would never be found in nature.

This medical debate on genetic technology has contributed to the appearance of the view of the 'perfect body', which in some way works against people with disabilities in the areas of food modification and cloning (Turmusani, 2005). It was claimed that these debates have political proposition on society's policies and practices towards people with disabilities. For instance, it is believed that the medical debate on euthanasia and eugenics have led to public recognition and support of policies and practices that eradicate imperfect bodies or minds. As a result, it is vital to take precautions when utilising the result of genetic research in the social policy making process. The ongoing procedure of developing universal code of ethical practices in social and technological research impacting people with disabilities is significant but equally significant is the debating processes and their production (Hurst, 2000; DAA, 2001).

To this wise and in relationship to the persons with disabilities, it is the view of some people that this is the better chance for a better and healthier life for this group of population, but other fear that it is "playing God" or try to "programme" a human being. Davies (2008) claimed that each of these views is right in certain ways as genetic engineering could be used to enhance people's lives, but it could also be used to harm people's lives. If researchers could produce more effective and accurate processes to manipulate human DNA, incurable diseases nowadays will get cure. Birth defects will be totally eliminated as doctors will be able to change child's genes ever before delivery, as this will lead to cure of hereditary diseases (Falk & Chong, 2008).

In this paper, the authors will expose the international regulations on genetic engineering on the rights of persons with disabilities; the issues against genetic engineering for persons with disabilities will be pointed out; the possible gains or merits of genetic engineering as a treatment option for persons with disabilities will be highlighted; discuss the possible dangers of genetic engineering to persons with disabilities and give recommendations.

GENETIC TECHNOLOGY AND PERSONS WITH DISABILITIES

From history, the proposition of genetic research contributed to a widespread negative response and rejection of anything less than complete and perfect and therefore, those with disabilities were as a result considered as lesser human beings (Turmusani, 2005). Therefore, this led to the creation of the view of disability as deviance and persons with disabilities as a special species whose lives are not worth living. This is then used far and wide to justify 'euthanasia' and the exclusion of defective bodies (Barile, 2003; Albert, 2004).

As scientific research expand our knowledge of the human genome and the brain, the number of persons identified with a specific condition that may lead to learning difficulties/disabilities will continue to grow. The two of the most common genetic disorders that include learning disabilities are Down's syndrome and Fragile X. Down's syndrome is a genetic condition caused by the presence of an extra chromosome in the body's cells. Down's syndrome is not a disease, and it is not a hereditary condition. It occurs by chance at conception, while Fragile X is one of the most common inherited causes of intellectual impairment, and the most common known genetic cause of autism. The common qualities usually include:

1. Mental disabilities, which range from learning disabilities to intellectual disabilities
2. Attention deficit and hyperactivity
3. Anxiety and unstable mood
4. Autistic behaviours
5. Long face, large ears, flat feet
6. Hyper extensible joints, especially fingers
7. Seizures (epilepsy) affecting persons with Fragile X

Jatau, Uzor and Lere (2001) identified the three major causes of disabilities as pre-natal, perinatal and post-natal. The pre-natal cause according to them is heavily linked to hereditary, diseases and drugs while the later two are actually occur later in life. The persons with disabilities are being marginalized in the society, with series of mere treatment ranging from forced sterilization, denial of medical treatment, mercy killing (euthanasia), physical and sexual abuse, neglect and homicide (Gruskin& Daniel, 2008).

In various attempt to finding solutions to the above conditions using genetic technology, various disability right crusaders has queried that genetics technology and genetic research is not the answer to persons with disabilities' problems. Conversely, they see it as contributing factors for creating disability when seeking perfection to bodies and minds. Disability right crusaders had long rejected genetic research, and solicited for caution when using such research (Inclusion International, 1996; Albert, 2004). They challenged that genetic research had harmful effect on persons with disabilities and that such research had been ripping off the rights of persons with disabilities and encouraged social discrimination. They argued that society should see ahead of the individual and their biology (genes) into the wider social, political and environmental factors in line with the social perspective on disability (Turmusani, 2005).

With this, the widespread argument has brought about the move to defend the rights of persons with disabilities as regards the genetic technology. The UNESCO's Universal Declaration on the Human Genome and Human Rights has hitherto acknowledged this key issue in Article 8 and clearly states that no one should be subject to discrimination on the basis of genetic characteristics (UNESCO, 1997). For instance, many countries lack legislations to protect the rights of persons with disabilities and some countries have poor human rights records. This could further lead to risk of abuse by genetic technology such as selective abortion, and eugenics policies. Turmusani (2005) opines that there is a general agreement concerning the impact of genetics on people lives and this is coupled with caution towards cloning technology. In truth, the World Health Organisation condemned human cloning. Cloning means the creation of genetic duplication of another human where genetic code is copied deliberately from one person to make another person with the same genetic material. The social implication of this is that human cloning is seen as disturbing the relations within the family structure. Besides, human cloning is expected to be used to strengthen rather than to fight society's prejudices, and discrimination against persons with disabilities.

With this, the UNESCO's Universal Declaration on the Human Genome, which is based on a human rights approach to life, recognizes the need for regulating genetic research for protecting the dignity and integrity of human beings (UNESCO, 1997), on the basis that there should be pressing need to develop ethical codes of practice concerning genetic research relating to persons with disabilities. This is in addition with the right to life and the right for a decent living especially for those with intellectual disability and those in institutions. This

does not undermine the right for independent living and inclusion in community life (Mandesi, 2004).

THE ISSUES AGAINST GENETIC ENGINEERING FOR PERSONS WITH DISABILITIES

Ethicists have usually been more worried about possible problems with and propositions of improvement of genetic engineering than they have been about gene therapy. Primarily, there are worries similar to those about gene therapy that not enough is known and there may be unpredicted unsafe consequences. These worries may be even more severe given that the attempts are made not just towards normalcy but into strange new area where humans have never gone before.

The following are some other vital arguments:

1. Genetic engineering limits children's freedom to shape their own destinies. Falk and Chong (2008) maintained that if parents are able to reshape their children makeup, they are in a sense noting the genetic remarks that make their entire lives. If it is possible that parents give green eyes in place of brown eyes or make them tall in lieu of medium height, their choices will have a direct, longlife implications on the children. This means that genetic enhancement is immoral because it artificially reshapes person's lives, in which they will not want it to be so. In that case, it portrays a fundamental violation of their rights as human beings.
2. Some fears exist that genetic engineering will lead to eugenics. It was noted and recently announced that plans to use cutting edge science to eradicate a condition of autism spectrum disorders, in an attempt to make life better for them (Colson, 2006). Prenatal testing, combined with abortion-on-demand, has made persons with Down syndrome an endangered population. The reason behind this disagreement remains that human genetic development enable inequity against persons with disabilities.
3. Following the above, argument exist that genetic engineering leads to vast social inequalities. This will in the long run, create a society where the affluent will benefit genetic enhancement like improved height, higher intelligence, perfect eyesight, than the impoverished. This discrepancy may be aggravated by the fact that, those who are genetically engineered will benefit perfect health than the other who could not benefit, thereby becoming intolerable and leading to inequalities.
4. Other believe that genetic engineering is based on moral issues, particularly involving religion, which query whether man has the right to manipulate the laws and course of nature. This type of opposition is attuned to both with "creationism," the belief that God created humans just as they are, and also the belief in evolution. On the other view, humans' consciously enhancing their genes is considered different than allowing the natural process of evolution to "choose" the genes we have.
5. Some critics believe that genetic engineering is dehumanizing because it will create nonhuman, alienated creatures. Persons who are genetically engineered will be alienated from themselves, or no longer feel human, or the human race will feel alienated from itself. They would not have a sense of being part of the human race and could feel like a separate species.
6. There are beliefs that any technology that offers benefits will usually come with risks as well. They believe that in order to make wise decisions about using a

technology, we must appreciate its potential impacts well enough to decide whether the risks are acceptably low. They identify areas of health risk which imply that foods made from genetic engineering crops are naturally unsafe, and that, for instance, refined products derived from genetic engineering crops, such as starch, sugar and oils, are different than those derived from naturally bred crops. Moreso, crops from genetic engineering can potentially cause environmental problems that result directly from the engineered characteristics. Crop can infiltrate toxins to the human body, thereby causing health, behaviour problems to persons with disabilities.

THE POSSIBLE GAINS OF GENETIC ENGINEERING TO PERSONS WITH DISABILITIES

It may be true that genetic engineering may be one of the greatest advances in recent history together with the discovery of the atom and space flight. But, with facts enumerated so far, governments of the world are enacting laws to control what sorts of experiments are done involving genetic engineering especially in the developed world. For instance, laws on prohibition on cloning or any experiments involving the cloning of humans had already been enacted in United Kingdom. As genetic engineering is going to become a very conventional part of our lives now or in near future, as a result of the benefits involved.

The following are some of the benefits:

1. Gene therapy is often viewed as morally agreeable, though caution is encouraged. The main debates in favour are that it presents the potential to cure some diseases or disorders in the sufferers and prevents diseases in those whose genes are liable to those disorders or diseases. If carried out on reproductive cells, gene therapy could keep persons from carrying such genes that the persons got from their patients.
2. Even as critics are correct that a world with genetic engineering will bring about inequalities. On the contrary, it is debatable that a world without genetic engineering, is even more unequal. Persons who are genetically engineered can aspire to be anything in life or excel in any career they choose to be, be it astronauts, doctors or any profession of their choice.
3. Some believe it to be true that genetic engineering may limit children's independence to rebuild their own destinies. However, it is likewise correct that all persons' destinies are already limited by their natural genetic makeup, a makeup that they are born with and cannot change. For instance, a person with visually or hearing impairment would not be able to read courses in medicine/ surgery and other professions that involve the use of sight and hearing like being a pilot. In a way or the other, our destinies are determined by the genes we are born with.
4. Furthermore, it is arguable that genetic engineering might help to level the playing field. Genetic engineering could give persons greater inborn ability to accomplish their dreams and pursue their own happiness (Seck, 2007). Somewhat than allow persons' choices to be limited by their genetic makeup, it is nice to give each person the competence of becoming whatever he or she wants to achieve, and allow him or her to attain his or her potentials, willpower and determination.
5. Seck (2007) further maintained that we should not allow our fear of change to prevent our society from exploring this promising new field of science, that the field that promises so many medical and social benefits. He stated that the strategy that

defines itself against the core idea of scientific progress cannot succeed. Instead of attempting to bury our heads in the sand, we should seek to harness genetic engineering for its positive benefits, even as we take careful steps to ameliorate its potential harms.

6. The critical argument in support of engaging in genetic engineering is that it could make life better by enhancing certain traits of persons with disabilities. We create more importance on intelligence, beauty, strength, endurance, and certain personality characteristics and behavioural tendencies, and if these traits were found to be due to a genetic component we could enhance people by offering them such traits. Supporters of genetic engineering point out that many persons try to improve themselves in these ways already, by diet, use of vitamins and minerals, exercise, education, prosthesis, cosmetics, and even plastic surgery. Persons are trying to do these things for themselves, and parents are seeking alternative ways of managing their disabilities. If exercising is to improve strength, agility, and general fitness is a valuable goal, and if education to increase their mental capabilities, then embracing genetic engineering is a worthwhile venture for persons with disabilities.

RECOMMENDATIONS AND CONCLUSION

Genetic engineering is a complex process that can be applied for many things from transforming organisms such as plants to serve humanity better, and manufacturing helpful pharmaceutical products, and even providing hints to the evolutionary procedure. Despite the fact that arguments abound that genetic manipulation process seems to result in more disadvantages than advantages, these arguments and views are often overstated. Even if no one can say for sure the future of any field of human endeavour, genetic engineering seems to be a practicable method through which many problems of modern society can be solved.

Although numerous disadvantages of genetic engineering exist, they have been highly overstated. It is therefore necessary to recognize and understand the genetic basis of all diseases, not only to find faults in experiments. For genetic diseases, the answer lies in finding cure rather than managing with lifelong and often inadequate treatments. Vaccines have been developed through genetic engineering and have nearly expunged some of man's most frightened diseases. Although, vaccines do create harm and dangers to people, the overstatement of the disadvantage and likely harms in these experiments deflect attention from the research needed to solve these problems and prevent others. There is therefore need for direction of the potential dangers of such research and be balanced against the real disasters caused by other sources. In an attempt to find solutions to this therefore, there should be established regulations and published safety guidelines to reduce the dangers of research. These guidelines and safety guidelines will gradually relax because such research will have been proven to be safe. This will better put in focus those areas that call for arguments and conflicts. Weighing these pros and cons will determine whether our society will accept or reject genetic engineering as an option for persons with disabilities.

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