

Genetic engineering for purposes of human enhancement poses risks that justify regulation. I argue, however, that it is inappropriate to use human rights treaties to prohibit germ-line genetic engineering whether therapeutic or for purposes of enhancement. The scope and weight of human rights make them poor tools for regulating a rapidly developing technology such as genetic engineering. On the other hand, international treaties are appropriate regulatory tools as long as prohibitions are not put in terms of human rights.

Introduction

It is easy to sympathize with those who are concerned about human genetic engineering. While the use of genetic engineering for therapeutic purposes that do not affect future generations has held out great promise and inspired a range of studies, it has also led to problems including deaths and leukemia (Boylan and Brown 2001, 29). Germ-line engineering, which affects future generations, holds out the promise of preventing genetic diseases, especially monogenetic diseases such as hemophilia, Franconi's anemia and amyotrophic lateral sclerosis, but it is not clear what the risks will be. There are also dreams of using genetic engineering for purposes of enhancing human traits. While it is not clear at present how far we will be able to accomplish this, if we are successful it may create troublesome inequalities and worries about changes in human nature itself. Some fear not just untoward side effects, but catastrophe. Francis Fukuyama writes about humanity being transformed into a posthuman future, and Lee Silvers worries that humans might be engineered to the point where there are separate species of the GenRich and the Naturals (Fukuyama 2002; Silvers 1997, 246-247).

Those who are impressed with visions of potential dystopias sometimes argue that humans have a human right to their own genetic identity. According to George Annas, Lori Andrews and Rosario Isasi, "cloning and inheritable genetic alterations can be seen as crimes against humanity" (Annas et al 2002, 153). The

European Parliament has adopted a resolution providing that people have a human right to their own genetic identity (European Parliament, 1998, Article 1). Several international treaties have also grounded prohibitions of germ-line genetic engineering and non-therapeutic genetic engineering on human rights (Council of Europe 1997, Article 13)

It is clear that regulation will be needed as we move forward. But what form should the regulations take? I argue that it is a serious mistake to adopt human rights treaties that specifically prohibit all germ-line engineering or all genetic engineering for purposes of human enhancement on the grounds that such genetic alterations violate human rights. I also argue that it is a mistake to use human rights treaties to ban human reproductive cloning. The adoption of treaties based on such putative human rights, serve to weaken human rights generally. International treaties regulating human genetic engineering are appropriate, but any prohibition should be viewed as a temporary regulation based on risk assessment and cultural values that can change in light of new developments – not as a human right.

I begin by noting several current international human rights treaties and a proposed international human rights treaty to prohibit certain forms of human genetic engineering. I then discuss general features of human rights that need to be reflected in human rights treaties. Finally, I turn to a consideration of germ-line genetic engineering and genetic engineering for purposes of enhancement.

Human Rights Treaties and Proposals

The clearest prohibitions of germ-line and non-therapeutic genetic engineering are to be found in The Council of Europe's *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*. Article 13 of the *Convention* states,

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 1997.)

This appears to ban reproductive cloning, and the The Council of Europe's *Additional Protocol on the Prohibition of Cloning Human Beings* removes any doubt. Article 1 of the *Additional Protocol* makes it clear beyond doubt that reproductive cloning of humans is prohibited (Council of Europe 1998, Article 1). Article 11 of UNESCO's *Universal Declaration on the Human Genome and Human Rights*, also prohibits human reproductive cloning, and Article 12(b) implicitly rules out genetic engineering for purposes of enhancement (UNESCO 1997). Article 12(b) states,

The applications of research, including applications in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole. (UNESCO 1997.)

These prohibitions are closely tied to previously accepted human rights. Violations of the prohibitions are said to be violations of dignity and hence of the human right to respect for dignity. Article 2(A) of UNESCO's *Universal Declaration on the Human Genome and Human Rights*, for instance, states in part that "everyone has a right to respect for their dignity..." (UNESCO 1997).

Additional international human rights treaties have also been proposed. Annas et al. propose an international "Convention on the Preservation of the Human Species" that would outlaw germ-line genetic

engineering and cloning (Annas et al. 2002, 154- 157). They argue that germ-line engineering may one day be able to alter human nature and hence to undermine the common human nature on which the system of human rights depends (Annas et al 2002, 153). Along these lines, it might be thought that if there are any human rights at all, then there is a human right not to have the necessary conditions for the having of such rights altered.

What is striking about these documents is how specific, and yet how sweeping, the prohibitions are. They are specific in that they single out certain specific areas of genetic engineering – reproductive cloning, germ-line genetic engineering, and, in some cases, non-therapeutic genetic engineering. They are sweeping in that such activities are simply prohibited – now and forever.

Capturing Human Rights in Treaties

It is important to begin by reflecting on both the scope and weight of human rights. Consider, first, issues of scope. If there are human rights, they belong to all humans. Human rights are the rights of future humans as well as humans currently alive. They do not change from generation to generation. Nor do they change from culture to culture, though different cultures and different generations will interpret human rights differently and apply them with various statutes and regulations. This does not, of course, mean that every culture in the world does in fact accept human rights, for there are societies where human rights are routinely violated.

Treaties that capture the scope of human rights must have certain features. As James Nickel notes, their articles or provisions must be stated in sufficiently broad language that they can apply to different cultures throughout the world (Nickel 1987, 74-81). For human rights treaties to be effective, different cultures must be capable of providing different interpretations. In order to accomplish this, the rights should be stated in terms of principles rather than rules, to use Ronald Dworkin's distinction (Dworkin 1977, 22-28). Principles constitute reasons for action, but they do not necessitate action. Rather they have weight or importance (Dworkin 1977, 26). They can also conflict with one another and need to be balanced. Rules, on the other hand, apply in an all or nothing fashion. They are not weighed against one another and do not necessitate action (Dworkin 1977, 26-27). In United States law, for example, the First Amendment Free Exercise Clause that guarantees the right to religious freedom is a principle that sometimes conflicts with the First Amendment Establishment Clause that prohibits the state from adopting an official religion. On the other hand the Equal Employment Opportunity regulation that prohibits asking job applicants their religion is a rule that simply applies and is not balanced against other rules. Stating human rights in terms of principles rather than rules accounts for the way in which they can conflict and need to be weighed against one another. Stating human rights in terms of principles also provides the flexibility to allow human rights to apply cross-culturally while respecting the traditions of different cultures.

In addition, the broad scope of human rights requires that human rights treaties be stated in terms of provisions that will not become outdated with the advance of science. The principles that constitute human rights treaties should not be stated in terms of specific forms of technology or on the basis of current scientific assumptions that might change. Just as scientific theory will change over time in light of continuing research, cultural attitudes will also change over time. Activities that people find repulsive at one time may come to be accepted at another time and vice-versa. A case in point is in vitro fertilization (IVF). As Stephen P. Marks notes, when the techniques of IVF were first developed many felt revulsion and spoke of "test tube babies" (Marks 2002, 122-123). At the present time, IVF is widely accepted both emotionally and morally. Human rights treaties subject to the vicissitudes of advancing science and changing cultural norms cannot effectively apply human rights to future generations.

At the same time that human rights treaties need to be stated in language that is sufficiently general to be broadly applicable, the language must also be sufficient clear that it provides guidance. The trick is designing human rights documents that are flexible enough to be open to a range of interpretations while still being specific enough to capture the principles that constitute human rights.

The weight of human rights also needs to be considered. Human rights treaties are the heavy weapons of regulation. They not only apply transnationally and crossculturally, but also carry tremendous moral and legal force. They provide reasons for condemning national policy and, in extreme cases, for infringing on national sovereignty. Some have argued that governments that violate human rights are to that extent not even legitimate governments (Buchanan 1999, 52-56). Human rights, like other rights, are moral trumps that have the power to defeat policy justifications based on welfare considerations (Dworkin 1977, xi). As Mary Ann Glendon has noted, rights are not open to easy negotiation and compromise (Glendon 1991). Hence, issues that require negotiation and compromise should not be framed in terms of human rights. It should also be noted that the force of human rights is diluted as its rhetoric is expanded to cover more and more territory. Like all heavy weapons, human rights rhetoric needs to be used sparingly.

It turns out, in light of these considerations, that prohibitions on genetic engineering should not be regarded in themselves as human rights. Nor should they be derived from more general human rights of genetic integrity or dignity.

Human Rights and Prohibitions on Genetic Engineering

It is certainly true that germ-line genetic engineering, reproductive cloning, and genetic engineering for purposes of enhancement pose dangers that make them unjustified at the present time. On the other hand, the time may come when genetic engineering can safely be used to prevent diseases such as Tay Sachs or Huntington's. If human rights are used to prohibit germ-line engineering in such cases, serious problems regarding their weight arise. Suppose that germ-line engineering is prohibited because there is a human right not to be subjected to such engineering. In cases such as Tay Sachs Disease, this would be a right that no reasonable person would want to claim or have exercised on his or her behalf. In order to avoid such absurdity, the right would have to be regarded as weak and capable of being overridden or specific exceptions would have to be carved out from time to time as science advances. Either way, treating human rights as having so little force would seriously undermine the importance of human rights treaties.

Similar considerations may also arise regarding genetic enhancements. While present attempts to genetically enhance people are no doubt too dangerous to allow, there may come a time when such enhancements could be done safely in a manner that would not be objectionable to those who are enhanced. A slightly enhanced immune system might be an example.

In short, creating blanket prohibitions of germ-line genetic engineering on the grounds that there is a human right not to be subjected to such engineering produces a dilemma. If the rights are treated as genuine human rights, the rights trump consequentialist considerations based on beneficial therapies that might be developed, and this has absurd results. If, however, the rights are treated as weak and capable of being overridden by such consequentialist considerations, then they do not function as rights at all. In this way creating a human rights treaty to broadly prohibit germ-line engineering or enhancement engineering actually serves to weaken human rights.

The issue of genetic enhancement raises additional concerns regarding the use of human rights. Here the problems primarily concern the scope of human rights. If there is a human right not to be genetically enhanced, then the right must apply to humans generally. It must apply in the present and the future as

well as in all cultures. The problem is that what counts as an enhancement will vary depending on various cultural and technological considerations. This can be seen by taking a closer look at the therapy-enhancement distinction. Perhaps the easiest way to understand this is to see it as based on the distinction between maladies (diseases, disabilities and disorders) and normal functioning. Just what falls on either side of the distinction can vary depending on the structure of society, since what counts as a disability often depends on how society is set up. Alan Buchanan et al. argue that different societies have different dominant cooperative frameworks (Buchanan 2000, 79). A dominant cooperative framework sets the conditions that must be met for one to be able to compete for positions in that society and to function well as a member of the society. What counts as a disability within a society will, in many cases, depend on the dominant cooperative framework adopted by the society. For example, attention-deficit hyperactivity disorder (ADHD) may be regarded as normal functioning in a society wealthy enough to accommodate the behavior in its education system, but a disability in a society unable to adjust to the behavior associated with ADHD. In addition, what counts as a disability in a particular society may change over time, as the dominant cooperative framework evolves. A society may develop genetic techniques to deal with a disability, given its current dominant cooperative framework, and then have the disability become part of normal functioning later as the dominant cooperative framework changes.

Such considerations have troubling implications for human rights treaties that allow genetic engineering for purposes of therapy, but not enhancement. Genetic techniques that are prohibited as enhancements in one society may be permitted as treatments in another society. Moreover, what is permitted or prohibited will change from time to time within a society. The use of human rights in this context appears to be arbitrary. It is difficult to see how treating such specific prohibitions as human rights could have the universality and clout that human rights are supposed to confer if their application was contingent on changes in the dominant cooperative framework.

Human Rights to Dignity and Genetic Identity

It might be argued that this apparent arbitrariness is really only apparent because there is a more general human right that can be used to explain why these changes are legitimate interpretations of an underlying principle. But what could the underlying right be? I begin with the putative general right to one's genetic identity. A right to one's genetic identity makes sense when interpreted as a right to genetic privacy. One has a right to keep one's genetic information confidential within certain limits. On the other hand, it is not coherent when interpreted to prevent germ-line engineering. If one interprets genetic identity so rigorously that any change in one's genetic structure is a change in one's identity, then beneficial therapies are ruled out with absurd results, as previously noted. If, however, genetic identity is construed so that there is a core genetic identity, a sort of essence of the individual, then germ-line engineering may be able to proceed without affecting that identity. Germ-line engineering that prevents a disease, for example, does not threaten the identity of the individual because having a particular disease need not be part of the individual's identity. This is part of the reason we want to speak, for example, of a person living with HIV-AIDS, rather than speaking of an HIV-infected person. In short, the right to one's genetic identity, if it exists, does not justify a blanket prohibition on germ-line genetic engineering or genetic enhancement. Nor can it be used as a general principle to justify suppressing what counts or does not count as enhancement within the changing landscape of dominant cooperative frameworks.

It should also be pointed out that while issues of individual identity and authenticity are important, individual identity should not be reduced to genetic identity (Rovane 2002). It is not clear why having a unique genetic identity should be regarded as sufficiently important to spawn a human right. After all, as is often noted, identical twins are not harmed merely by the fact that they are identical twins (Häyry 2004, 10).

Similar arguments can be constructed regarding the human right to dignity. If dignity requires respect for a core set of personal traits, then genetic engineering that does not undermine those traits is not prohibited. This can include germ-line genetic engineering and even genetic engineering for purposes of enhancement. If, on the other hand, it simply means that the human genome is inviolable, then obviously beneficial therapies are ruled out.

Regarding prohibitions on germ-line engineering and genetic enhancements as human rights generally lacks theoretical appeal. Human rights ought to serve as justifications for the statutes and regulations they spawn. In this respect, prohibitions on germ-line genetic engineering and genetic enhancement look a lot more like regulations that follow from human rights than human rights themselves. Background justifications in terms of human dignity or human genetic identity also fail to provide the needed justification.

Cloning

These arguments also undercut some of the most prominent reasons given for supposing that reproductive cloning should be viewed as a violation of a human right. It is sometimes argued, correctly at the present time, that reproductive cloning is simply too dangerous to tolerate. It is also sometimes argued that reproductive cloning is repugnant and that we should pay attention to our feelings of repugnance (Kass 1998 and Midgley 2000). Along the same lines, it is sometimes argued that reproductive cloning would violate cultural understandings such as assumptions about family relationships and expectations. If a human right prohibiting cloning is grounded in current values or concerns about dangers, then there may come a time in the future when these conditions change. Similarly, if the human right is grounded on current cultural understandings, then there may come a time when these change. In either case, the basis of the putative human right is undermined or at least needs to be overridden.

Some have also argued that reproductive cloning is a violation of a more general human right to genetic identity or dignity. This is clearly the position, for example, of Council of Europe and UNESCO. But, it was argued in the previous section that this will not work. Moreover, as is frequently pointed out, identical twins clearly have human dignity, notwithstanding their genetic identity (Häyry 2004, 10).

Conclusion

There is no doubt that germ-line and non-therapeutic genetic engineering including reproductive cloning pose risks. They pose risks of adverse effects, and they can be used for immoral purposes. Regulations are in order. In many cases, the regulations should take the form of national statutes. This is especially true when the distinction between therapy and enhancement is at issue. Individual nations have the ability to craft statutes that reflect the subtlety of current local conditions. Such regulations can be passed, amended or repealed as the changing situation warrants. Treating human rights in this way would weaken them by reducing them to the status of mere regulations. In other cases, international treaties may be appropriate. This is especially true in cases where science has not progressed to the point where genetic engineering can be carried out with reasonable safety. But, the treaties should not be stated in terms of human rights. Rather they should be treaties that can be amended as needed and formed on the basis of compromise without the heavy hand of human rights.

We are at the beginning of the science of genetic engineering. It is not clear what advances will be made in the science, and it is not clear how the culture will change in light of those advances. The potential for

benefit as well as harm, along with our current profound ignorance, counsels in favor of taking small regulatory steps rather than sweeping prohibitions based on human rights.

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