

PARENTAL RESPONSIBILITY, AUTONOMY AND GENETIC ENHANCEMENT

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A research report submitted to the
Faculty of Humanities, University of the Witwatersrand, Johannesburg
in partial fulfilment of the requirements for the degree
Master of Arts, Applied Ethics for Professionals.

Johannesburg, 08 April 2014

Abstract

This report analyses the responsibilities and harms that are imposed upon parents when genetic enhancement is made institutionally available and shows that there is a counter-intuitive impact upon parental autonomy. The institutional availability of genetic enhancement may be a good thing and may increase autonomy. My thesis is that harm is caused to parents because of the negative implications that arise from the institutional availability of genetic enhancement: their autonomy may be diminished irrespective of their reasons for rejecting genetic enhancement.

Declaration

I declare that this report is my own unaided work. It is submitted for the degree of Master of Arts, Applied Ethics for Professionals, in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination in any other university.

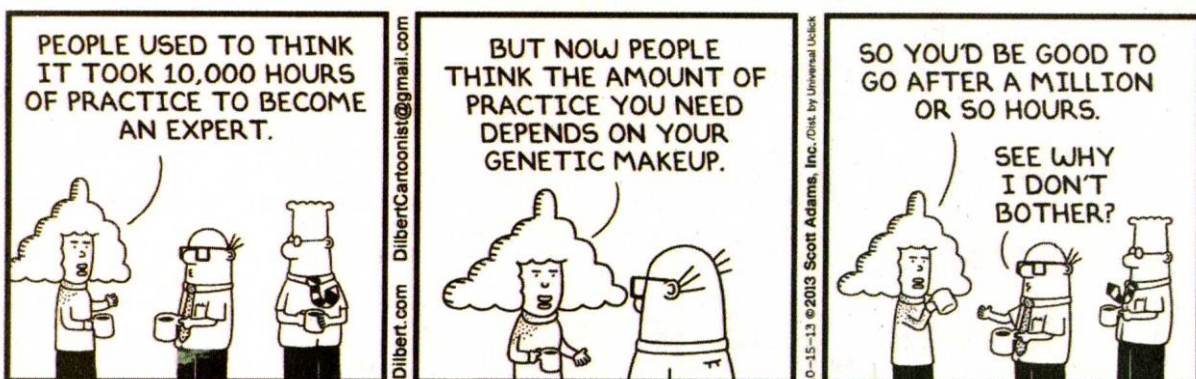
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08 April 2014

My thanks are extended to Professor Shirley Pendlebury who first taught me to write in 1978 and commented upon early drafts of this report. To Professor Arnold Christianson, geneticist, fellow student and friend who assisted me with some of the technical aspects of this report. All errors are of course my responsibility. And to Dr. Dylan Futter, philosopher, and supervisor of distinction.

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1. Introduction

I investigate in this report the responsibilities and harms that are imposed upon parents when genetic enhancement (GE¹) is made institutionally available and the consequent counter-intuitive impact upon autonomy for parents who would reject GE. GE is some procedure performed upon an embryo, either intrauterine or pre-implantation, that manipulates its genetic make-up in order to enhance or improve the future child² in some way. The institutional availability of GE may *ipso facto* be a good thing and may seem to increase autonomy. If one agrees with GE it may be chosen; if not, it may be rejected. However, certain negative implications arise from the institutional availability of GE that militate against parents' ability to reject GE. My thesis is that these implications constrain parents' ability to reject GE for whatever reason and that their autonomy is consequently degraded.

The negative implications that arise from the institutional availability of GE are: first, parents must bear the technical and emotional costs when deciding to enhance or not; second, they are burdened by the responsibility to justify their decision, as well as a retrospective responsibility once their child is born and for the duration of their lives to justify their selection of GE or not; third, they may be pressurised by society to conform to certain ideals of enhancement; finally, the default assumption that all children are the subject of genetic lottery is forever removed. These burdens and pressures accrue to parents who would select GE for their child as well as to parents who would reject GE.

For parents that select GE, the negative implications would be weighed against the benefits that they would derive from GE. However, the focus of this report is upon parents who would reject GE. Because of the negative implications, parents are constrained from merely rejecting GE. Their autonomy, rather than being amplified by the institutional availability of GE, may paradoxically be reduced.

¹ "GE" means genetic enhancement, genetically enhancing, genetically enhance, genetically enhanced, etc. depending upon context and nearly always self-evident.

² I use the word "child" throughout. In virtually all cases the word "person" or "adult" could be used instead or appended. It makes no difference to my argument, so for readability I continue with "child".

Following the arguments provided by Gerald Dworkin³ and by drawing an analogy with the institutional availability of euthanasia (analysis by J. David Velleman⁴) and the institutional availability of prenatal genetic diagnosis (analysis by Elizabeth Hildt⁵), I conclude that it is the institutional availability of GE that causes harm. Irrespective of their reasons, parents who are against GE are placed in an invidious position, where they would rather not have had the availability of GE in the first place. Once the *status quo ante* has disappeared, it can never be regained.

Dworkin argues that the view that more choice is always preferable to less is false. Agreeing with the general point, it is my project to show that in the specific case of the institutional availability of GE, it is the provision of more options which causes harm. This position is contrary to the fundamental tenets of a liberal Rawlsian world where the provision of greater range of options or more choice is integral to the determination of leading a good life, however defined by the individual, and is taken to increase autonomy.

Traditional anti-GE arguments deal with the action of GE undertaken by parents in terms of what GE does to them, to their GE child or to their relationship. The arguments focus upon: the parents and what they become (that their motivation and *weltanschauung* is in some way morally defective⁶); the GE child (that she is incapable of accepting responsibility for her own life as she is not longer the product of genetic lottery but rather the consequence of designer parents who have usurped her autonomy, compromised her open future, undermined her accomplishments or eliminated her uniqueness⁷); and the relationship between the parents and the GE child (that the relationship is compromised and that conventional love is not possible⁸). I do not pursue these lines of argument as they are well canvassed in the literature.

These traditional anti-GE arguments focus upon parents who select enhancement and the child who is the subject of the enhancement. No attention has been paid in the literature to the implications that the institutional availability of GE has upon parents who do not select GE. The

³ Dworkin, G.; *The Theory and Practice of Autonomy*.

⁴ Velleman, J. D.; "Against the Right to Die".

⁵ Hildt, E.; "Autonomy and freedom of choice in prenatal genetic diagnosis".

⁶ Sandel, M. J.; "The Case Against Perfection: What's Wrong with Designer Children, Bionic Athletes, and Genetic Engineering".

⁷ Habermas, J.; *The future of human nature*.

⁸ McGee, G.; "Parenting in an era of genetics".

fundamental ethical problem dealt with in this report is the conflict between the apparent increase in autonomy provided by the institutional availability of GE and the pressures and influences arising from that availability which, upon reflection, erode autonomy. As this is an unexplored area, and as we shall see, the implications are significant, my attention is confined to parents who would choose not to enhance their child irrespective of the reasons. Accordingly I do not submit an all-things-considered argument against GE that would perforce weigh the benefits of selecting GE against the harms that the institutional availability of GE generate.

I have not found anything in the literature that specifically deals with the effect upon, and responsibilities that accrue to, the parents that do not select GE. In private correspondence with Professor Nicholas Agar he suggests that he too is not aware of any literature on this topic. He writes, “I’m not aware of much discussion of harms that might arise at the level that you mention. Just having children the natural way becomes an explicit decision to reject enhancement. Society might presumably spare those parents some harm by taking that choice out of their hands”.⁹

In this report, I initially examine the meaning of “genetic enhancement”, as this in itself is an imprecise term. In the section “Choice and autonomy” I link the exercise of choice and rationality to that of autonomy and explain how the institutional availability of GE may be seen to increase parental autonomy. In “Are more choices better than fewer?” I apply Dworkin’s analysis to the specific instance of the institutional availability of GE and show that more choice is not better because of the negative implications that arise. Because of them autonomy for parents is not necessarily enhanced and may well be compromised. Under “Analogies” I examine parallel examples provided by the availability of euthanasia and the availability of prenatal genetic diagnosis. Finally, I refute criticisms that may be levelled against my thesis.

1.1 Contemporary relevance of the issue

Much of genetic enhancement as a science and a discipline is located in the future. It is far from manipulating the genetic make-up of an embryo to achieve predictable results in the phenotype of the future child. Even assuming that it were possible to introduce genetic variability to an embryo, the complexity of determining the full effects and side-effects immediately and over the

⁹ August 6, 2013. Prof. N. Agar is professor of ethics and an associate professor at Victoria University of Wellington, New Zealand.

life span of the embryo and eventually the child is a monumental scientific challenge. The pleiotropic nature of genes will not be easy to avoid or control.

Despite this, the rapidity of scientific development, while unpredictable as to outcome, is self-evident as to pace. Writing now in September 2013, the issue of three-parent babies has entered the public domain. A three-parent baby is one conceived from a combination of two ova, from different women, fertilized by the sperm of the father. This procedure, it is claimed, could prevent up to 50 diseases from being passed on. However the interaction between the genes of the two “mothers” remains unpredictable.¹⁰

But philosophy is not deterred by the unlikely or the unpredictable or even the impossible. Nicholas Agar claims that, “Science so often confounds the best predictions, and we should not find ourselves unprepared for the genetic engineer’s equivalent of Hiroshima. Better to have principles covering impossible situations than no principles for situations that are suddenly upon us”.¹¹ Allen Buchanan (*et al*) locate the GE debate firmly in the public arena as well as linking it to their concept of a just society when they write that the primary objective of their book is to answer the question, “What are the most basic moral principles that would guide public policy and individual choice concerning the use of genetic interventions in a just and humane society in which the powers of genetic intervention are much more developed than they are today?”¹² In concurrence with these authors, I submit that we are obliged to be prepared and be certain, if possible, of our ethical and normative positions when the reality is upon us.

I believe that the focus upon parents who do not select GE is novel and is relevant to the development of GE. My argument could serve the purpose of guiding public policy regarding the provision and availability of GE. As Velleman argues regarding the provision of euthanasia, it is possible to differentiate between a public provision of the “service” and a private need or desire for that same service.¹³ It will be for others to argue for the public/private distinction in the provision of GE, but this report will hopefully ground that debate with a deeper understanding of the implications of the institutional availability of GE.

¹⁰ Hunter, P.; “Questions about three-parent babies”, pgs. 58-59.

¹¹ Agar, N.; “Liberal Eugenics”, 1999, p. 172.

¹² Buchanan, A. *et al*; *From Chance to Choice: Genetics and Justice*, p. 4.

¹³ Velleman, J. D.; *op. cit.*, p. 89.

With GE we may be at an historical cusp. GE technology is neither well nor fully developed. If the institutional availability of GE is undesirable, then disallowing the availability of this technology for GE purposes could avoid the harm it causes. As Dworkin suggests¹⁴ it is conceivable that once GE is fully developed and widely available then, while resisting the elimination of the choice, we would desire a world in which the choice was not available at all!

¹⁴ Dworkin, G.; *op. cit.*, p. 77.

2. Genetic enhancement

Genetics is a rapidly expanding discipline where technologies and terminologies are malleable. The moral issues surrounding genetic enhancement and those relating to genetic enhancement *and* responsibility are not constrained generally by the specific meanings ascribed to terms, but it is, of course, as well to be as exact as possible.

Eric Parens says that the term enhancement “is so freighted with erroneous assumptions and so ripe for abuse that we ought not even to use it”.¹⁵ He suggests that any other terms that may be selected would suffer from the same problem. I will accordingly continue to use the word enhancement.

An enhancement (as it applies to people) requires some normative evaluation as to whether the enhancement is a good or a bad thing despite the word itself implying “improvement” or “betterment” or “enrichment”. “Enhancement” also seems to connote some procedure, generally medical, that is performed on an organism or person to achieve the desired result. For my purposes “genetic enhancement” means:

some (medical) procedure performed upon the genome of an embryo, either pre-implantation or intrauterine, in order to change its genotype, with a view to altering favourably or beneficially (according to the parents) the phenotype of the future child.

To be precise about “enhancement”, I will utilise a continuum that resides on either side of normal-species function¹⁶. Normal-species function means the statistical measurement of an average of a certain population, whereby the characteristics and behaviour of a child (or person) can be measured and evaluated. Outside the statistical norm, however defined, the child or future child is considered to be sub-normal or abnormal. On this continuum **genetic therapy** or genetic therapeutic intervention seeks to ensure that the future child is born with and conforms to a species-normal set of characteristics. Typically this therapy would seek to eliminate disabling genetic diseases like sickle cell anaemia or cystic fibrosis.

¹⁵ Parens, E.; “Is Better Always Good? The Enhancement Project”, p. 2.

¹⁶ Daniels, N.; “Normal Functioning and the Treatment-Enhancement Distinction”, pgs. 309 – 322.

I position **genetic enhancement** along the same continuum, where normal-species function and behaviour is located in the middle and sub-normal-species function is on one side. What I refer to as “supra-normal species” function is located on the other side. In other words the characteristics of the future child are statistically outside of the norm, but in a way that is better than the norm. This could apply to height, assuming we regard a greater height as a good thing, or greater intelligence, or longer memory, or perfect pitch. It could apply to behavioural dispositions like less aggression or greater empathy, if we could agree how these were to be measured. It is the notion that a child can be bettered or improved (and that may be a good thing) that drives that entire endeavour of GE. It is this betterment or improvement, constructed in whatever way parents see fit, that would motivate parents’ selection of GE.

It is not important to my thesis to apply normative descriptions to either the objectives or the actual outcomes of GE as my project does not focus upon parents who select GE. It is sufficient to note that supra-normal species functions are characteristics on the same continuum but on the other side to sub-normal species function.

Resnik & Vorhaus introduce two further elements to my definition: that of permanence and that of intent. According to them, “The *sine qua non* of genetic modification is permanent genetic alteration: the intentional production of human offspring with artificially induced genetic changes, or ‘designer babies’”.¹⁷ These elements are important to validate my argument as responsibility can always be evaded or mitigated if changes are temporary or if there was no intent to perform a certain action.

GE can be confined to interventions with or on or into the embryo. The science is uncertain, but it seems reasonable to assume that GE has to occur early in the embryo’s life. It is possible that in the future procedures will be performed on germline cells prior to fertilization leading to permanent changes (i.e. carried forward to future generations) in the genotype. This would impart even a greater duty to resolve the ethical issues regarding GE, as no longer would just one future child be enhanced but all progeny emanating from that child.

¹⁷ Resnik, B. R. & Vorhaus, D. B.; “Genetic modification and genetic determinism”, p. 2.

Along with the uncertainty of the science, come the inevitable warnings regarding the risks and hazards associated with GE. For the purposes of this report, it seems reasonable to assume that GE at some stage will become a safe procedure. The issues regarding the relative safety of GE as the science progresses are not germane to the arguments that are presented.

It is clear too that the delivery of GE initially will be expensive, too expensive to argue that it would be institutionally available. However, as with many medical developments in the past, the costs reduce rapidly. At any rate, it is not relevant to this report to address the issues regarding the costs and commercial viability of GE. It seems entirely reasonable to assume that the costs of GE at some stage will be low enough, that GE will be sufficiently widely and publically accessible, that enabling legislation will be promulgated and that medical professionals will be trained and proficient in the technologies. At some stage in the future, the appellation of “institutional availability” can be applied to GE. “Institutionalization” does not imply that GE would be acceptable to most or all sectors of society, nor that the traditional arguments against GE would have been dispensed with or resolved. Strong feelings for and against GE will probably remain, evidenced by the institutional availability of abortion (in some countries) and the societal conflicts that are generated as a result.

3. Choice and autonomy

It is intuitive and largely accepted that the greater the number of options available the greater is one's ability to lead a good life.¹⁸ It is in the determination of a good life that one exercises autonomy in selecting between options. Presented with a greater number of options and the ability to select between them, autonomy is expanded and a better life can be achieved. Provided there is some assumption of rationality (subjective or objective), individuals are obliged to justify their selection in some way. In this section I examine the philosophical underpinnings of this intuition by referring briefly to the writings of Aristotle, Rawls, Dworkin and John Christman. I link the notions of the exercise of choice and rationality to that of autonomy: in the exercise of autonomy, rational decisions are made which can be justified. In the light of this, the institutional availability of GE may seem to increase parental autonomy.

For Aristotle, to become virtuous involves accepting responsibility for what one does and the choices that one makes, and this is done in a rational way. He writes, "What then is choice, or what sort of thing is it, since it is none of the things mentioned? It is obviously something willing, but not everything that is willing is something chosen. But might it just be one that has been deliberated about first? For choice is involved with reason and thinking things through".¹⁹ And, "Since, among the things that are up to us, the desired thing that has been deliberated upon is what is chosen, choice would be the deliberate desire of things that are up to us, for having decided as a result of deliberating, we desire in accordance with our deliberation".²⁰ "Deliberation" implies a process of reasoning that presumably has to be rational, at least to the person making the choices.

For Dworkin the constitutive value of being able to make choices refers to the value that arises not from the causal effects of making a choice, nor from the value of the choices for their own sake, "but as definitive of a larger complex that is itself valued".²¹ This larger complex is the rational exercise of choice in the development and pursuit of a life path and is "constitutive of a certain ideal of a good life".²² This life path is determined by the selections that one makes.

¹⁸ See Rawls, J.; *A Theory of Justice*, p. 400, footnote 2, for his long list of supporting philosophers.

¹⁹ Aristotle, *Nicomachean Ethics*, III, 1112a.

²⁰ Aristotle, *ibid.*, III, 1113a.

²¹ Dworkin, G.; *op. cit.*, p. 80.

²² Dworkin, G.; *ibid.*, p. 81.

Dworkin says, “What makes a life ours is that it is shaped by our choices, is selected from alternatives, and therefore choice is valued as a necessary part of a larger complex”. The value of choice accrues to the person responsible for selecting between alternatives, and any increase in the number or availability of options increases the constitutive value to that person.

Arguably a life without choice would place us at a similar level to an automaton for without the need for decisions, no rationality would be required. On the other hand, too many options would lead to Kierkegaard’s “despair of possibility”, a situation in which possibility “appears to the self ever greater and greater, more and more things become possible. ... At last it is as if everything were possible – but this is precisely when the abyss has swallowed up the self”.²³

Rawls emphasises, too, the relationship between choice and rationality and why we make choices. He says, “the concept of rationality invoked hereis the standard one familiar in social theory. Thus in the usual way, a rational person is thought to have a coherent set of preferences between the options open to him. He ranks these options according to how well they further his purposes; he follows the plan which will satisfy more of his desires rather than less, and which has the greater chance of being successfully executed”.²⁴ It is clear that for Rawls no harm can come from a greater number of choices: “But from the standpoint of the original position, it is rational for the parties to suppose that they do want a larger share, since in any case they are not compelled to accept more if they do not wish to, nor does a person suffer from greater liberty”.²⁵

More importantly, Rawls links the idea of choice to his notion of good as follows: “The main idea is that a person’s good is determined by what is for him the most rational long-term plan of life given reasonably favourable circumstances. A man is happy when he is more or less successful in the way of carrying out this plan. To put it briefly, the good is the satisfaction of rational desire”.²⁶

Aristotle refers to “reason and thinking things through”. Dworkin presumes a rationality that underpins the decisions that one makes to attain a good life. Rawls assumes that a person is

²³ Dworkin, G.; *ibid.*, p. 73 quoting Kierkegaard, S. A.; *Fear and Trembling and the Sickness unto Death*, trans. Lowrie, W., Anchor Press, Garden City, 1954, p. 169.

²⁴ Rawls, J.; *op. cit.*, p. 143.

²⁵ Rawls, J.; *ibid.*, p. 143.

²⁶ Rawls, J.; *ibid.*, p. 93.

rational and has a “coherent set of preferences”. They all point to a justificatory process of decision making that will explain, at least to oneself, the reasons for making certain decisions or selection between alternatives. This justification need not indeed make any sense to others, but may. In the former case it could be referred to as subjective rationality and in the latter as objective rationality. Either way it seems improbable that a person could pursue their definition of what constitutes a good life without a rational justification of what options to select. I do not mean to pursue the issue of rationality any further; for my purposes it seems that a rational selection from a range of options must be justifiable, if only to oneself.

The exercise of choice and the justification thereof is integral to the concept of autonomy. In many respects choice, rationality, responsibility and autonomy are woven together in the critical determination of our goals and our lives. Dworkin defines autonomy as follows:

Autonomy is conceived of as a second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes, and so forth and the capacity to accept or attempt to change these in light of higher-order preferences and values. By exercising such a capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are.²⁷

According to John Christman, to be autonomous:

is to be one’s own person, to be directed by considerations, desires, conditions, and characteristics that are not simply imposed externally upon one, but are part of what can somehow be considered one’s authentic self.²⁸

The central thought that emerges is that increased choice and the ability to exercise that choice leads to a better ability to determine one’s self: and in this way autonomy is enhanced. The practical exercise of autonomy is the ability to choose between options in a rational manner and to accept responsibility for those choices. It is generally accepted that a greater range of choice is better than less choice. The good life is achieved by rationally selecting from an array of choices.

The corollary is that any constraint or external influence upon choice and the ability to exercise that choice and the reduced ability to determine what kind of person one is results in a diminution of autonomy. This is not to imply that autonomy is an unconstrained freedom to do whatever one likes. Many aspects of what defines a person are unalterable. Christman writes,

²⁷ Dworkin, G.; *op. cit.*, p. 20.

²⁸ Christman, J.; *Autonomy in Moral and Political Philosophy*, p. 2.

“Our embodiment, for example, is not something which we can alter other than marginally, and numerous other self-defining factors such as sexual orientation (for some), native language culture and race, are not readily subject to our manipulation and transformation, even in a piecemeal manner”.²⁹ To suggest that a choice is free and unfettered in all respects is a fantasy. If we were to deny the possibility of choice because of a notion that choice must be absolutely free from constraint and influence, then there would be no choice in the world at all. We are all subject in some way to Christman’s “embodiment”.

Autonomy is constrained, consciously or otherwise, by laws, enculturation, education, habits and to a large extent by the impact that one’s decisions have upon the people around one. With due regard to these constraints and in particular with regard to the impact upon other people, the exercise of autonomy enables one to make choices according to one’s own preferences. This view of autonomy reflects “the Kantian brand of liberalism that places autonomy of persons at centre stage. Rawls’ *Theory of Justice* was seen as the modern manifestation of this Kantian approach to justice, where justice was conceived of those principles that would be chosen under conditions of unbiased rational decision-making (from behind the veil of ignorance)”.³⁰

It would seem then that the availability of GE is a good thing, as it increases the options available to parents, it has a constitutive value to them and increases their autonomy. This in no way indicates a normative evaluation of GE itself: it is the provision of the option that is the issue under debate. GE can be selected if you desire GE, or may not be selected if you do not desire GE. Aristotle would view the selection of GE as “the deliberate desire of things that are up to us”. The rejection of GE would express a deliberate aversion “of things that are up to us”. For Rawls, the increase in options available enables parents to better implement their life plans and to have a greater chance of success thereat. They can choose between enhancing their child and not enhancing their child, depending upon their own preferences, which preferences, being their own, need not be subscribed to or understood by anyone else.

Choices can also be categorized according to the extent of the impact that they have upon the world and other people. In a typology of choices, there is a qualitative difference between

²⁹ Christman, J.; *ibid.*, p. 23.

³⁰ Christman, J.; *ibid.*, p. 28.

choices that are self-regarding and those that directly affect other people. Choices are rarely made in isolation and the big choices are those that tend to affect those around us. We choose between eating an apple or a pear, or wearing shoes or sandals, or sleeping in the afternoon or not. These trivial choices are what constitute the minutiae of our lives and seem to not have much significance in the greater order of things. The bigger choices tend inevitably to affect other people: who to marry, whether to have children or not, to euthanize a terminal parent, to abort an unplanned child, to enter into an arranged marriage, to commit adultery? In fact decisions that affect other people are the ones that are deemed important and are the ones that attract moral debate. There is no doubt that the choice to enhance or not a future child, deeply, profoundly and permanently affects another, however defined. Jurgen Habermas agrees: “The realization that our hereditary factors were, in a past before our past, subjected to programming, confronts us on an existential level, so to speak, with the expectation, that we subordinate our being a body to our having a body”.³¹

Notice that it is not required to assess the benefits that GE itself can bring. It is enough to assume that there are benefits that arise from GE itself to a greater or lesser extent. In a Rawlsian world the availability of GE is a good thing, as opposed to a world in which GE is not an option. The availability of the option enables the furtherance of one’s life plans, irrespective of whether the outcome of GE achieves its initial purpose. That is not to suggest that if GE were out and out a bad thing that the availability of thereof would then be a good thing. It is rather to suggest that if at least some people (perhaps only one) were to perceive or derive benefits from GE, then it is sufficient to argue that GE is a good thing, as it enables the exercise of discretion as whether to select GE or not.

It is sufficient to conclude that if the range of choice is expanded, as it is with the institutional availability of GE, then autonomy is augmented. This largely accords with our intuitions. I will show however that autonomy is not augmented by the institutional availability of GE, despite appearances to the contrary. That is the topic of the next chapter.

³¹ Habermas, J.; *op. cit.*, p. 54.

4. Are more choices better than fewer?

It is against the background that more choice amplifies autonomy and less choice reduces autonomy, that Dworkin questions the assumption that “for the rational individual more choices are always preferable to fewer”.³² He suggests that more choices are not always better than fewer because of the *negative* implications that may arise from more choice. These are not implications that arise from one’s embodiment or the exercise of one’s rationality or from the inherent desire to lead one’s own life. They are implications that arise from the situation itself. According to Hildt, Dworkin’s “point is, rather, that certain situations may bring with them negative implications which arise from an increased number of options. Such situations could support the belief that certain options might better remain withheld”.³³

For parents who choose not to enhance their child, in an environment of more choice (the choice whether to enhance or not), each negative implication can to a greater or lesser extent be applied to the availability of GE. Each implication, rather than allowing an unfettered choice, other things being equal, encourages parents to select GE. They represent a fundamental constraint upon their ability not to select GE and thus reduces their autonomy. The *status quo ante*, which allowed parents to not enhance their child with no justification, no added responsibility and no pressure, is now gone and cannot be regained.

If this is the case and the negative influences are so powerful then the option of choosing not to enhance one’s child, in an extreme case, is not an option at all! One may be compelled to select GE despite there being an apparent choice not to. I do not mean to argue this extreme position, but rather to show that the negative implications are of such a nature that it cannot be simply assumed that the institutional availability of GE is a good thing.

Following Dworkin’s typology³⁴ the negative implications are decision making costs; responsibility for choice; pressure to conform and exercise of choice.³⁵ I will examine these situations and Dworkin’s examples and see how they apply to the institutional availability of GE.

³² Dworkin, G.; *op. cit.*, p. 63.

³³ Hildt, E.; *op. cit.*, p. 68.

³⁴ Dworkin, G.; *op. cit.*, pgs. 62 – 81.

³⁵ Dworkin refers to increased choices and welfare decline as an additional implication but they are not relevant for this report.

Dworkin excludes certain situations where more choices are obviously worse than fewer: firstly, if the number of choices is increased but the set is insufficiently commensurate or incompatible with the original choices then this situation is excluded. For example, the choice between a rare fillet steak, a fresh trout and piece of rotten meat (a choice between three items) is not improved by adding another piece of rotten meat to the range (now a choice between four items), as the set of choices is disjointed. Dworkin explains as follows, “We are not considering the case where we have some (partially) disjoint set which happens to have a larger number of choices than the first”.³⁶ Secondly, situations in which the probability of achieving what one wants are decreased by more choices are also excluded. For example, if one is to place a bet upon a horse winning a race, say between two horses, it is not better to have more horses to choose from, as this reduces the chances of making a winning bet. Finally, if the cost of choice is great and contingent, then these situations are likewise excluded. For example, if one wants to travel to London reasonably expeditiously, the situation is not improved by offering the choice of a direct flight costing a million dollars versus a normally priced flight via Paris. Dworkin’s thesis relies upon an “implicit other-things-being-equal clause”.³⁷

None of these exclusions apply to the institutional availability of GE: the choice between accepting GE or rejecting GE are commensurate with one another; the availability of GE does not decrease the probability of achieving what one wants; and we have assumed that at some stage in the future the real costs will be reasonable and there is no reason to suppose that contingent costs (e.g. a tax on GE children!) will arise.

I turn now to each of the negative implications and examine how Dworkin deals with them and how they apply to the institutional availability of GE.

4.1 Decision making costs

If it is correct to assume that the choices we make should to some extent be rational, at least to ourselves, then there are always some costs to acquire the information to make that decision. In many cases these costs are insignificant. Many of the choices people make or could make are constrained by law and custom and habit and accordingly the cost of making these decisions is

³⁶ Dworkin, G.; *ibid.*, p. 65.

³⁷ Dworkin, G.; *ibid.*, p. 65.

low. For example, one could choose to drive on the incorrect side of the road (and some people do), but the law prescribes which side of the road one should drive on. One could eat scorpions and crickets, but by upbringing and habituation we rather desire to eat prawns and snails. One could choose to get out of bed at 10 o'clock but by habit one arises at 7 o'clock. In each of these cases there is a minimal cost of making the decision. Larger "life" decisions do entail costs: what house to buy or which school to send one's children to or which university to attend? Each decision of this nature requires time and effort, largely expended in the search for information and counsel in order to make a choice, between many options, that is rational and furthers one's life plans. Dworkin does not spell it out but the implication is clear: if there is no choice then there are no decision-making costs. If one is allocated a council house and that is the only place where one can live, then there is no decision and no costs. If one's children are assigned to a school or university in the area, then that is the end of the matter.

The costs of choosing between performing GE or not performing GE upon one's future child arise from two sources: the technical decision and the emotional decision. A technical decision requires the acquisition of information relating to the efficacy of the technology. It requires an understanding of the procedures involved and the effort needed. It requires an evaluation and selection of the various enhancement options available. It requires an assessment of whether the enhancement would be suitable for one's future child and whether it would accord with one's life plans. All of this information has to be evaluated against the option of not choosing GE.

The emotional costs generated by the decision-making process relate to what Dworkin refers to as the "psychic costs".³⁸ Parents dealing with the magnitude of either enhancing *or* not enhancing their future child will have to be certain that they are doing the right thing. This determination would be undertaken in terms of their moral understanding of themselves and their future child and their respective positions in the world. It would, explicitly or implicitly, have to deal with and accordingly resolve for themselves the traditional arguments for and against GE. The institutionalization of the availability of GE may reduce some of the costs; however the moral "costs" remain as institutionalization implies structural and procedural availability without necessarily resolving the moral issues.

³⁸ Dworkin, G.; *ibid.*, p. 67.

It could be argued that if one simply chooses not to enhance one's child, then there are no costs. The technical costs, those of having to obtain information would be minimal, but the emotional costs remain. Despite not enhancing one's child being the "natural" position, the enormousness of the decision remains if GE is institutionally available. Accordingly the emotional costs remain.

Currently, the actual costs involved in choosing or not choosing GE will be varied and difficult to quantify. For parents in the future it will be important to make such quantification. According to Dworkin, "the making of choices is not a costless activity, and the assessment of whether one's welfare is improved by having a wider range of choices is often dependent upon an assessment of the costs involved in having to make these choices".³⁹

4.2 Responsibility for choice

We have seen that in the exercise of autonomy rational choices are made. If a choice is made autonomously, one bears responsibility for that choice. If one were to not bear responsibility, then the action would be akin to the action of a machine or mute automaton. I will look briefly at how Aristotle and Dworkin account for the responsibility that arises when choices are made and then apply this to the selection of GE or not.

When Aristotle seeks to determine whether it is in our power to be virtuous and make the right choices he says:

Virtue is up to us, and likewise also vice. For in those cases in which acting is up to us, not acting is also up to us, and where it is up to us to say no, it is also up to us to say yes; so if it is up to us to act when this is a beautiful thing, it is also up to us to refrain from acting when this would be an ugly thing to do, and if it is up to us not to act when this would be a beautiful thing, it is also up to us to act when it is an ugly thing. But if doing the things that are beautiful or ugly is up to us, and likewise refrain from doing them, and this is what it is to be good or bad people, therefore being decent or base is up to us.⁴⁰

For Aristotle the determination of moral responsibility is whether an agent is susceptible to blame or praise. Praise or blame can be accorded if and only if the actions are voluntary: the

³⁹ Dworkin, G.; *ibid.*, p. 66.

⁴⁰ Aristotle, *ibid.*, 1113b.

agent must be able to make a decision regarding the action and the agent must have full knowledge of what she is doing.⁴¹

Dworkin says,

At the most fundamental level, responsibility arises when one acts to bring about changes in the world as opposed to letting fate or chance or the decisions of other actors determine the future. Indeed, once I am aware that I have a choice, my failure to choose now counts against me. I now can be responsible, and be held responsible, for events that prior to the possibility of choosing were not attributable to me. And with the fact of responsibility comes the pressure (social and legal) to make “responsible” choices.⁴²

Dworkin uses the example of the availability of amniocentesis to demonstrate his point, which is picked up by Hildt. I return to this example under “Hildt and prenatal genetic diagnosis”.

Prior to the development of genetic technology, parents were only partly responsible for the pre-birth growth of their child (insofar as the health and status of the mother affected the health of the foetus), and largely responsible for the post-partum growth, development and education of their child. Without the technology, the genetic nature of a child was beyond the bounds of parental and human responsibility, because parents were utterly incapable of doing anything about it. On the one hand, it could be argued that parents by virtue of having a child bear all the consequential responsibility of having that child, including its genetic make-up as constructed by the pairing of their respective chromosomes. On the other, Aristotle would argue that if the genetic status of the child is an unintended “involuntary” consequence of a choice (to have sex), then no responsibility can be attached.

In an environment where the choice of GE is available parents are presented with a binary choice: GE your child or do not GE your child. There is no middle ground between the options. It is the availability of options that now obligates parents to make a selection, one way or another. There is no way for parents to escape the necessity to make a decision and there is no return to a state in which they are not required to make a choice; and for this they bear

⁴¹ Eshleman, A.; “Moral Responsibility”, pgs. 4-5.

⁴² Dworkin, G.; *op. cit.*, p. 67.

responsibility, prospectively to make the choice, and retrospectively for the consequences of that choice.

Parents who choose to enhance their child bear the prospective responsibility for that choice. If they are responsible then they must be able to justify their decision to enhance, either to themselves, to each other or to society generally. As we have seen in “Choice and autonomy” the reasons may be subjective or objective.

So too must the parents who choose *not* to enhance their child, irrespective of their reasons, bear the responsibility for their choice. They cannot avoid the responsibility by claiming that they are making a negative choice or that they have chosen not to act. As rational parents they must be able to justify this choice, a task which did not exist prior to the availability of GE and from which they cannot escape once GE is available. As Dworkin suggests the “failure to act” counts against one and the responsibility accrues even though responsibility was not attributable prior to the “possibility of choosing”. Again the justification for their choice need not be assessed against any objective criteria; the responsibility for the choice and the requirement to justify the choice remain irrespective of the reasons.

Once the decision to enhance is made, then a further enduring, and retrospective, responsibility accrues to the parents of the child. Recall that according to the definition, GE is intentional and is permanent. Parents bear the responsibility for the genetic make-up of their child, who is no longer the result of genetic lottery. They carry the post-facto burden of responsibility for the state of their child, as it grows, is born and matures into an adult. The phenotype of the person is as a result, at least partly, of the genotype, which was determined by the GE. It doesn’t seem improbable that parents will be constantly evaluating the success of their enhancement exercise according to the conceptions they had at the time of the enhancement.

Parents who select **not** to enhance their child by intentional omission or abstention are similarly burdened by the ongoing responsibility of the genetic make-up of their child, albeit unenhanced. Not to enhance one’s child is an intentional and permanent decision. This burden does not disappear once the decision is made. The foetus grows, the child is born and it too matures into an adult. The unenhanced embryo, which parents chose not to enhance, becomes the unenhanced adult. The parents cannot escape the retrospective responsibility of having chosen not to enhance

their child, as the evidence of that decision confronts them every day. Again, this responsibility cannot be evaded by an appeal to passivity. Nor can it be evaded by a wish for the *status quo ante*, for that is all that it can remain - a wish.

Confirming the argument that both kinds of parents are responsible, Habermas says, “In the context of eugenic practice, acts of this type – *by omission as well as by execution* – lay the grounds for a social relationship in which the usual reciprocity between persons of equal birth is revoked”.⁴³

Sandel is critical about the effect that GE will have upon parents who select it. He does not generally deal with the effects that the institutional availability of GE will have upon parents who do not select it. However, he has this to say, confirming the burden of responsibility that accrues to both sets of parents: “Though some maintain that GE erodes human agency by overriding effort, the real problem is the explosion, not the erosion, of responsibility. As humility gives way, responsibility expands to daunting proportions. We attribute less to chance and more to choice. Parents become responsible for choosing, *or failing to choose*, the right traits for their children”.⁴⁴

One of the arguments often presented in favour of GE is that as with every other tool that parents use to raise and improve their children, GE is just another tool in their arsenal. GE can improve the child and reduce or eliminate any or all limitations. Maureen Junker-Kenny asks, “Why accept limitations as fate? ... This question reveals itself as an attempt by those eager to remodel the physical basis of an individual life to shift the burden back to the other side. What now seems to be in need of justification is the acceptance of a person’s contingent genetic make-up as a given, indeed, as the inviolable basis of individuality”.⁴⁵ Simply put, parents have to justify why they are not joining the herd!

4.3 Pressure to conform

⁴³ Habermas, J.; *op cit.*, p. 64. Emphasis added.

⁴⁴ Sandel, M. J.; *op cit.*, p. 13. Emphasis added.

⁴⁵ Junker-Kenny, M.; “Genetic Enhancement as Care or Domination? The Ethics of Asymmetrical Relationships in the Upbringing of Children”, p. 8.

Dworkin argues that an increase in choice can bring sanctions and pressures to bear upon the decision maker which did not exist prior to the increase of choice. He concedes “that people may have a right to such increased choices or because it is simply desirable to do so, such pressures have to be tolerated”.⁴⁶ The pressures and possible sanctions are brought to bear by family, friends and society in general.

Dworkin by way of example refers to the then (and now) controversial method to control the sex of one’s child: amniocentesis to determine the sex of the foetus and if incorrect or unwanted, abortion thereof.⁴⁷ Interestingly he alludes to the possibility of separating male sperm from female sperm (a genetically based procedure and now a reality with flow cytometry) to less traumatically determine the sex of the child. If flow cytometry became institutionally available enabling parents to determine easily and safely the sex of their child, the pressure from husbands, grandparents and society would rapidly arise. The evidence from China where there is a traditional preference for boys proves the point. The skewing of the ratio of boys to girls is evidenced even before the implementation of the one-child policy. According to Wei Xing Zhu:

In the absence of intervention, the sex ratio at birth is consistent across populations at between 103 and 107 boys born for every 100 girls. However, in many countries, mainly in South and East Asia, the sex ratio deviates from this norm because of the tradition of preference for sons. Historically, preference for sons has been manifest postnatally through female infanticide and the neglect and abandonment of girls. Where this persists, it mainly consists of failure to access necessary medical care. However, since the early 1980s selection for males prenatally with ultrasonographic sex determination and sex selective abortion has been possible. The highest sex ratios are seen in countries with a combination of preference for sons, *easy access to sex selective technology*, and a low fertility rate, as births of girls must be prevented to allow for the desired number of sons within the family size.⁴⁸

Presumably those parents who want to comply with the preferences or demands of family and society have less of a problem with the means to do so (abortion or infanticide), however abhorrent they may seem to others. The problem is for those parents who choose, for whatever reason, not to comply. For them, either the demands of society are unreasonable or the means to comply are problematical, or both. It seems incontrovertible that in these societies the greater the

⁴⁶ Dworkin, G.; *op cit.*, p. 69.

⁴⁷ Dworkin, G.; *ibid.*, p. 68.

⁴⁸ Zhu, W. X.: “China’s excess males, sex selective abortion, and one child policy: analysis of data from 2005 national intercensus survey”, p. 1. Emphasis added.

ease with which sex selection technology can be applied thus reducing or eliminating at least the abhorrence of the means to comply, the greater will be the pressure to conform to societal preferences.

Peter D. Kramer discusses three areas of enhancement where societal pressure is prevalent today, and where an increase in choice has changed the nature of the “original position” and led to an undesirable pressure to conform. Firstly, it can be argued that the taking of steroids in order to improve athletic performance is desirable, despite the possible side-effects. However the choice to take steroids has a bearing upon other competitors who may choose not to chemically enhance their performance. Kramer says, “The strongest reason for banning steroids in competition has to do with coercion, or, more precisely, ‘free choice under pressure,’ as Thomas H. Murray puts it in his essay ‘Drugs, Sports and Ethics’. Once a few athletes take steroids, others remain free not to do so, but only at the cost of forsaking goals to which they have devoted many years of painful effort. The choice not to take drugs has been diminished”.⁴⁹ The notion of “free choice under pressure” is paradoxical because, as we have seen (in “Choice and autonomy”), there is no situation in which the choice of anything can be devoid of influence or pressure. No choice can be utterly free, and as the import of the choice increases so do the surrounding pressures. The pressure that Murray refers to is that if steroids are not available, the not-taking-of-steroids, which is not a choice, draws no pressure. This is self-evident! Once steroids are available (even if not institutionally available but widely available none-the-less) then the not-taking-of-steroids, now a choice which one is entitled to make, ostensibly a free choice, is now made under pressure. That pressure arises largely from the pressure to conform and more explicitly from the pressure to compete, to equalize the “playing field” and to win.

Secondly, Kramer argues that the free choice under pressure applies to models faced with the choice of breast enhancement. “What was once (arguably) a social good – allowing a woman to gain the appearance that gives her a sense of well-being – becomes a clear social ill, the requirement, putting it in the severest terms, that a woman undergo mutilating surgery in order to pursue her chosen career”.⁵⁰ Finally, Kramer turning to the topic of his book, Prozac, says that the free choice under pressure arises from the “possibility of chemical ‘enhancement’ of a variety

⁴⁹ Kramer, P. D.; *Listening to Prozac*, p. 273.

⁵⁰ Kramer, P. D.; *ibid.*, p. 273.

of psychological traits – social ease, flexibility, mental agility, affective stability – that could similarly be coercive. (...) A socially desirable drug (Prozac) turns from boon to bane because it subjects healthy people to demands that they chemically alter their temperament”.⁵¹ In both these situations the increase of choice changes the nature of the original position and creates an undesirable pressure to conform.

It is speculative to characterize how pressures would be brought upon parents once GE is available. Children are rarely seen as the private domain of parents, despite parents’ right to reproductive freedom and privacy. Children are the future and every other intervention (e.g. education, health and well-being) is seen, at least in part, as a societal responsibility to produce contributing members of that society. Enhancement, however defined, could conceivably become an arena of intervention for other stakeholders. It is not a leap of faith to imagine that these pressures could be enormous. This borders upon a debate regarding eugenics, being an engineering of individuals to achieve some or other general societal goal. I do not mean to extrapolate the pressure upon individual parents that may come from relatives and friends to society generally, but this clearly would be a source of concern were GE to become freely available.

Finally, if there is any doubt that societal pressure will be a factor in future then we need look no further than Rawls. Provided the talents of the most advantaged are used for the common advantage, then anything that enhances these talents is in accordance with the difference principle. Rawls says, “In the original position, then, the parties want to insure for their descendants the best *genetic endowment* (assuming their own to be fixed). The pursuit of reasonable policies in this regard is something that earlier generations owe to later ones, this being a question that arises between generations”.⁵² A “reasonable policy” would at a minimum be defined by some measure of institutional availability and containment of risk and cost. Rawls does not elaborate further on this claim and generally avoids the issue of eugenics, but GE seems entirely consistent with his conceptualization of a just society. If he is correct, then the pressure upon parents to conform to “reasonable” GE policies will be immense.

⁵¹ Kramer, P. D.; *ibid.*, p. 273.

⁵² Rawls, J.; *op. cit.*, p. 108. Emphasis added.

It can be argued that if a policy of GE is adopted by those in the original position, and is accepted and sustainable, then the pressure to conform will be eliminated: everyone will select GE as a matter of course. The option to not select GE would disappear, being replaced by a new *status quo* which allows for no choice. This may be a logical possibility; the implication is that all moral objections to GE have been removed (by the decision-makers behind the veil of ignorance) and that no-one would have any reason to not select GE. If this is correct, it seems that all moral problems could be so resolved. This is not Rawls' claim and in the case of GE it is improbable that this would occur.

4.4 Exercise of choice

The negative implication of more choice that Dworkin refers to here is that an increased choice may lead to a “decrease in the likelihood of exercising previous choices”.⁵³ Dworkin points out that by “increasing the options available one changes the nature of the old options and may, therefore, affect the likelihood of individuals exercising such options”.⁵⁴ Regarding GE, the *status quo ante* requires no choice – no GE was a certainty. However, an increase in choice, which will allow GE to be selected, will perforce remove the certainty and decrease the frequency of GE *not* occurring.

More important than the reduction in the frequency of GE not occurring is Dworkin's point that the increase in choice can impact and even change the nature of the original position. The example that he uses is the accessibility of divorce where previously divorce was unobtainable or illegal. Marriage in an environment of no divorce was regarded as irrevocably permanent. This permanence would impact, even determine, the expectations of couples getting married, their commitment to the marriage, their assurance of fidelity and their tolerance of each other. These all change in a society that tolerates the availability of divorce and, even if individual standpoints are at odds with societal and legal norms, it is reasonable to assume that there would be some impact upon expectations and commitments. Dworkin argues that, “It is surely naive to suppose that the mere presence of a choice which need not be taken cannot alter the original situation”.⁵⁵

⁵³ Dworkin, G.; *op. cit.*, p. 69.

⁵⁴ Dworkin, G.; *ibid.*, p. 71.

⁵⁵ Dworkin, G.; *ibid.*, p. 72.

Dworkin expresses the concept by way of the following examples: “If I touch you, I make it impossible for anyone to speak to you while speaking to someone untouched by me. If we allow people to work on the Sabbath, we make it impossible for anyone to work six days a week, and be assured that everyone else will rest on the Sabbath. And people may want to have that assurance ...”.⁵⁶

The application of this is that once GE is made available, parents and society can no longer assume that the genetic lottery has determined the make-up of their child or any other child. No longer is the make-up of the child independent of the choices made by its parents. No longer can any child be assumed to be the consequence of aeons of genetic lottery, moderated only by parents’ selection of each other as breeding partners. The institutional availability of GE forever changes the nature of what was the default and the knowledge and assumptions that went with it.

This implication functions at a different level to those previously discussed. The previous implications operate at an individual level i.e. the decision-making process of parents in an environment of GE availability are directly impacted by the negative implications. However, the uncertainty of knowing who is enhanced or not removes a basic assumption of one another’s equality, an assumption that goes to the foundation of our human functioning. Habermas says, “By depriving the fusion of two sets of chromosomes of its contingency, the intergenerational relations lose the naturalness which so far has been a part of the taken-for-granted background of our self-understanding as a species”.⁵⁷ Habermas does not specifically deal with parents who would not select GE, nor need he as he argues against GE generally. However, his point dovetails neatly with that of Dworkin’s: the nature of the original option, while still available, is changed and in this case possibly severely so. Our very understanding of ourselves may be altered. Consider now the parents who have chosen not to enhance their child: for them too their understanding of those around them (or perhaps only their child’s contemporaries) is changed. It is impossible for them to escape the doubt of what has happened to all the children around them. Habermas concludes, “Getting used to having human life biotechnologically at the disposal of our contingent preferences cannot help but change out normative self-understanding”.⁵⁸

⁵⁶ Dworkin, G.; *ibid.*, p. 71.

⁵⁷ Habermas, J.; *op. cit.*, p. 72.

⁵⁸ Habermas, J.; *ibid.*, p. 72.

As we contemplate the possible extremes to which GE can take us, it is conceivable that the existential threat that comes from the uncertainty of knowing who is genetically enhanced or not is the greatest harm that the institutional availability of GE delivers.

4.5 Summary

Dworkin suggests that less choice is better than more only in certain situations. Negative implications arise from the institutional availability of GE that have to be taken into account in an all-things-considered argument. It is arguable that what Dworkin calls “costs” and what Hildt refers to as “negative implications” of the institutional availability of GE are on their own, and in themselves, harmful to parents. These are the costs, the responsibilities, the pressure to conform and the transformation of the default position. Taken together as a group the impact upon the ability to choose GE, or not, is apparent. Once the choice of GE is institutionally available there is no way to avoid the implications as they are embedded in the situation; accordingly there is no way to avoid the impact upon parental autonomy.

While the focus has been upon parents who would not select GE for whatever reason, as opposed to those who select GE, there is a further category: parents that select GE because of the desire to avoid the negative implications. For them their autonomy is similarly reduced, as their ability to make a choice in accordance with their own reasons has been reduced.

In “Choice and autonomy” it was shown generally that an increase in choice is a good thing and increases autonomy. If GE is made available as an option this is indeed seems to be the case. In this section we have seen that Dworkin’s framework as applied to the institutional availability of GE shows that it is not necessarily true that more choice is better. For parents who would not select GE, for whatever reason, the force of the negative implications may well be intolerable. Some parents may endure the harms; others may select GE because of them. Either way parents’ autonomy is, at least, not self-evidently increased by the availability of GE.

5. Analogies

We have already seen that the science of GE is located in the future. While it seems advisable to develop ethical strategies prior to the wide-spread availability of GE, the obvious difficulty is that there is uncertainty, sometimes great uncertainty, as to how the science will impact upon the development of life goals and aspirations. In an attempt to clarify the crystal ball a little, I examine two areas in biomedical ethics that provide contemporaneous parallels to the availability of GE: the first is euthanasia and the second is prenatal genetic diagnosis. The arguments by Velleman and Hildt focus on the institutional availability of euthanasia and prenatal genetic diagnosis and both argue that it is the availability thereof respectively that causes harm.

5.1 Velleman and euthanasia

Velleman argues that the availability of euthanasia is in itself harmful, irrespective of whether the choice is exercised or not.⁵⁹ He contends, following the cue from Dworkin, that more choice is not necessarily better than less and, even further, can be worse. Indeed having options available in the form of a choice between two outcomes (or more) generate pressures that are undesirable. Once a choice is presented, it is no longer possible to have the original position or status quo without choosing it. Velleman says, “And having the status quo by default may have been what was best for him, even though choosing the status quo is now worst”.⁶⁰ Velleman uses the example of a dinner invitation, which could be applied to any invitation. I could be invited by a friend of mine to go flying in his light aircraft. The option to fly with him did not exist before he invited me. Now, although the invitation may be desirable at some level (e.g. it’s exciting), I do not trust his skills, and I have to formulate a reason to decline the invitation. I now have an obligation that did not exist before the invitation was issued, a responsibility to explain why I do not want to fly with him. This explanation, being a rational agent, must itself be rational, at least to me. The choice of flying (whether I fly or not) has now created a situation which did not exist when the *status quo ante* prevailed. In fact I prefer the *status quo ante*, but that has disappeared, forever, once the choice to go flying has been created by way of the invitation. Velleman says,

⁵⁹ Velleman, J. D.; *op. cit.*

⁶⁰ Velleman, J. D.; *ibid.*, p. 84.

“Having choices can thus deprive one of desirable outcomes whose desirability depends on their being unchosen”.⁶¹

Applying this argument to the provision of euthanasia, Velleman says that “the most important way in which the option of euthanasia may harm patients, I think, is that it will deny them the possibility of staying alive by default”.⁶² Because the default position is no longer that, as it has to be selected, a responsibility arises that was not there initially. Velleman continues: by “offering someone the choice of euthanasia would not only cause his existence to be perceived as his responsibility; it would actually cause his existence to become his responsibility for the first time”.⁶³

The negative implications that arise from the institutional availability of euthanasia parallel those that arise from the availability of GE. The burden of responsibility to justify one’s choice (to stay alive), the pressures from society to conform (select euthanasia as that is better for family and society) and the way that the increased choice changes the nature of the old option (one’s continued existence is now one’s responsibility for the first time) resonate with the problems that arise from the institutional availability of GE.

The latter part of Velleman’s argument is disanalogous for our purposes: the patient is presumed to be a rational being, and much of Velleman’s argument examines the effect that the choice of euthanasia has upon this patient. In particular, the patient in choosing to continue life is obliged to justify that choice, a burden that may be too onerous to bear and may lead, paradoxically, to the patient no longer having a reason to live. This report has not focused upon the benefits and harms that may accrue to the “patient” (in this case the child) as a result of GE. It has focused upon the harms that accrue to the *parents* in the GE environment.

Velleman adopts a weaker version of his argument when he suggests that euthanasia can be permitted, to be exercised at a private level, without any institutionalization thereof. It is the indiscriminate availability of euthanasia that is institutionally supported that causes harm and

⁶¹ Velleman, J. D.; *ibid.*, p. 84.

⁶² Velleman, J. D.; *ibid.*, p. 85.

⁶³ Velleman, J. D.; *ibid.*, p. 87.

which Velleman argues against. He prefers a system whereby euthanasia can be appropriately offered or declined according to certain requirements, which will mitigate the harms.

It seems likely that this distinction could be applied to GE. The availability of GE at only a “private” level would decrease the disposition of parents to seek it out, decreased by the absence of factors that render it institutionally available: expense, lack of access and absence of legislation. Indeed the impediments to selecting GE in the event that it is not institutionally available arguably maintain the *status quo ante* as there is no choice to be made and accordingly none of the negative implications arise. This may provide a clue for the future development of policies; but how one legislates the provision of GE in such a way that it is not generally available remains to be seen.

5.2 Hildt and prenatal genetic diagnosis (PGD⁶⁴)

An interesting and relevant analogy is provided by the institutional availability of amniocentesis which allows for PGD, the science of which is more developed than that of GE. The contemporaneous issues and debates regarding the choice of PGD offer insight into the debate around the choice of GE. Elisabeth Hildt deals with the choice that parents are confronted with when PGD is available in “Autonomy and freedom of choice in prenatal genetic diagnosis”. This article was written in 2002, where PGD was becoming increasingly available and pre-implantation genetic diagnosis was still in its infancy and follows the same structure for analysis as supplied by Dworkin and as used above. Dworkin refers to amniocentesis in the same context, writing in 1988.

Amniocentesis allows for the withdrawal, largely without risk, of amniotic fluid from the fetal sac. The fluid is analysed (PGD) allowing for certain genetic aspects of the foetus to be determined (including sex) and for some genetic defects to be detected if present. Amniocentesis is more often indicated in high risk pregnancies, such as those in older women.

If parents choose PGD and in the event that the result of PGD is favourable then there is no further issue. However in the event that the result is unfavourable, that the foetus is compromised

⁶⁴ Hildt abbreviates prenatal genetic diagnosis as “PGD” in her article. “PND” or “PD” seem the more accepted abbreviations but I retain Hildt’s usage for the purposes of this report.

in some way, then the decision to abort or not has to be made. Termination of the pregnancy may not be something parents wish to contemplate in the event of an unfavourable result, yet the possibility of abortion is inherent in the choice of PGD. If they choose to abort the foetus, then they are responsible for the demise of that foetus. If they choose not to abort the foetus, then they are responsible for the emotional, financial and societal burdens that may ensue.

On the other hand, if parents choose not to undergo PGD and perchance the functioning of the child is sub-normal, then they too are responsible for the emotional, financial and societal burdens that ensue. They had the choice to take an action that may have removed these consequences. Hildt says, “Responsibility has to be taken not only for carrying out PGD and selective abortion, but also for not carrying out PGD or not carrying out selective abortion – these latter options having been the normal course of things in bygone days”.⁶⁵

Dworkin alludes to the development of the technique of amniocentesis and the removal of legal restrictions on abortion and concludes:

These two circumstances now imply that if parents bring, say, a Down’s syndrome infant into the world, they bear responsibility for this action; a responsibility that could not be attributed to them prior to the possibility of determining the normality of the foetus and the legal possibility of terminating the pregnancy. Now, both in their own minds and those who are aware of their decision, they must assume responsibility for the correctness of their choice. The defective child – if they choose to bear it – can no longer be viewed as inevitable bad luck or as an act of God or as a curse.⁶⁶

For Hildt, the availability of PGD impacts upon the autonomy of the parents. While a respect for the autonomy of parents may indicate that the choice of PGD is a good thing, the negative influences indicate that the decision is not a free one. Hildt says, “I consider it highly problematic to refer in a general way to autonomy in order to legitimate the broad use of genetic testing. It seems clear that an increase in choice offered by PGD also leads to various implications that may negatively influence the freedom of the persons involved”.⁶⁷

⁶⁵ Hildt, E.; *op. cit.*, p. 69.

⁶⁶ Dworkin, G.; *op. cit.*, p. 67.

⁶⁷ Hildt, E.; *ibid.*, p. 70.

The negative implications parallel those discussed in “Are more choices better than fewer?” above. First, there are the decision-making costs. Hildt says, “For the couples involved there are also the costs in time and effort for acquiring the necessary information. For being able to make a reasonable choice it is necessary that the couple be well-informed of the various options available and the context in which these options have to be seen”.⁶⁸ Regarding the psychic costs Hildt refers to the practical and ethical issues that surround possible termination of a pregnancy as well as that “for the women involved it may be a life-long burden to think they may have made the wrong choice”. Second, the responsibility for choice, that didn’t accrue to parents prior to the development of PGD, is now manifest. Hildt writes,

Since the introduction of PGD, the situation has changed. Recently, the feeling has surfaced that parents who decided against PGD are retrospectively to be made responsible for genetic disorders suffered by the child – disorders which could have been identified, and therefore avoided, with the help of PGD. The argument runs as follows: Parents who decide not to undergo PGD or not to terminate pregnancy after PGD have to bear the responsibility for their action.⁶⁹

Third, the pressure to conform comes from the “growing expectation that responsible parents should – in their own best interest as well as in society’s best interest – in case of risk undergo PGD followed in case of severe genetic disorder by termination of pregnancy”.⁷⁰ Finally, under the rubric “Exercise of choice”, the *status quo ante* is no longer available as a situation without responsibility. Hildt concludes, “Thus, the option to carry out PGD also changes the nature of the old options. In view of the availability of PGD, a pregnancy without genetic testing – which was formerly the normal situation – now becomes a deliberate choice for which responsibility has to be taken”.⁷¹

With PGD the focus of the argument is not the decision to abort a genetically defective child against the decision to endure the hardships of raising the child (and the hardship for the child herself); the focus is upon the implications that the availability of PGD generates. It is the negative implications that impact upon the autonomy of parents as they are pressured to undergo PGD. The reasons to reject PGD are irrelevant; it is the very availability of PGD that creates an

⁶⁸ Hildt, E.; *ibid.*, p. 68.

⁶⁹ Hildt, E.; *ibid.*, p. 69.

⁷⁰ Hildt, E.; *ibid.*, p. 69.

⁷¹ Hildt, E.; *ibid.*, p. 70.

environment that negatively impacts upon the autonomy of parents and one where it is conceivable that they would prefer not to have had the choice in the first place.

There are parallels between the development of PGD as a diagnostic tool in 2002 and the nascent technology of GE today. As the institutional availability of PGD generates responsibilities that may be too onerous, so too does the institutional availability of GE. The negative implications generated by the availability of PGD are the same as those generated by the institutional availability of GE. The choice that parents have to make and responsibility that they have to bear when accorded the choice of PGD, irrespective of whether it is for diagnostic reasons as opposed to the pursuit of enhancement, are the same that parents bear in the face of the availability of GE. The pressure to select PGD compares to the pressure to enhance one's child. Both impact the ability to choose freely between alternatives and accordingly diminish the autonomy of the parents.

6. Criticisms

There are a number of criticisms that may arise against my thesis that the availability GE causes harm. The first is derived from Dworkin's argument that it is possible to foreclose an option, thereby rendering it, in a sense, not an option at all. The second is that the "natural" way of conceiving children, precludes the choice of GE, rendering it, again, not an option at all. The third is that societal pressure is inconsequential to parents in the light of reproductive freedom so cherished in the Western world. The final criticism is that enhancement as a concept is so devoid of coherence that any action that appeals to it as its *raison d'être* is doomed to meaninglessness. I deal with each criticism in turn, none of which render my thesis invalid.

6.1 Foreclosure

Dworkin argues that choices can be restricted to symbolise or express a moral relationship. By way of example, he discusses the notion of precluding completely "alternative sexual relationships"⁷² in a marriage, thereby showing that the relationship is of a deep and meaningful nature. Dworkin talks about "foreclosing" the idea of infidelity, which he defines as not simply declining the option of infidelity but "abandoning the very idea of the option".⁷³ Dworkin doesn't expand on what he means by foreclosure; but taking the example of foreclosing infidelity in a marriage a little further we can see how it would operate. Foreclosure in this instance would encompass as least some or all of the following elements: a public announcement that occurs when marriage vows are made; a sense of permanence about the vows, which implies that they are not subject to revision each time temptation crosses one's path; a strength of renunciation of infidelity which is at a different level than merely choosing not to be unfaithful; and, for those who are religious, a commitment to fidelity in the eyes of God. For Dworkin this is a way of "manifesting certain ideals"⁷⁴, in the case of marriage, the ideal of an enduring and profound relationship.

It could be argued that the idea of GE can be "foreclosed", thereby eliminating the choice between enhancing one's child or not. If the possibility of choosing GE is foreclosed, then any

⁷² Dworkin, G.; *op. cit.*, p. 75.

⁷³ Dworkin, G.; *ibid.*, p. 75.

⁷⁴ Dworkin, G.; *ibid.*, p. 75.

consequences that emanate from that situation would not exist. Accordingly any harm that results from the availability of GE could not occur! This would represent a return to the *status quo ante*.

For Dworkin's argument to gain traction, we need, firstly, to understand the notion of GE as a possible harm to the moral relationship between the parent and the future child. Habermas would argue with that there is indeed a moral relationship, even at an embryonic stage. He says that one of the arguments against GE refers to "a prenatally induced self-devaluation; to a harm to her own moral self-understanding. What is affected is a subjective qualification essential for assuming the status of a full member of a moral community".⁷⁵ Habermas is avowedly anti-GE for many reasons that relate to the relationship between parent and the enhanced child. Here he confirms the moral responsibility that a parent has towards a child.

Secondly, we need to understand if the elements of foreclosure referred to above can be applied to GE. A foreclosure by parents of GE would presumably have to be public, permanent, and committed (and possibly made before God). It would have to be made before a child is conceived. It would not be subject to revision each time a further child is conceived.

What ideal is manifested or what moral relationship is expressed or symbolized by foreclosing GE? The obvious answer is that there is no moral relationship prior to conception as there is no thing or person or embryo with whom to have a relationship. Leaving aside the difficulties raised by this issue, it seems that the one condition that Dworkin requires, that of a moral relationship, cannot be met.

Further, it is difficult to envisage any process that would match the rigour and societal importance of a marriage ceremony that would constitute a foreclosure of GE.

Despite the difficulties, parents may in their own terms foreclose GE. Yet the negative implications remain. Possibly only the costs of the decision-making process are removed, but parents continue to bear the responsibilities and to endure the pressures and to operate with the uncertainty of the status of the children around them. These are not removed by foreclosure of

⁷⁵ Habermas, J.; *op.cit.*, p. 81.

GE. GE remains available and it is the availability thereof that generates the harms irrespective of the position of the parents.

6.2 The natural way

The second criticism is that the “natural” way of conceiving children, at any rate the way that has propagated the human species for aeons, precludes the choice of GE, rendering it, again, not an option at all. This argument would proceed along the lines that the process of conception and embryonic growth occurs well away from laboratories and medical professionals. The “natural” way often has little to do with any cognisance (as we all know!) of the procreative consequences of sexual partnering. The resultant embryo is just an un/fortunate product which bears no further thought regarding its enhancement or otherwise. The naive or ill-informed parent, when confronted with the availability of GE, may simply say that it has no relevance for her. “What is there to discuss?” or “My way, my mother’s way, my grandmother’s way of producing children is quite OK”, may well be the claims. Under these circumstances it is difficult to argue that any harm occurs as a result of the institutional availability of GE.

Yet GE remains institutionally available, which for rational and informed parents cannot be precluded by an appeal to lack of knowledge; nor by an appeal to the fact that the conception was a result of a natural process rather than in vitro fertilization (or some future equivalent). The fact remains that if GE is institutionally available, then it is just that. Only if the requirement for rationality is dropped can it be argued that parents may make a non-deliberate choice of not choosing to enhance their child: in this event, the costs and responsibilities that accrue to parents may be obviated.

6.3 Societal pressure

The third possible criticism is that societal pressure is inconsequential to parents in the light of their right to reproduce freely. However the pressures imposed by society can be immense despite this right. The nature of the pressure that can be applied by society is seen in the debate around abortion.

One of the cherished rights in Western liberalism is reproductive freedom, in particular the choice of when to reproduce and with whom to reproduce. However reproductive freedom and

the autonomy that it embodies does not extend willy-nilly to a freedom to do with an embryo whatever one wants. According to anti-abortionists this freedom does not include the right to abort a foetus because the foetus as a future person has a right to life. An embryo is not an entity without rights, however construed. The pro-abortionists argue that the right a mother has to her own body trumps whatever rights accrue to the foetus. Mapping this situation onto autonomy, the pro-abortionist would argue that denying the right of a mother to abort her foetus, consequentially, reduces her autonomy. The anti-abortionist denies that abortion has anything to do with autonomy; the deontological rights of the foetus win every time. As we know these positions have resulted in arson and murder in the USA.

The relevance of this debate to GE is that autonomy, insofar as it extends to reproductive freedom and the choice of GE, is not (generally) unconstrained by other considerations as interpreted by other people. Anti-abortionists adopt proprietary positions in regard to parents' unborn children, a position not inconceivable to imagine with regard to the status of the "to-be-enhanced" embryo. This is not to weigh up the issue of killing versus enhancement. The point is that reproductive freedom does not immunise one against the pressures that other people may choose to exert and how they do so. Simply, other people may assume proprietary positions regarding the enhancement or otherwise of children not their own, thereby exerting pressure.

6.4 Enhancement

The concept of enhancement was dealt with earlier in terms of positioning it on a continuum with species-normal function in the middle and sub-normal and supra-normal functioning and characteristics on either side. According to this continuum it is possible to differentiate, to some extent, between therapy and disease prevention on the one hand and enhancement on the other. The former is considerably less fraught with moral problems than the latter. For Norman Daniels, "the line between disease and disability and normal functioning is thus drawn in the relatively objective and non-evaluative context provided by the biomedical sciences, broadly construed".⁷⁶ The latter is harder to define particularly as some enhancements may be or become morally obligatory. Daniels seeks for some middle ground, which he calls a "base-line". "The central conceptual issue, and the focus of considerable controversy, is whether the concept of disease

⁷⁶ Daniels, N.; "Normal Functioning and the Treatment-Enhancement Distinction", p. 315.

and disability, and the treatment-enhancement distinction that depends on it, can be drawn by reference to a ‘natural base-line’, such as departures from species-typical normal functioning, or whether the concepts of disease and disability are fundamentally evaluative”.⁷⁷ Daniels project is, rather than to draw a line precisely between treatment and enhancement, to show what is morally permissibly and morally impermissibly along this continuum. “Even if the treatment-enhancement distinction does not provide us with a simple criterion for deciding what genetic interventions are permissible and impermissible, there is good reason to think that many enhancements will pose serious problems not posed by treatments”.⁷⁸ As with Daniels, the exact distinction for this report is not important. Therapy or treatment seeks to move the future child along the continuum from sub-normal functioning closer to species-normal functioning; so too does enhancement seek to move the future child towards more or greater supra-normal functioning. Inherent in the movement along this continuum is not where the ‘base-line’ is drawn or where the exact boundaries are of species-normal functioning are but that the objective of enhancement is some improvement or betterment of the future child. If the child now functions better or has improved characteristics than what it would have been without enhancement, then that is presumably a good thing, at least for the child.

The criticism of my thesis arises from the difficulty in determining what actually constitutes an enhancement as a result of a genetic procedure. If it cannot be defined or at least some coherent understanding achieved, then the entire notion of GE may be rendered meaningless. It is beyond the scope of this report to determine what enhancement denotes. Suffice to say that it is parents’ personal view and understanding of enhancement that leads to their reasons for selecting to enhance their child or not. If GE is institutionally available then at least part of the decision to enhance or not is based upon parents’ sense of what, in their view, constitutes enhancement. To that extent it matters not for my thesis whether that understanding is coherent or defined. Agar agrees: “I place GE in the context of a liberal political philosophy and argue that prospective parents should have a constrained freedom to choose genetic enhancements that conform to their particular values”.⁷⁹ This accords well with Rawls’ view that the ability to make one’s own

⁷⁷ Daniels, N.; *ibid.*, p. 318.

⁷⁸ Daniels, N.; *ibid.*, p. 320.

⁷⁹ Agar, N.; “Thoughts about our species future ...”, p. 29.

decisions and choices is in integral part of liberty. None of the issues dealt with in this report hinge on the coherence of parents' understanding of enhancement.

An example will serve to demonstrate how fluid the notion of enhancement is and, even if at worst enhancement is an incoherent notion, that it does not affect my argument. Dena S. Davis contrasts the perceived rights of deaf parents to have a deaf child with the harm that is caused to the child because of the denial of its right to an open future.⁸⁰ Reproductive freedom is a right cherished in America (where Davis writes) and this freedom, how ever defined, seems to extend, by way of GE, to the kind of child that one wants. In 1983 the President's Commission wrote, "The silence of the law in many areas of individual choice reflects the value this country places on pluralism. Nowhere is the need for freedom to pursue divergent conceptions of the good more deeply felt than in decisions regarding reproduction".⁸¹ Deaf parents argue that deafness is not a disability, that their quality of life is no worse than hearing people and that deafness can be viewed more as cultural phenomenon rather than a medical condition. "It turns out that some deaf couples feel threatened by the prospect of having a hearing child and would actually prefer to have a deaf child. The knowledge that we will soon acquire will, of course, provide us with the technology that could be used to assist such couples in achieving their goals".⁸² Deaf parents have a right to want deaf children, and if this can be brought about by genetic manipulation, then their life goals can be fulfilled.⁸³

It seems counter-intuitive, possibly even abhorrent, to imagine that causing deafness is an enhancement in any sense of the word. The fact remains that deaf parents, according to their world view, can desire an "enhancement" for reasons that to hearing parents may seem irrational. Granted that this may be an extreme example, but if parents are to have the liberty to choose how they are to enhance their child then they have the liberty to justify that decision to themselves in whatever way they see fit. Parents who choose not to enhance their child can similarly do so for whatever reasons they see fit. No argument in this report depends upon the rationality or

⁸⁰ Davis, D. S.; "Genetic dilemmas and the child's right to an open future."

⁸¹ Presidents Commission for the Study of Ethical Problems ...", p. 56 quoted by Davis, D.S.; *ibid.*, p. 4.

⁸² Nance, W. E.; "Parables" in *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, ed. Bartels, D.M. (et al), Aldine De Gruyter, New York, 1993, p. 92 quoted by Davis, D. S.; *ibid.*, p. 3.

⁸³ Davis argues, for a variety of reasons, that deliberately causing a deaf child is a moral harm, but these reasons need not concern us here.

otherwise of that decision but rather, as we have seen, upon the responsibility to justify that decision.

To belabour the point, all the arguments in this report regarding the harm caused to parents by the institutional availability of GE who select not to enhance apply also to deaf parents who would select not to “enhance” their child to become deaf!

7. Conclusion

According to a BBC News Technology online post on 3 October 2013, a US patent has been granted for a Family Traits Inheritor Calculator that can “predict the risk of inheriting specific diseases as well as details such as height, weight, eye colour and even personality”.⁸⁴ According to the company, 23andMe, this for prospective parents “is an enjoyable way *to dip their toes into genetics*”.⁸⁵

Genetic enhancement technology will develop in ways that are unpredictable. It will develop without regard to the treatment-enhancement distinction. It will develop without regard to the harm caused to parents who enhance their children, nor to the children who are enhanced. It will develop without regard to the harm caused to parents who choose not to enhance their children.

This report highlights the negative implications that arise for parents that choose not to enhance their children when GE becomes available. It shows that rather than parental autonomy being enhanced by the choice of GE, it is diminished. This thesis is paralleled by the institutional availability of euthanasia and PGD and withstands the criticisms that may be levelled against it.

⁸⁴ The post is reproduced in its entirety in the Appendix. A subsequent post (BBC News Technology, 26 November 2013, <http://www.bbc.co.uk/news/technology-25100878>) reports that the US Food and Drug Administration has imposed a ban on 23andME offering personal genetic screening to the general public. The company continues to address the FDA’s concerns.

⁸⁵ Emphasis added.

8. Appendix

<http://www.bbc.co.uk/news/technology-24381149> referenced 5 October 2013.

23andMe's "build-a-baby" patent criticised

A US patent for a database that uses DNA testing to tell prospective parents which traits their future offspring may inherit has been criticised by experts.

23andMe says its Family Traits Inheritor Calculator can predict the risk of inheriting specific diseases as well as details such as height, weight, eye colour and even personality.

Couples send the firm a saliva sample to see what their babies might be like.

But critics have called the project "ethically and socially treacherous".

Designer babies

The patent suggests the database could also be used by fertility clinics to find appropriate donors.

But the Mountain View, California-based firm was quick to say this was no longer part of its plan.

"At the time 23andMe filed the patent, there was consideration that the technology could have potential applications for fertility clinics so language specific to the fertility treatment process was included in the patent," it said in a blog post.

"The company never pursued the concepts discussed in the patent beyond our Family Traits Inheritance Calculator, nor do we have any plans to do so."

Instead it described the tool for prospective parents as "an enjoyable way to dip their toes into genetics".

But critics remain concerned that such technology could be misused.

"It would be highly irresponsible for 23andMe or anyone else to offer a product or service based on this patent," said Marcy Darnovsky, executive director of the Center for Genetics and Society.

"It amounts to shopping for designer donors in an effort to produce designer babies.

"We believe the patent office made a serious mistake in allowing a patent that includes drop-down menus for which to choose a future child's traits.

"A project like this would also be ethically and socially treacherous."

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