



## Genetic Engineering and the Consent of Future Persons

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### Abstract

The debate over whether germ-line genetic engineering is justified on the basis of the consent or presumed consent of future generations is mired in philosophical confusion. Because of this, the principle of informed consent fails to provide a reason to restrict germ-line genetic engineering. Most recent bioethicists ground the consent requirement on individual autonomy. While conceptually coherent, the notion of individual autonomy also fails to provide a reason for prohibiting germ-line genetic engineering. Moreover, it offers little in the way of useful guidance for regulating genetic engineering. I argue, however, that respect for autonomy in the sense of moral agency – the ability to reflect on moral considerations and conform one's behavior to those reflections – provides a principle that can be used for a nuanced evaluation of proposals for genetic engineering.

### Introduction

The doctrine of informed consent is central to medical ethics. It is now a widely accepted legal and moral principle that competent adults are not to be subjected to medical treatment without their consent (Faden and Beauchamp 1986, chapters 4-6; Appelbaum et al. 1987, chapter 2). In addition, genuine consent requires knowledge of relevant facts (Faden and Beauchamp, 248-55). This standard is even embedded in human rights documents.<sup>1</sup> Some have thought that this poses a problem for germ-line genetic engineering because future generations will not have consented to being genetically engineered (Billings et al. 1999, 1873-75; Fletcher 1983, 542-43; Habermas 2003, 85-86; Harding 1991, 486-87; Lappé 1991; Marks 2002, 122-23).

I argue that it is a conceptual confusion to talk of future persons consenting to present practices. As a result, it is a confusion to reject germ-line engineering because it will affect persons in the future who have not consented. I also argue that the notions of hypothetical consent, proxy consent and presumed consent cannot be spelled out with sufficient precision to justify regulation

of germ-line genetic engineering. In general, the doctrine of informed consent is not helpful in offering guidance for regulating germ-line genetic engineering. Instead we should consider the value of moral autonomy, which turns out to provide a nuanced way of evaluating various proposals for genetic engineering. It does not, however, provide justification for a blanket prohibition of germ-line genetic engineering, even when it is for purposes of enhancement.

### **Current and Subsequent Consent**

Speaking of the lack of consent of future persons is ambiguous. It might mean that they do not consent at the present time because they do not exist – lack of current consent. It might also mean that they will not consent when they do come to exist – lack of subsequent consent. Both of these produce absurdity. Consider first lack of current consent. Talk of the present consent of future persons involves a conceptual confusion because it is incoherent to speak of a person who is not yet born as currently consenting to an action at the present time. Hence, it is also conceptually incoherent to speak of a future person as currently failing to consent to an action. It follows that it is also absurd to speak of this failure as providing a reason for prohibiting a present action.

It is tempting to think that what really matters is lack of subsequent consent, not lack of present consent. Work on paternalism several decades ago explored the issue of subsequent consent for past actions, and the insights generated are also useful in the present context. While philosophers such as Rosemary Carter and Gerald Dworkin relied on subsequent consent to justify prior paternalism, Joel Feinberg, Tziporah Kasachkoff and John Kleinig produced compelling arguments for not relying on subsequent consent (Carter 1977; Dworkin 1972; Feinberg 1986; 182-183, Kasachkoff 1994; Kleinig 1984). On their arguments, consent plays a moral role that cannot be fulfilled by subsequent consent. They correctly argue that consent functions as way of allowing another to do what would otherwise be morally or legally impermissible. Consent functions to facilitate, or at least not prevent, an action (Kasachkoff 1994, 17; Kleinig 1984, 98).

Consent is closely connected to rights. As Heidi Hurd argues, consent can create rights as well as turn what would otherwise be a wrongful act into an act that is right. It can, for example, give another person a right to do something that would otherwise be wrong (Hurd 1996, 123-124). In addition, consent is built into the structure of various rights to provide one way of waiving or of not standing on a right (Alexander 1996, 165-166). This is true in the case of the right being dealt with here – the right not to be medically treated without one's consent. In this case, consent is so integral to the structure of the right that the right is partially defined in terms of consent. There is no right, *per se*, not to receive medical treatment. It is not wrong, for example, to treat a child or a person with a severe mental disability who is not able to consent.

Rights that have consent built into their structure have two important functions. They protect the right-holder in a particular area from incursions by making such incursions morally wrong or illegal. They also protect the right-holder from the claims based on considerations of general welfare (Dworkin 1977, xi). Second, consent allows the right-holder to control these normative protections and hence to shape the behavior of others. Hence these rights also provide for the right-holder's autonomy as well as protecting the right-holder from harm. (The assumption, of course, is that those tempted to violate rights will be motivated by such normative considerations.)

In order for consent to play these vital moral and legal roles the consent must be given prior to the activity that would otherwise constitute a violation of rights or other impermissible act. Stealing my property, to use Kasachkoff's example, remains an act of theft, even if I later approve of the act. I cannot convert what was a theft into an act of borrowing (Kasachkoff 1994, 15). If the

consent incorporated into the notion of a right such as the right not to be medically treated without consent could be subsequent, then rights could not play the role they do. Right-holders who claim their rights in order to protect themselves from incursion would be offered scant protection if we had to wait to see whether consent is forthcoming in the future. Rights that serve to protect the right-holder against claims based on welfare considerations, for example, would be weak protection indeed if we could not be sure whether the right would be waived by future consent. “Subsequent consent” does not function as consent at all. What seems to be consent after the fact is in fact, as previously noted, something more like forgiveness or approval (Feinberg 1986, 182-183; Kasachkoff 1994, 18; VandDeVeer 1986, 67-69).<sup>2</sup>

In the end, it is a conceptual confusion to speak of future persons as consenting to present practices. If this does not make sense, then it will not do to base justifications and conclusions on this concept. This includes the view that germ-line genetic engineering is unjustified because the consent of future generations is not secured.

Even if it made sense to talk about the subsequent consent of future persons, lack of consent would not provide a justification for a blanket prohibition on germ-line genetic engineering. In fact, it provides little useful guidance. We are typically in no position to make reasonable predictions about what people in future generations will approve of and hence what they will consent to. The problem is that the cultural context may change over a number of generations. In addition, we are not able to predict what technologies will be available in the future and how they will shape values. Finally, we do not know how the moral and political debates that influence policy will turn out. Jürgen Habermas is correct that even such goods as enhanced intelligence and memory may not be desired by some people (Habermas 2003, 85-86). As Habermas notes, memory, for example, can become a curse for people who have things they need to forget (Habermas 2003, 85; Reiss 1999, 85).

Søren Holm gives additional reasons for rejecting the argument that germ-line genetic engineering is morally problematic because the future generations affected did not consent (Holm 2002, 88). Holm notes, for instance, that it is quite usual to make decisions that have far reaching effects on one’s descendants (e.g., deciding what country to live in). If these decisions are not problematic, why should we regard germ-line engineering as a problem? Holm also points out that lack of consent would have to be equally problematic even if future generations were benefited (Holm 2002, 88). It would be absurd, however, to refuse to engage in germ-line genetic engineering to prevent a person from being born with a devastating genetic disease such as Tay Sachs on the grounds that the future persons would not have consented.

It might be thought that all of this is simply another way of making the case for those who claim that germ-line engineering is unjustifiable. Whether such talk of informed consent is conceptually incoherent or practically impossible, it might be argued, there is no consent and hence no justification. This reply does not succeed, however. As previously noted, we cannot understand the notion of the right protected by the consent requirement wholly independently of consent. Hence, the right not to be subjected to medical treatment without consent applies to those who are in some sense able to consent. If it does not make sense to speak of future generations consenting to a particular present treatment (e.g., germ-line genetic engineering), then it does not make sense to say that they have a right not to be treated without their consent.

### **Hypothetical Consent, Proxy Consent and Presumed Consent**

If it is a confusion to speak of the consent of future persons, it might instead be argued that talk about future consent is really just a shorthand way of talking about hypothetical consent, proxy consent, or presumed consent. I begin with a consideration of hypothetical consent. On this view, germ-line engineering is wrong if the person who will be affected by it *would* not have consented to it. Unlike subsequent consent, there are cases in which it is not a conceptual confusion to speak of hypothetical consent (what a person would consent to). This is most clear when we know the values of a formerly competent patient who is not rendered incompetent. In some cases we can also make a reasonable prediction based on the current cultural context. For example, in most cases, though certainly not all, a person who is brought unconscious into an emergency ward would want to receive life-saving medical treatment.

This will not work in the case of future persons, however. The problem is that the persons are in the future. We are not now in a position to speak coherently of what future reasonable persons would consent to *at the present time* when decisions regarding germ-line engineering are being made. It might be replied that we can speak of what they would consent to *in the future*, but this simply loops us back to the issue of subsequent consent, and it is clear from the previous section that that gets us nowhere.

The major problems with hypothetical consent also arise if we attempt to use proxy consent as a reason for regulating germ-line genetic engineering. If we cannot know what a person would consent to, we are not in a position to substitute consent for that person. As Beauchamp and Childress note, substituted judgment (proxy consent) only works for previously competent persons in cases in which the person deciding knows what the person would have wanted (Beauchamp and Childress 2001, 100). It does not work for never competent persons and certainly not for persons who will not be born until some time in the distant future. What we can do, however, is to act in what we believe to be the person's best interest. In this case, the consent of the person being treated drops out of the picture and is replaced by a best interest standard.

But, can't we at least presume consent in the case of primary goods – goods such as intelligence that are reasonable to value whatever else one values? Fritz Allhoff, for instance, argues that we can presume the consent of future persons to germ-line engineering that enhances primary goods (Allhoff 2005, 50). The problem is that for any particular primary good we can always imagine a person who has a set of values such that he or she would reject the primary good. Some might even reject enhanced intelligence on the ground that it creates envy in others or makes it more difficult to pursue other character important character traits, as Habermas has noted (Habermas 2003, 85-86). In order to develop an argument for permitting germ-line genetic engineering in such cases, we need to argue that persons, as moral agents, are committed to certain values that can be enhanced. It will not do simply to talk about what they would or might or could be presumed to consent to based on their actual future values.

In light of the confusions generated by speaking of consent and hypothetical consent, it would be better simply to directly consider reasons for germ-line genetic engineering. Considering the reasons that justify the doctrine of informed consent in the first place is a good way to begin, since it promises to capture the intuitions that lead to talk of consent while avoiding the confusions implicit in applying the notion of consent to future generations.

## Autonomy

Most who write about the doctrine of informed consent claim that consent is important because it protects autonomy (Beauchamp and Childress 2001, 77; Hurd 2002, 124). Bioethicists often spell out autonomy in terms of self-governance according to which one is autonomous when one is able to act in accord with one's personal or authentic values (Beauchamp and Childress 2001, Chapter 3). This includes both being free from certain sorts of duress or coercion and having adequate information. Different analyses of autonomy specify in various ways what counts as duress and adequate information. I shall refer to this sort of autonomy as "individual autonomy" in order to distinguish it from moral autonomy (the ability to act as a moral agent). We cannot rely on individual autonomy to provide reasons for regulating germ-line genetic engineering. Individual autonomy is characterized in terms of individual desires and values; and, as previously noted, we are not now in a position to know what desires and values persons in future generations will have. This is true even in the case of primary goods. As Søren Holm notes, it is not clear why we should refrain from germ-line engineering if we cannot foresee a definite harm to future generations (Holm 2002, 88). This is certainly true in the case of specific desires that future persons might have.

A better bet is to seek guidance by relying on moral autonomy. Moral autonomy consists of the ability to reason and act in accord with the requirements of morality. Those who have this capacity are moral agents. Moral agents have the ability to formulate and reflect on moral principles, to notice the morally relevant features of various situations, to provide moral justifications for a range of actions, and to respond with appropriate moral feelings such as sympathy and compassion.

Immanuel Kant provided the classical statement of morally autonomy. For Kant, a person acts autonomously when the person acts on the basis of reasons that could be adopted by everyone without inconsistency. Kant stated this rather formally in terms of the first formulation of the categorical imperative – "Act only in accordance with that maxim through which you can at the same time will that it become a universal law" (Kant [1785] 1996, 73). For Kant, merely acting on the basis of authentic desires is not enough to achieve autonomy. Note that my characterization of moral autonomy is considerably broader than Kant's. In particular, the notion of moral autonomy offered here does not require acceptance of Kant's view of the categorical imperative.

On the basis of respect for moral autonomy, we have reason to engage in genetic engineering (germ-line or somatic) to the extent to which it could enhance moral agency – the ability to perceive the morally relevant features of situations, have the requisite moral emotions, formulate moral justifications and act in light of them. Those who are committed to being moral agents also have reasons to seek enhancement of these qualities insofar as they can improve moral agency. We also have reason to refrain from genetic engineering to the extent to which it undermines moral agency. Genetic engineering that enhances the ability of a person to suppress violent urges when reason dictates clearly enhances moral agency, while genetic engineering that deadens his or her empathy detracts from moral agency.

What is central is our respect for the value of moral agency itself, not our respect for the particular choices of individuals who do not yet exist. Respect for moral autonomy provides a nuanced way of thinking about germ-line genetic engineering. It does not, however, provide reason for simply prohibiting such engineering, even if genetic engineering is used for purposes of enhancement.

Ronald Munson and Lawrence Davis also note that autonomy is the crucial value protected by consent, but they argue for a much stronger conclusion. They argue that since potential progeny do not exist they have no autonomy that could be tampered with and hence "...nothing to protect by their requiring 'informed consent'" (Munson and Davis 1992, 143). As a result, there is no work for consent to do in protecting their autonomy. Munson and Davis are right that consent is a non-issue. The reason that consent is a non-issue, however, is because it fails to function to permit what would otherwise be a violation of autonomy, not because it is impossible to thwart the autonomy of non-existing persons. In particular, there are worries about moral autonomy. Respect for moral autonomy and hence moral agency, as opposed to respect for the choices of particular agents, requires us to act so that the people who come after us will be able to act as morally autonomous beings, whatever their values and desires.

## Conclusion

What lies behind the argument that germ-line engineering should be prohibited because of a lack of consent is a concern for autonomy. There are, however, different ways of looking at autonomy, and it is moral autonomy rather than individual autonomy that is relevant for considerations of germ-line genetic engineering. Moral autonomy does not, by itself, provide a reason for a blanket prohibition of germ-line genetic engineering whether for purposes of therapy or enhancement. It does, however, provide a principle for evaluating particular proposals for germ-line genetic engineering.<sup>3</sup>

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## Notes

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<sup>1</sup> Chapter II, Article 5 of 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* provides that "an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it" (Council of Europe 1997). Article 5(b) of UNESCO's *Universal Declaration on the Human Genome and Human Rights* provides that free and informed consent shall be obtained prior to medical research or treatment or diagnosis affecting an individual's genome (UNESCO 1997).

<sup>2</sup> John K. Davis is right to argue that substantive consent cannot be equated with forgiveness, but this is simply because talk about subsequent consent has no meaning (Davis 2004, 287-88). At best we can forgive or approve after the fact.

<sup>3</sup> I am indebted to Fritz Allhoff for his helpful comments on a previous draft.