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Choosing among possible persons: The ethics of prenatal selection in the postgenomic age



Choisir parmi des personnes possibles : l'éthique de la sélection prénatale à l'âge postgénomique

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ABSTRACT

The “spectre of eugenics” is often raised about various current reproductive practices that imply a form of choice between future possible persons. Some of these practices are linked to genetic technologies such as pre-implantation genetic diagnosis, others merely entail the choice of a procreator having specific traits, such as in artificial insemination with donor. The weight and limits of this reproof of eugenics are examined, with special attention to the conceptual problems resulting from confusing choices involving virtual persons with the selection of existing persons.

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R É S U M É

Le « spectre de l'eugénisme » est souvent évoqué au sujet de diverses pratiques procréatrices contemporaines qui impliquent une forme de choix parmi des personnes futures possibles. Certaines de ces pratiques sont liées à des technologies génétiques, comme par exemple le diagnostic préimplantatoire, d'autres se ramènent au choix d'un procréateur ayant certaines caractéristiques, comme par exemple l'insémination artificielle avec donneur. La portée et les limites de ce reproche d'eugénisme sont ici examinées, en particulier les apories qui résultent de la confusion entre les choix qui impliquent des personnes virtuelles et la sélection de personnes existantes.

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1. A casting mistake

In October 2014, the American and international press reported an interesting case of medical error, which happened in a rural Midwestern community. Two white women used the services of the *Midwest Sperm Bank* for donor insemination [1]. The lesbian couple chose the donor

on account of several characteristics that included the fact that he was white. There was a mix-up in semen samples and it turned out that the donor was black. The couple sued the sperm bank for damages. According to media reports, they did not have a problem with having a mixed-race daughter, whom they loved unconditionally. However, in the interest of their child's well-balanced development, they planned to move to a more open and ethnically diverse community and were suing to recover expenses linked to this change in living circumstances. The British

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daily *The Guardian* published a rather stern editorial entitled: “Designer babies? It looks like racism and eugenics to me.” [2].

Two questions spring to mind. Is the characterisation of these actions as racism and eugenics appropriate? To those tempted to answer in the affirmative, the next question would be: “Would the couple’s action have been evidence of racism and eugenics if these women had simply chosen a blonde, blue-eyed man to father their child *naturaliter*, without involvement of a professional service?” The question seems important in order to distinguish, as grounds for possible moral censure, the choice as such from its technological implementation.

This news item well illustrates the way the concept of eugenics operates within contemporary popular discourse and to some extent academic bioethical discussions as well. Yet there are obvious differences with the historical eugenics of the first half of the past century. The latter were based on the assumption that the State was justified in intervening intrusively in the field of human reproduction, with a view of discouraging the reproduction of “undesirables”, i.e. persons thus labelled by social or racial prejudice, as well as dominant medical ideologies. Outside of totalitarian countries such as Nazi Germany, the main tools of such endeavours were laws allowing for non-voluntary sterilisation [3]. In contrast, when the proverbial “spectre of eugenics” is being raised in connection with current reproductive practices, it refers to private actions that do not result from any collective policy or explicit guidance. This is why critics of current reproductive technologies often use the term “liberal eugenics”, implying a kinship between past and current eugenics, but transposed in the context of modern liberal democracies [4,5]. In the past, explicit, state-sponsored discriminatory or even murderous ideologies were openly implemented. In our day, the conventional wisdom is that implicit ideas about desirable characteristics of one’s offspring float around, unwittingly shaping the “free” choices of individuals and couples in a consumerist society. Denouncing a common wrong-making feature in both the old and new eugenics is a powerful rhetorical gesture. However, some technology-friendly authors bite this bullet and use the term ‘liberal eugenics’ approvingly, as referring to defensible choices, in reproduction for instance [6]. ‘Liberal eugenics’ also provides a useful general label to denote opinions that are favourable to extensive choices in reproduction and genetics (this is the terminological choice of the ‘eugenics’ article in the *Stanford Encyclopedia of Philosophy* [7]).

An implicit, unspoken idea seems to hover over many such controversies, namely that there is something wrong with wanting to give birth to one kind of child rather than another and that this intention, no matter how private and free of explicit pressure, is already tainted with the ugly brush of eugenics. However, there is an obvious limit to this moral disapproval: having children of a certain kind is an unavoidable secondary effect of choosing to have them with a particular person. After all, humans do not mate at random, as is the case for lower organisms in the models of elementary population genetics. As long as people fall in love with one another rather than with their

genomes, this should not be a major concern and we need not worry that every kind of reproduction is eugenic. Nevertheless, it seems that the eugenics “meme” has implications in many controversies involving the notion of choosing possible persons, with or without involvement of technology.

2. Eugenics, the spectre

In public and academic debates alike, the term ‘eugenics’ often operates as a mere term of moral blame. It is not rare that in journalistic or bioethical commentaries, one can replace “this is eugenics” by “I don’t like it” without much loss of meaning. Still, invoking eugenics as a means of moral disapproval may be defensible, if indeed arguments are advanced to defend it. To evaluate such claims, one approach would be to identify mentions of eugenics about current practices and to see what concrete ethical concerns are flagged in this way. This will be done here about pre-implantation genetic diagnosis (PGD).

As mentioned earlier, these debates reveal a degree of distrust towards such reproductive choices as are made explicit and deliberate by modern technology, whereas they were left to chance before. These misgivings seem particularly acute when such choices bear on gametes and embryos. Interestingly, when this choice boils down to the low-tech selection of a particular partner with whom to have a child, it seems less objectionable. This is a reversal from historical eugenics, which was focused entirely on the selection of “adequate” procreators. In contrast, the reproof of eugenics today conflates two aspects. On one hand it is “anti-choice” to varying extents. On the other hand it is critical of technology, evincing what one might call an “anti-promethean” moral stance. Critics often deplore what they see as the technological transformation of procreation into a kind of manufacturing, a shift away from the traditional view of the giftedness of life towards the hubris of controlling and designing future children according to predefined norms, and a loss of human virtues of humility and human solidarity in the face of fate. This is not exactly the same critique as one that would focus exclusively on the choice dimension, independently of the means, technological or not, of realising this choice. We will keep this distinction in mind as we examine the controversy over PGD. This diagnostic technique is discussed here because it has attracted much criticism explicitly referring to eugenics. In Switzerland as well as in some other European countries this anti-eugenic language was incorporated into legal reasoning [8].

3. The ethical and legal debate about PGD

In Switzerland, PGD was outlawed at the outset and is still illegal to this day. Parliament and the Federal Government are in favour of lifting this prohibition but this will require a change in the Constitution, no less. The Swiss people will eventually have to vote twice on this issue (the first vote, held in June 2015, was in favour of legalising PGD). Meanwhile, Swiss couples needing PGD travel to more permissive countries to obtain this service.

The arguments in favour of prohibition that have been influential are related to three types of moral concerns:

- the moral standing of the early human embryo;
- the moral disapproval of ‘liberal eugenics’;
- the ‘expressivist’ concern that PGD sends a derogatory message to persons with disabilities.

A recent statement of the Swiss Catholic Bishop’s Conference briefly touches upon each of these concerns, which will be examined in turn:

“Indeed a society does not become better when it allows itself to select those it considers to be ‘good ones’ and to eliminate the others. (...) The Church will never agree to consider the screening, the selection and elimination of human beings as a progress. (...) If one wants today to prevent the birth of children with disabilities at all costs, then persons with disabilities see their dignity called into question.” [9].

The moral standing of the embryo is an old problem where oft-refuted arguments are constantly rehashed, since the champions of “personhood from conception” never tire of flogging that particular dead horse. As did others, we have shown that considering early embryos as the moral equivalent of people raises unsurmountable difficulties, in part because the earliest stages of human development do not possess the biological underpinnings of numerical identity [10,11]. Furthermore, the search for a defined moment in prenatal development at which moral standing accrues to the embryo/foetus is probably a wild goose chase [12]. The quote above exemplifies a common rhetorical device used to suggest that the early embryo is somehow “one of us”, by talking vaguely about “human beings”. One could reconstruct the underlying reasoning in this and other similar pronouncements as follows [13].

Of an embryo whose fate depends on being selected or rejected on the basis of PGD, it can be said:

- 1) this embryo is a living being;
- 2) this living being is human;
- 3) therefore this embryo is a living human being;
- 4) but intentionally ending the life of a human being is forbidden (except in self-defense and similar cases);
- 5) therefore it is forbidden to intentionally end the life of this embryo.

The equivocation that makes this syllogism flawed is that “human” and “human being” have different meanings in proposition 2 on one hand, 3, 4, and 5 on the other. In 2, “human” is a taxonomic qualifier, stating that this embryo belongs to the species *Homo sapiens* rather than any other species. In 3, 4 and 5, the term “human being” is used as a synonym for a human person, with all its normative implications. The latter are simply smuggled in without proper explicit argument. Therefore, there is no plausibility to the view that selecting embryos on the basis of PGD is similar to choosing among pre-existing human beings,

who might have gone on living and who will be eliminated instead.

Selecting embryos is not like selecting persons. However, realising this makes the problem far more difficult, because it becomes much harder to grasp what is being selected. How about selecting *possible* persons? This harks back to what the bioethical literature calls the non-identity problem, which we will not revisit extensively here (see for instance [14]). It is however important to stress how deeply intuitions about “potential persons” or “possibly future persons” can be misleading. It seems that we cannot help thinking about such entities as somehow pre-existing as a kind of virtual reality. Elsewhere, I have called this the *Paradox of the Platonic Boarding Gate*:

“It is as though we believed implicitly that the souls of future persons are sitting at a kind of virtual boarding gate, holding their boarding passes for the journey towards terrestrial existence. They have every reason to be anxious: will next flight not be overbooked? (...) And what about health? Is a life heavily burdened by illness and/or disability still desirable? Is it better to live at all costs rather than wait for eternity at the boarding gate?” [15].

These pseudo-questions arise from the illusion that there exists a reservoir of personal identities that wait to be propelled into the world and into a physical body. Perhaps these intuitions are reinforced by the fact that in PGD, the substrates on which selection operates are embryos and ultimately DNA, genomes, “real stuff” that exists in physical reality, even though such entities embody potentialities for possible human beings. But these potentialities are just that: mere potentialities, and none of our moral intuitions pertaining to existing persons need to apply in this case.

4. Genes as *Fatum*, education as *forum*

Perhaps a more promising argument against pre-implantation selection would focus directly on the selection of potentialities as grounded in genomes. This seems to be the basis of Habermas’ disapproval of liberal eugenics and specifically of PGD [4]. Habermas makes a distinction between choosing genetic fates and influencing the destiny of one’s children by raising them into a specific culture and giving them educational opportunities that, perhaps unavoidably, manifest particular parental preferences. As long as these influences are not outright tyrannical or anti-social, they are acceptable since they are transmitted through dialogue and communication. In contrast, Habermas conceives of choosing particular genomes as an overbearing, ontologically irresistible influence. This is immoral because it represents a unilateral form of control-taking over one’s offspring. Once born, the child is subjected to a form of planning that she has no way of accepting or rejecting, unlike any educational programming that parents would try to impose. On this view, the immorality of liberal eugenics resides in the predetermination of a life plan for the future person, and the selection of a particular genome is supposed to embody this predetermination.

¹ The author’s translation from French.

Two objections to this line of argument spring to mind. The first relates to the concrete applications of PGD in the present and foreseeable future. PGD is only workable if there is a clear genetic basis for whatever condition is being selected against. Furthermore, the selection has to operate on the necessarily limited number of embryos available in a cycle of in-vitro fertilization: the more traits one selects, the lower the probability that any of the available embryos will pass muster. In current practice, this limits the scope of selection to a set of grievous monogenic disease rather than other genetic traits. In addition, the panel of genetic diseases actually investigated is also limited by the low number of embryos, so that whatever genetic diagnosis is performed by PGD will have to be tailored to the particular genetic risk of the couple contemplating the procedure. As a result, the selective element in PGD really amounts to avoiding a few catastrophic diseases rather than the imposition of a defined life plan. Moreover, to equate the fact of not choosing a very serious disease or disability with an authoritarian deprivation of opportunity is quite implausible.

The second problem with the anti-PGD argument presented above resides in the conception of the genome that it presupposes. This “genomic metaphysics”, which we have criticized elsewhere [16,17], associates genes with the defining, unchangeable characteristics of a person and fuels a representation of the genome as an embodiment of one’s “true” nature. Genes are destiny, *fatum*, whereas postnatal phenotypic influences such as education are a matter of communicative action, in the *forum* of genuinely human exchange. The genome is thought of as an irresistible, unanswerable inner voice, whereas education is on the side of culture, dialogue and freedom. However, this radical ontological opposition is rather simplistic. Genomes are not deterministic life plans, if only because the biological traits that they control are usually far upstream from the sort of personal characteristics that are relevant to biographical choices. Nor are postnatal influences necessarily benign. Many oppressive cultural and educational practices restrict a child’s opportunities far more heavily than any genetic selection through PGD will ever achieve.

Perhaps the morally most complex and politically most powerful objection to PGD is the expressivist objection, which states that PGD and other prenatal diagnostic or screening procedures send a discriminatory and offensive message to persons with disabilities [18]. In effect – so the objection goes – these procedures undermine their dignity by implying that lives without their disability would be preferable and that it would have been better (for whom?) if they had not been born. This objection has many ramifications that cannot be explored here, not even sketchily. The objection’s weight partly hinges on the distinction between illness and disability and the extent to which disabilities and illnesses can be seen as part of one’s core identity [19]. Moreover, the discourse of disability studies has given credence, at least in academic circles, to the identity view of disability, i.e. the notion that disability, far from being objective, is essentially a relational feature resulting from society’s typically inadequate response to

bodily impairments. This view fosters an ongoing polemic with biomedical and bioethical discourse on this subject (see, for instance, [20]). However, it can be argued that the dogma of the social construction of disability has impoverished our factual and ethical understanding of biologically-defined impairments and of the genuine misfortune that many of them represent. As a result of this denialist stance, the very idea that the occurrence of such impairments is worth preventing, also when they supervene on the existence of future possible persons, becomes ethically obscure and perhaps even politically incorrect. Yet this is precisely the ethical argument that needs to be made. In addition – and less controversially – the right to make autonomous reproductive choices must trump the ideological harms flagged by the expressivist objection [19]. In the end, it is hard to see why reproductive autonomy should be incompatible with the effort of addressing seriously the concrete harms of discrimination against people living with disabilities.

5. Postgenomic selection?

Much of the moral objections to selecting possible persons through PGD are based on an essentialist conception of the genome, which sets genetic causation apart from the many causal chains that contribute to shaping future persons. Also, this genome-as-identity view converges with the identity view of disability and reinforces incorrect intuitions that selecting against impairments is substantially analogous to selecting against some kinds of people. Once these essentialist understandings are critiqued, their ethical consequences are less plausible. Still, one should anticipate successor technologies to PGD, which could conceivably allow more intrusive genetic selective practices in the future.

One candidate technology is non-invasive prenatal testing (NIPT), which is based on the discovery that there is free foetal DNA in the bloodstream of pregnant women, detectable as early as seven weeks of pregnancy [21]. Diagnostic use of this discovery has been made possible by considerable progress in DNA sequencing technology together with vastly more powerful bioinformatics methods for the interpretation of data. At present, routine NIPT is limited to specific cytogenetic analyses (detection of trisomy 21, 18, and 13) rather than genetic tests strictly speaking. Furthermore, in the way it is implemented today, it is used as a screening test that still requires invasive confirmatory testing (such as amniocentesis) in cases where NIPT returns an anomalous finding. Nevertheless, it is anticipated that the increased analytical power that genomics currently brings to the assessment of genetic disease in children and adults will eventually be applied to NIPT. This would make NIPT a more powerful technology than PGD because it does not rely on in-vitro fertilization. On the other hand, this very advantage, i.e. the fact that NIPT is applicable to normal pregnancies, limits its use as a selective procedure, since only one pregnancy at a time can be tested. One ethically troubling aspect of PGD is the fact that several embryos exist simultaneously and one or two of these co-existing embryos is selected. However, this selective aspect is less prominent in prenatal testing,

unless one believes that NIPT would foster the notion of a “tentative pregnancy”, a focus of controversy that was already present on the topic of amniocentesis in the early days of prenatal genetic diagnosis [22]. The fact that a single foetus is usually being tested at a time makes NIPT a kind of self-limiting technology, albeit for a different reason than for PGD (for the latter, the self-limiting aspect is the fact that presumably fertile couples must use in-vitro fertilisation). Nevertheless, NIPT is not a mature technology. Since its future developments are difficult to anticipate with any accuracy, continued bioethical attention is certainly warranted.

Disclosure of interest

The author declares that he has no conflicts of interest concerning this article.

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