Special Section: Open Forum

Right Problem, Wrong Solution: A Pro-Choice Response to "Expressivist" Concerns about Preimplantation Genetic Diagnosis

COLIN GAVAGHAN

In August 2005, the United Kingdom's Human Fertilisation & Embryology Authority (HFEA) launched a public consultation, seeking views on the use of preimplantation genetic diagnosis (PGD) for the detection of cancer genes.[1] The issue was considered by the Authority to be a possible source of particular controversy because it involved extending the range of conditions for which PGD can be licensed in a potentially important way: As well as testing for genes that would *definitely* cause disease traits, such as cystic fibrosis and muscular dystrophy, this would involve genes that would only *possibly* manifest themselves phenotypically. In other words, there is a very real chance that such an application of PGD would result in the destruction of perfectly healthy embryos.

Aside from the possible danger of "false positive" results, this further extension of PGD seems likely to provoke a range of familiar responses to the technology. On the day that the consultation was launched, Josephine Quintavalle, Director of Comment on Reproductive Ethics (CORE), argued on CORE's web site: "We are looking at issues which go to the heart of our attitudes to disability, and the offensive message that is sent in this instance is that the disabled or sick are better off not being born."[2]

Although CORE's underlying agenda may plausibly be suggested to owe more to a concern for protecting the embryo than with possible harm or offense to disabled or sick people,[3] Quintavalle's comment is resonant of a particular species of objection to PGD and similar techniques, a species of objection directed at what is deemed to be a judgment inherent in such techniques about the value of certain lives. Sometimes described as "expressivist" objections,[4] these have proved some of the most genuinely troubling for proponents of a liberal approach toward PGD. Although some objections to PGD, and biotechnology more generally, rely on religious or conservative views about the "naturalness" of reproductive technologies[5] or the status of the embryo,[6] and others rest on philosophically questionable fears of harm to the resulting children,[7] the expressivist objection raises a concern that transcends political or religious views. Furthermore, the threat of which it warns is posed not to hypothetical future people or nonsentient embryos, but to living people with actual rights and interests.

In this article, I hope to show that advocates of a pro-choice approach to PGD need not and should not disregard concerns about the effects of this technology on disabled people. However, it is by no means clear that the best way of addressing such concerns lies in stricter regulation of reproductive technolo-

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gies. On the contrary, it may be that, in seeking to limit the use of PGD to scenarios where there is a real risk of genetic disability or illness, bodies like the HFEA are, in fact, reinforcing the negative messages about which advocates of the "expressivist" position are justifiably concerned.

Disability-Oriented Objections to PGD

Not all concerns about the effect of widespread use of PGD on disabled or ill people are properly regarded as expressivist in character. Indeed, it may be the more substantial body of disability-oriented arguments are of a substantially different sort. Before scrutinising the differences, though, it is perhaps informative to consider the common factors shared by all such arguments.

Although they differ in other respects, all the objections considered here proceed on the basis that, however widespread the use of PGD eventually becomes, there will continue to be *some* disabled people in our society. Otherwise, these objections would be meaningless; what would it mean to worsen the situation of disabled people in a society in which there are no disabled people?

Obviously, PGD will not eliminate the possibility of disability through accident (including injuries sustained at birth), but it is also overwhelmingly likely that, even as PGD becomes more accurate, it will remain imperfect; some genetic disabilities will "slip through the net." Furthermore, it is also highly improbable that a situation will arise where every prospective parent will wish to utilize PGD. A Public Consultation carried out jointly by the HFEA and the Human Genetics Commission, the results of which were published in November 2001, revealed that 30% of individual respondents were opposed to PGD in general,[8] whereas 8 of the 20 respondents "who indicated some experience of disability, including carers, families as well as disabled individuals themselves"[9] voiced general opposition. Even in Andrew Niccol's science fiction dystopia *Gattaca*, which imagines a society wherein the use of PGD is all but compulsory, some nonconformist parents elect to entrust their children's genes to chance, having what are regarded as "faith babies."

For those who regard human life as acquiring full moral status at conception, the use of IVF deliberately to create more embryos than will ever become children is itself ethically problematic, irrespective of how the decision is made as to which of them to implant. Such people, it may be presumed, will never utilize PGD technology. Furthermore, some of the very people whose concerns this article explores—those disabled people who object to the use of PGD to "screen out people like them"—may prefer in most cases to entrust the genetic endowment of their own children to chance or occasionally to make more surprising choices about how to use PGD.

A second common factor among the otherwise varied disability-oriented arguments is the belief that a pro-choice approach to PGD will cause harm or offense to those disabled people already alive or who will continue to be born. This "harm" may be relative to (a) their present status, (b) the "able-bodied" population, or (c) some notion of what their status *should* be in a future society; how we respond to such claims may depend very much on which of these adverse comparisons is being postulated.

In other respects, though, the various disability-oriented arguments differ substantially. For the purposes of this analysis, I have suggested a fairly

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simplistic division into what I have termed objective and subjective concerns; it is only to the latter that I apply the epithet "expressivist,"[10] and it is predominantly to those that the major part of my argument applies, but I shall nonetheless attempt, where appropriate, a limited response to the objective concerns.

Objective Harms

Perhaps the most concrete species of possible harm relates to the actual impact of widespread PGD on the status and prospects of the disabled within society. This involves an objective determination—whatever they might think, their position actually *is* weakened. The most straightforward suggestion is that a reduction in the numbers (either absolutely or as a proportion of the population) of persons affected by particular conditions will reduce the perceived importance of finding cures, treatments, or ways to improve the lives of those remaining affected persons. As regular commentator on disability issues Tom Shakespeare says:

> [A]s a condition becomes rarer, the impetus to discover a cure or treatment diminishes. This reinforces my wider feeling, that genetic screening will never be total, which means that the proportion of congenital impairment may be reduced, but not eliminated, which means that disabled people will be further isolated, face increasing prejudice, and the pressure to make society accessible to all will be reduced.[11]

This is what Allen Buchanan has deemed the "loss of support" objection.[12]

Shakespeare offers no empirical evidence in support of his contention that such a reduction would lead to a diminution in support, but his thesis is not implausible. Is it, we might reasonably wonder, likely that millions of pounds of research funding would be given over to the investigation of potential treatments for conditions that affect only a handful of people? Is it likely that buildings and buses would have been rendered "wheelchair accessible" if there were but a few dozen wheelchair users?

It is also, however, possible that in certain practical respects, the position of some existing disabled people (or those who will nonetheless come to exist) may be improved by a reduction in the number of similarly affected people. A condition (such as cystic fibrosis) that may require access to kidney dialysis or to organ transplantation will often see affected parties forced to "compete" with other candidates for scarce resources. Their chances of receiving treatment, we might reasonably expect, will improve in inverse proportion to the number of similarly affected individuals who are also vying for those resources.[13]

Even were we to accept, though, that the position of existing affected people will, on balance, be weakened by preventing the birth of similarly affected people (and it is quite possible that their position could be weakened in some respects, while being strengthened in others), this does not inevitably lead us to any particular conclusion as to how this "harm" should be redressed. We might consider that the fear of a loss of support to existing disabled persons could, and should, be met by guarantees of support, not necessarily by requiring reluctant parents to add to their numbers.

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Furthermore, as several writers have noted, if the "loss of support" concern is deemed to outweigh all other concerns or interests, it seems to have implications beyond the issue of genetic testing; for reductions in the numbers of disabled persons might be brought about just as surely by workplace safety laws[14] and treatments that cure, rather than "screen out," those affected by disabling conditions.[15] Does the "loss of support" argument require that we abandon such initiatives and treatments?

In pointing to such extreme (and perhaps absurd) consequences, it is not my intention to ridicule or trivialize the concerns that underpin the "loss of support" position. It is entirely plausible that people affected by uncommon disabilities face all manner of obstacles that would be made easier were there more similarly affected people.[16] But it is surely obligatory to consider whether there are other, less restrictive ways in which the lot of such people might be improved before taking the extreme step of abolishing health and safety laws or requiring reluctant parents to give birth to severely handicapped babies.

Subjective Harms: Causing Disabled People to *Feel* Devalued

If the concern is about how existing disabled persons will feel in the face of this technology, then the measurable impact, in terms of reduction in political strength or public sympathy, may be less relevant than the personal, subjective testimony of actual disabled people. And there exists ample evidence of distress and offense in the face of the perceived message that, as one commentator put it, "some of us are 'too flawed' in our very DNA to exist; we are unworthy of being born."[17] To evaluate this concern, it is necessary to consider who, precisely, it is that is thought to be sending this message. For the purposes of this discussion, I have considered separately the suggestions that (a) it emanates from parents, and (b) it emanates from "society."

By Their Parents

Marsha Saxton has made some obviously deeply personal contributions to several collections on reproductive technologies. In one chapter, she recalls her own first exposure to the choices posed by the existence of prenatal testing:

> I remembered the spina bifida newsletter when I first read about the AFP [alpha-feto protein] test available to detect spina bifida and other neural tube defects. I remember having mixed feelings. Could I choose to abort a baby with my own disability, end the life of someone somehow an even closer kin to me than my own child? . . . Another thought emerged: if this test had been available to my mother I might never have been born.[18]

The last sentence seems to describe a sort of psychological anguish arising from a sort of counterfactual parental rejection. If my mother had had the option of this test, Saxton seems to be saying, she would have rejected me.

A similar sense of hurt has been expressed by Deborah Kent, who has written of her disappointment in the face of the reactions from her parents and husband at the prospect of giving birth to a child that shared her genetic blindness:

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> I feel that I have failed when I run into jarring reminders that I have not changed their perspective. In those crushing moments I fear that I am not truly accepted after all.[19]

It is not difficult to understand how such a belief—that their very existence was a result only of their parents' lack of choice and that, given that choice, they would have been rejected—could be painful to anyone who values their relationship with, and the esteem in which they are held by, their parents. Does this, then, provide a concrete example of harm caused by PGD (or, as in Saxton's scenario, to prenatal tests)?

There are, I believe, at least three possible responses to the "rejection" concern that, although not necessarily allaying all of the concern felt by people like Saxton and Kent, at least give pause with regard to the coherence of those concerns or their direct relevance to a liberal approach to PGD. First, it might be pointed out that, in one way or another, most of us owe our existence to the lack of choice open to our ancestors; had sex education, effective contraception, and perhaps the notion of female reproductive autonomy been available to the generations that preceded us, it is more than likely that, somewhere in our genetic lineage, an ancestor would have elected not to have as many children, not to have children at precisely that time, or indeed not to have children at all, with the result that *we* would never have come to exist. Presumably, few of us would consider that this provides a reason for denying those choices to women today.[20]

Should this realization prove comforting to those who, like Saxton, are concerned about what her mother might have done had prenatal testing been available to her? Perhaps she might retort that, while my ancestors may indeed have elected not to have a child, or another child, or a child at that precise time, they would not have been rejecting *this particular child*, and certainly not on the grounds of certain characteristics that this child possessed. This is the position adopted by Theresa Degener—

> Of course, the non-selective abortion of a pregnancy that was undesired from the start also views the fetus as a burden, but this evaluation is not based on an individual characteristic of the potential child, but on aspects that are unrelated to the fetus, such as the woman's living conditions and the way she wants to lead her life. The special character of selective abortion lies in wanting to opt for a so-called norm(al) child and reject a disabled child.[21]

—and is what Adrienne Asch has deemed the "any-particular distinction": whereas "most abortions reflect a decision not to bring any fetus to term at this time . . . selective abortions involve a decision not to bring this particular fetus to term because of its traits."[22]

Are Degener and Asch right to assume, though, that a decision to "screen out" a disabled embryo is unique in its implicit negative connotations about certain existing children? Are decisions to avoid the birth of a fifth or sixth child, a child born into conditions of poverty, or, as in Parfit's famous example,[23] a child born to a girl too young to look after it properly devoid of any such connotations? In exactly the same way as, for Saxton, the decision to avoid the birth of disabled children constitutes a rejection of, and affront to, existing

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disabled people, do not these other decisions tacitly imply negative evaluations of children born into large families, into poverty, or to young teenaged mothers?[24]

Those who agree with Saxton, then, must demonstrate why a decision to avoid the birth of a disabled child sends an emotionally harmful message to existing disabled people, whereas a decision to avoid the birth of a child into difficult social or economic—as opposed to genetic—circumstances does not send an analogous message to poor families, large families, or families with very young mothers, all groups who are already, to some extent, the subjects of social stigma.[25]

The second objection takes issue with the assumption that, in opting not to give birth to a disabled child, prospective parents are devaluing life with disability. Hans Reinders has suggested that it is possible for prospective parents to screen out (or abort) an embryo (or fetus) with a particular condition without making a discriminatory judgment about people with that condition:

> If a couple after having had a prenatal test decides to abort the fetus because it is affected by Down [*sic*] syndrome, they can justify this decision by referring to what they think they are capable of in raising a family.[26]

As Allan Buchanan notes, there may be a number of reasons why parents wish their children to possess certain traits that do not necessarily presuppose a discriminatory attitude against those who lack them: "One may wish to avoid serious strains on one's marriage, on one's ability to fulfill responsibilities to one's other children, or on scarce social resources."[27] Furthermore, prospective parents may simply wish their children to share certain of their own characteristics, perhaps in pursuit of some kind of "genetic immortality," perhaps because they simply feel that they will be more easily and happily assimilated within the existing familial environment if they do.[28]

An interesting, though controversial, example of such a desire for similarity was the well-publicised attempts by Candy McCullough and Sharon Duchesneau to ensure their child was "deaf like them."[29] Such attempts did not presuppose a belief that the life of the hearing was in any sense inferior to that of the deaf, merely that their lives are sufficiently different to constitute a barrier to sharing certain of the same experiences as their parents.

Whatever the precise reason, there may be a number of possible explanations for parents preferring a child with certain qualities, none of which involve a generalized assumption of inferiority of those without those qualities. In the case of those traits conventionally regarded as "disabilities," the reason may simply be a recognition, or belief, that they themselves lack the financial, physical, social, or emotional resources necessary to raise such a child; they may be recognizing their own limitations, rather than deeming the child as "substandard" or "unfit to live."[30] As Degener notes,

> there is as little harm in wanting to have a nondisabled child as there is in wanting to have a disabled child. . . . It is only when this wish for a nondisabled child is declared universal and it becomes mandatory to resort to supposedly infallible technological means to ensure that it is fulfilled that it becomes a danger and a duty.[31]

The third possible response to Saxton's objection is that, whether or not the choice of PGD is made available to today's potential parents, she will nonethe-

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less have to confront the evidently uncomfortable possibility that, had she had a choice, her mother might have opted for an abortion. At most, denying the option of PGD to another generation of potential parents will simply give rise to another generation like Saxton who will wonder, with varying degrees of emotional discomfort, what their parents might have done had they had the choice.

By "Society"

The view that "society" is sending a negative message to disabled people is well summarized by Susan Wendell. In *The Rejected Body*, she addresses the issue of prenatal testing, followed by abortion of any fetuses found to be disabled:

> [T]he widespread use of selective abortion to reduce the number of people born with disabilities . . . sends a message to children and adults with disabilities, especially people who have genetic or prenatal disabilities, that "we do not want any more like you."[32]

In a similar vein, Reinders observes that

> it appears as though our society is simultaneously sending two messages to the disabled and their families. The first message says, "Since you're here, we're going to care for you as best we can," but the second says, "But everyone would be better off if you were not here at all."[33]

while Bill Albert of Disabled Peoples' International has argued that "No one should have to live . . . in a society which values them so little it makes a social and medical virtue out of eliminating people who might be like them."[34]

Is it necessarily true, though, that "screening out" of certain genetic conditions implies a devaluing of *people* with those conditions? Attempts to eliminate smallpox, leprosy, or rickets were not taken to imply that those affected by such conditions were devalued, and it is unlikely that they regarded attempts to eliminate such diseases as offensive. As Reinders says,

> If research to eliminate cancer does not imply an attitude that supports discrimination against persons who suffer from this disease, why should clinical genetics be different?[35]

Reinders calls this the Distinction between the Person and the Condition (DPC) argument, according to which, "The charge of negative evaluation is completely unjustified, therefore. It is based on the false identification of persons with their conditions."[36]

As he goes on to acknowledge, though, whereas it is possible to destroy cancer cells while leaving alive those persons who were affected by them, the same cannot be said of screening out genetic disorders, where the only means by which the disorder can be avoided necessarily involves "avoiding" the person as well.[37] In other words, it is not simply the disorder that is being rejected, but the whole package of person-plus-disorder. As Edwards has written,

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> That there could be an "identity constituting" relationship between disability and identity is something which those who dismiss the expressivist objection rarely consider.[38]

This, perhaps, is distinct from attempts to eliminate somatic (or even treatable genetic) disorders.

Even were we to agree with Edwards about the "identity constituting relationship between disability and identity," it does not obviously follow that this should be restricted to disability that is genetic in origin. Rather, there is at least a plausible case for believing that other conditions, particularly those that act upon the brain, might also be thought to be "identity defining." This possibility has at least been seriously considered by a number of bioethicists in relation to conditions such as Alzheimer's disease.[39] Indeed, at least one author would argue that this expressivist objection could be applied to practically any attempt to "cure" a disabling condition, genetic or otherwise:

> If abortion on the basis of prenatal diagnosis sends a "we don't want your kind here" message, why would therapeutic interventions not do so as well—and the more successful the therapies are, the more effective the message? . . . If testing and abortion militate against social acceptance of disabilities as examples of human variation, why would testing and treating not do so as well?[40]

For present purposes, it is not necessary to consider precisely which disabling conditions might properly be regarded as "identity defining," and therefore to come within the ambit of the expressivist objection. It is sufficient that we consider seriously the possibility that some—those that impact most severely upon cognitive functioning, awareness of self, memories, and aspirations—can be said to be so. A treatment for Alzheimer's disease would result in a society where "different" people existed than one where Alzheimer's is not cured. If this is true, then attempts to eliminate Alzheimer's may well carry an implicit statement devaluing or rejecting those affected by the disease. Can we therefore conclude that society devalues or disrespects or rejects those with late-stage Alzheimer's?[41]

It might be thought, then, that the analogy between genetic screening and attempts to reverse the effects of plausibly identity-defining conditions such as Alzheimer's disease is stronger than some exponents of the expressivist objection seem to recognize. If this is so, then if we conclude that genetic screening sends a negative message to existing disabled people, then this must be equally true of existing mentally impaired individuals when we pursue "cures" for their conditions, "cures" which, I suggest, would replace them with different persons just as surely as PGD. If, on the other hand, we do not regard these efforts as implicitly devaluing existing mentally impaired individuals, then neither should we regard PGD as implicitly devaluing those affected by genetic disorders.

In this view, then, "screening out" certain conditions does not, or need not, send out a negative statement to anyone, by anyone, or in any event at least no more so than an attempt to cure a disease such as Alzheimer's. Even if this view is rejected, however, there exist a number of other reasons to doubt that a pro-choice approach to PGD would communicate a negative value judgment to the disabled.

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To evaluate the contention that the use of PGD involves an offensive "societal" message to disabled people, it is necessary to consider who or what "society" describes in this context. There are probably many different senses in which this term may be employed, but two in particular seem relevant to the present discussion. First, "society" may be thought to apply to those individuals and bodies entrusted, elected, or appointed to make decisions in the interests of the populace as a whole, while at the same time presumably safeguarding the rights and interests of minority groups or individuals within that populace; for the purposes of this debate, "society" might be thought to be embodied in the decisions of Parliament, of the courts, and of the HFEA.

The second sense in which "society" might be thought to send any sort of message might take an even more direct form, as when individual women or couples made the same sorts of decisions in sufficient numbers to communicate a single message to a particular section of the population, in this case "the disabled." If the majority of women or couples faced with a choice elected to screen for and reject embryos affected with cystic fibrosis, this might be thought to convey a negative message to those living with CF as to how they are viewed by, and the extent to which they are valued or accepted within, the society in which they live.

This latter conception may be dealt with in similar terms that I employed in addressing the objection in the preceding section. Disability activists like Marsha Saxton already appear (not implausibly) convinced that unrestricted and widespread access to PGD would result in negative judgments about certain traits becoming the norm in practice. Yet if it is this judgment—not by any state or executive agency, court or regulatory body, but by individual potential parents—that is offensive or devaluing to existing disabled persons, then we must ask whether we offer much solace by denying access to the means of implementing or demonstrating that judgment. Presumably some disabled persons will still be aware, or at least highly suspicious, that such attitudes exist and that the only reason they are not routinely implemented is that "society" in its other conception—the legislature, the courts, and the regulatory bodies—prohibit them from being so.

Indeed, it is perhaps not unlikely that those denied access to what they now recognize to be a technologically possible option may demonstrate their value judgments in other forms, for example, by lobbying the legislature, appealing to the courts, writing to newspapers or—as in the case of the Whitaker[42] and Masterton[43] families—traveling to less restrictive jurisdictions to give effect to their choices. Perhaps most straightforwardly, it might be assumed that opinion polls and public consultations will continue to demonstrate wide public sympathy for abortion on the grounds of serious fetal abnormality and PGD for "serious inherited conditions,"[44] a response that presumably conveys quite unambiguously the sort of value judgment some disabled persons find offensive.

The notion, then, that we could prevent "society" in the sense of the aggregate of potential parents from communicating negative value judgments by restricting their access to PGD is, I suggest, conceptually flawed, because it is likely that those values will continue to be expressed in other forms and through other media, and because it is likely that the more sensitive of observers will continue to *suspect* that such values exist in any event. The only way in which "society" in this sense could avoid the infliction of the offense that lies in the mass rejection of disabled embryos would be by exercising that

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choice in a manner that does not devalue such embryos. Depriving them of that choice, at best, does no more than mask the offensive judgment or more accurately—and perhaps more significantly—one of many possible manifestations of that offensive judgment.

What, then, of the role of "society" in that other sense, that is, as embodied in the decisions, permissions, and proscriptions of its decisionmaking bodies? Here, the response offered to the first sense of "societal" criticism seems to have less validity. I have suggested that a ban on certain uses of PGD may do little to reassure disabled persons that they are not being devalued by the "community of potential parents," because the only thing preventing them from acting according to those judgments is a system of legal restriction. Presumably, though, the same thing cannot be said of the authors of these very restrictions. If lawmakers elect to draw a line, permitting PGD for certain genetic traits or conditions but not for others, it is easy to see how this could be seen as a value judgment as between those traits or conditions. As Parens and Asch have said:

> Enlisting medical professionals to list the conditions approved for tests and exclude others as "not serious enough or burdensome enough" turns individual, private, parental decisions into socially supported ones. Also, it increases the likelihood that an explicitly devaluing message will be sent about people whose conditions are listed as "serious enough to avoid."[45]

At present, the HFEA allows PGD for the purpose of avoiding cystic fibrosis, but refuses to allow it for, say, avoiding a child with brown rather than blue eyes. Assuming that the debit side of the equation—the reasons *against* allowing PGD, such as the intrinsic value attributed to the embryo or the dangers inherent in the procedure—remain constant in both decisions, the justification for the differing response to these two uses of PGD must reflect a particular judgment as to the desirability of avoiding, respectively, children with CF and children with blue eyes. This judgment may rely on beliefs about the burdens such children may themselves experience, the burdens their births will impose on their parents, or the contribution they will be able to make to their "society," but it seems that some such belief is implicit in this act of line-drawing; and it is precisely in such beliefs that commentators like Saxton and Wendell discern an offensive message.

Supposing, however, that the role of "society" (as embodied in the legislature or the HFEA) in the decision of which traits to "screen out" was wholly value neutral; that is, if the choice were entirely that of the prospective parents. In such a circumstance, we could reasonably conclude that "society" sends no message to anyone, beyond the message that it is willing to respect the individual choice of individual potential parents in such matters. (The question of the extent to which it should adopt a facilitatory or enabling role, providing the means for prospective parents to make such decisions, is an important one that lies outside the remit of this article.)

Is the role of society in such decisions really as passive as this contention seems to require? At present, in the United Kingdom, this is certainly not the case; the availability of PGD is strictly curtailed by the terms of the Human Fertilisation and Embryology Act and by the requirement of licensing by the Human Fertilisation and Embryology Authority. PGD is available only for

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those traits the Authority permits, and to date it has sought to restrict this to those likely to pose "a significant risk of a serious genetic condition being present in the embryo."[46] Furthermore, it has explicitly excluded screening on the grounds of embryonic sex and—initially—for HLA compatibility alone.

What message does the Authority send out when it restricts the use of PGD in such a manner? All other considerations aside, it assuredly sends the signal that choices about PGD are not wholly private matters, to be arrived at by the prospective parents alone. As Reinders has said:

> Society does not allow us absolute freedom in any area of social life. . . . Free choice, therefore, is always restricted to publicly acceptable uses of freedom. . . . Consequently, if society accepts the prevention of disability as justified, it is because and only because it is regarded as a legitimate use of personal freedom.[47]

PGD, then, will be permitted only where there is a sufficiently compelling justification. But it is important to consider the possible implication of restricting PGD to "serious genetic condition[s]." If there is merit in the objection that "society" sends out negative signals to disabled persons when it allows prospective parents to screen them out of existence, then how much reinforced is that message when "society" expressly prohibits every other kind of screening?

I have argued elsewhere that the HFEA's approach to tissue typing was premised on a questionable interpretation of established ethical principles, and that it was, ultimately, spurious.[48] The important point for present purposes, however, is that the HFEA clearly regarded the use of PGD in the Hashmi case as being for the benefit of the future child; were this not so, then the fact that its use by the Whitakers would *not* benefit their future child would not amount to a significant distinction. Given that there was no prospect of curing beta thalassaemia, this could only be taken to mean that the potential future Hashmi child possessed some kind of interest in avoiding being born with the burden of this disease. Yet what message does this decision send to Zain Hashmi or to others who live every day with that same illness? A clearer example of PGD sending a societal message that "it would have been better had you not been born" would be hard to find.

If, in contrast, Parliament and/or the Authority were to permit any prospective parents to screen for *any* trait, whether or not it is associated with what is conventionally seen as a "disability," then it would be possible to argue that the value "society" is upholding is that of reproductive choice, whatever that choice may be. With regard to the specific traits that prospective parents might desire or reject, they could with some plausibility argue that they are entirely neutral; it would, after all, be difficult to argue that "society" was implicitly devaluing the "disabled" if it allowed couples like Duchesneau and McCullough to select genetically deaf embryos for implantation.

Clinical geneticist Angus Clarke espoused what is probably the orthodox line with regard to PGD when he wrote that "society must determine what types of disorder are sufficiently severe to warrant prenatal-screening programmes with the termination of "affected" pregnancies."[49] However, in allowing screening only to eliminate conditions deemed "sufficiently severe," it may be that some validity is accorded to the arguments of those who, like Marsha Saxton, feel that their society is making a statement that they are unwanted. The state's acceptance of PGD to screen out CF, Duchenne muscular dystrophy, or beta

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thalassaemia embryos would, perhaps, seem less value laden, less offensive, perhaps even less sinister to those living with such conditions were it also to accept the use of PGD to screen out embryos who had blue eyes, who were boys, or who had normal hearing, however much media hysteria was generated by such choices.[50]

The media response generated by the HFEA's 2005 consultation on genetic testing for cancer genes was predictable in its hyperbole, and it was not long before allusions were being made to "eugenics." But although it might be thought that an analogy between an optional test such as this and the coercive measures that accompanied the worst excesses of the eugenics movement is somewhat strained, there is a sense in which the United Kingdom's present approach to PGD might be thought eugenic in character. When law and policy restrict the use of PGD to the avoidance of children with genetic defects, denying it to those with other values and priorities, it becomes at least arguable that our approach to this technology, far from being driven by an agenda of promoting individual choice and respecting diversity, is underpinned by judgments about the value of those lives that are avoided. It is scarcely surprising if those affected by genetic illnesses or disabilities, or those who care about or for such people, look with some offense and suspicion at those laws and policies.

It is my contention, though, that their concerns could better be addressed by loosening the regulations applicable to PGD, thereby allowing those like Sharon Duchesneau and Candy McCullough, Alan and Louise Masterton, Michelle and Jayson Whitaker, or any other prospective parents to utilize this technology to implement their own values and preferences. In so doing, we might avoid the imposition by the state of a single, simplistic view of what constitutes "normality" and "disability," a view that is clearly not universally shared. The appropriate response—from the state, from the public, and from the Authority itself—to the HFEA's question about the desirability of testing for cancer genes should be: "We hold no view on this, other than that prospective parents should be permitted to make informed choices for themselves, free from coercion, and safe in the knowledge that whatever choice they make will be respected and supported." Nothing, I submit, could be further removed from the pernicious taint of eugenics.

Notes

1. Should embryo screening help parents prevent passing on a wider range of inheritable diseases? 2005, Aug 11. Available at: http://www.hfea.gov.uk/cps/rde/xchg/SID-3F57D79B-0D0A79FB/hfea/hs.xsl/1107.html.
2. Kill the carrier? New HFEA consultation. 2005, Aug 11. Available at: http://www.corethics.org/document.asp?id=cpr110805.txt&se=2&st=4.
3. Gavaghan C. "Pro-life" tactics on tissue typing. *BioNews Commentaries*, 2003, Apr 15. Available at: http://www.bionews.org.uk/commentary.lasso?storyid=1642.
4. See, for example, Edwards SD. Disability, identity and the "expressivist objection." *Journal of Medical Ethics* 2004;30:418–20; Scott R. Prenatal testing, reproductive autonomy, and disability interests. *Cambridge Quarterly of Healthcare Ethics* 2005;14(1):65–82.
5. Conservative commentator Francis Fukuyama, who has recently turned his attention to biotechnology, has written of "a desperate need for philosophy to return to the pre-Kantian tradition that grounds rights and morality in nature." *Our Posthuman Future: Consequences of the Biotechnology Revolution*. New York: Faber, Strauss and Giroux; 2002:112. Another eminent "biocon," Leon Kass, has regularly argued along the lines that "[s]eeking to escape entirely

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from nature (in order to satisfy a natural desire or a natural right to reproduce!) is self-contradictory in theory and self-alienating in practice." The wisdom of repugnance: Why we should ban the cloning of human beings. *New Republic* 1997;216(22):17–26. Available at http://www.pbs.org/wgbh/pages/frontline/shows/fertility/readings/cloning.html.

6. See note 5, Fukuyama 2002:91.
7. Such fears often fail to consider that, for the children born as a result of PGD, the alternative was not a more "normal" conception, but rather, nonexistence. This argument found its most famous expression in Derek Parfit's hypothetical case of the 14-year-old girl; *Reasons and Persons*. Oxford: Clarendon Press; 1984:357–61. See also, inter alia, Roberts MA. Present duties and future persons: When are existence-inducing acts wrong? *Law and Philosophy* 1995;14(3/4): 297–327; Gavaghan C. Deregulating the genetic supermarket: Preimplantation screening, future people, and the harm principle. *Cambridge Quarterly of Healthcare Ethics* 2000;9(2):242–61.
8. Joint Working Group of the HFEA and Human Genetics Commission. *Outcome of the Public Consultation on Preimplantation Genetic Diagnosis*. Nov 2001:12. Available at http://www.hgc.gov.uk/UploadDocs/DocPub/Document/pgdoutcome.pdf.
9. See note 8, Joint Working Group 2001:11.
10. Rosamund Scott draws a similar division between disability-oriented arguments; see note 4, Scott 2005.
11. Shakespeare T. Back to the future? New genetics and disabled people. *Critical Social Policy* 1995;15(2/3):22–35, at 31. Susan Wendell has expressed a similar concern in *The Rejected Body: Feminist Philosophical Reflections on Disability*. London: Routledge; 1996:54.
12. Buchanan A. Choosing who will be disabled: Genetic intervention and the morality of inclusion. *Social Philosophy & Policy* 1996;13(1):18–46, at 21. Laura M. Purdy also writes of the notion that "acting so as to avoid such births will lead us to reduce the social resources now allocated to the disabled." Loving future people. In: Callahan JC, ed. *Reproduction, Ethics and the Law: Feminist Perspectives*. Bloomington: Indiana University Press; 1995:312. See also Kitcher P. *The Lives To Come*. London: Allen Lane, The Penguin Press; 1996:200.
13. Philip Kitcher offers just such an example, of beta thalassemia in Cyprus: "As the incidence of thalassemia has diminished, help for the afflicted has increased: Because there is now less demand for blood transfusions and other treatments, the lives of thalassemia sufferers are now better than they were." See note 12, Kitcher 1996:85.
14. Hughes J. *Citizen Cyborg: Why Democratic Societies Must Respond to the Redesigned Human of the Future*. Oxford: Westview Press; 2004:144.
15. Buchanan A, Brock DW, Daniels N, Wickler D. *From Chance to Choice: Genetics and Justice*. Cambridge, U.K.: Cambridge University Press; 2000:266–9.
16. Buchanan et al. point to the example of so-called "orphan" drugs, that is, treatments for conditions so rare that it is not economically viable for pharmaceutical companies to develop or manufacture them. See note 15, Buchanan et al. 2000:268.
17. Saxton M. Disability rights and selective abortion. In: Solinger R, ed. *Abortion Wars: A Half Century of Struggle*. Berkeley: University of California Press; 1998:374–93, at 391.
18. Saxton M. Born and unborn: The implications of reproductive technologies for people with disabilities. In: Arditti R, Klein RD, Minden S, eds. *Test-Tube Women: What Future for Motherhood?* Pandora Press; 1984:301.
19. Kent D. Somewhere a Mockingbird. In: Parens E, Asch A, eds. *Prenatal Testing and Disability Rights*. Washington, DC: Georgetown University Press; 2000:62.
20. Even more troubling examples exist of choice-denying or even coercive circumstances that gave rise to great lives. The parents of the great abolitionist, Frederick Douglass, were a slave mother and a slave-owning father who may very possibly have raped her. It is surely possible to celebrate Douglass's life while at the same time celebrating that the circumstances that led to his birth will never be repeated.
21. Degener T. Female self-determination between feminist claims and "voluntary" eugenics, between "rights" and ethics. *Issues in Reproductive and Genetic Engineering* 1990;3(2):87–99, at 92–3.
22. Parens E, Asch A. The disability rights critique of prenatal testing: Reflections and recommendations. In: Parens E, Asch A. eds. *Prenatal Testing and Disability Rights*. Washington, DC: Georgetown University Press; 2000:15.
23. See note 7, Parfit 1984:357–61.
24. Precisely this point is made by James Lindemann Nelson: Prenatal diagnosis, personal identity, and disability. *Kennedy Institute of Ethics Journal* 2000;10:213–28, at 216.

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25. Perhaps the danger of conveying such a negative message to disabled people is more acute in view of the extent to which disabled people have already been devalued, discriminated against, and excluded from many aspects of society. It has also been argued (by, among others, a reviewer of this article) that these hardships have led to a shared sense of identity among disabled people, and that it is this identification with other disabled people that renders the expressivist message so hurtful. It would be unsurprising if the history of disabled people has given rise to certain distinct fears and concerns, but nonetheless, Nelson's analogy may not be entirely inaccurate. That poor people have, historically and currently, been excluded from many aspects of society—work places, social clubs, academia, legislature, and judiciary—can be demonstrated by reference to any number of sources (see, for example, Marshall G, Swift A, Roberts S. *Against the Odds? Social Class and Social Justice in Industrial Societies*. Oxford: Clarendon Press; 1997). Furthermore, that a sense of shared identity has grown up among poor people is, arguably, at least as true as the analogous claim regarding disabled people. That is, such a shared identity does exist, up to a point, and political movements have been built on the basis of the common obstacles they face (including the U.K. Labour Party), but it is by no means true that all people from economically deprived backgrounds, or with disabilities, regard those factors as being integral to their identities, nor that they feel a sense of community or identity with other poor/disabled people.
26. Reinders H. *The Future of the Disabled in Liberal Society: An Ethical Analysis*. Notre Dame, Ind.: University of Notre Dame Press; 2000:93.
27. See note 12, Buchanan 1996:32. A similar point is made by Bonnie Steinbock: Disability, prenatal testing, and selective abortion. In: Parens E, Asch A. eds. *Prenatal Testing and Disability Right*. Washington, DC: Georgetown University Press; 2000:119.
28. A point of view expressed by Mary Ann Baily, who candidly admits her own unease at the prospect of any future child she bore being co-opted into a "disability culture" from which she herself was excluded; Why I had amniocentisis. In: Parens E, Asch A. eds. *Prenatal Testing and Disability Right*. Washington, DC: Georgetown University Press; 2000:68–9.
29. Spriggs M. Lesbian couple create a child who is deaf like them. *Journal of Medical Ethics*, Online eCurrent Controversies, May 2, 2002. Available at http://jme.bmjjournals.com/cgi/reprint/28/5/283.pdf#search=%22%22lesbian%20couple%20create%20a%20child%22%22.
30. See note 24, Nelson 2000:215–6. See also note 22, Parens, Asch 2000:15.
31. See note 21, Degener 1990:95.
32. See note 11, Wendell 1996:153.
33. See note 26, Reinders 2000:4.
34. Albert B. The new genetics and disability rights. Presentation to EU Conference "Human Genetic Testing, What Implications", Brussels, May 6, 2004. Available at: http://www.dpi.org/en/resources/topics/documents/bioethics-english.pdf. See also Disabled people speak on the new genetics. DPI Europe Position Statement on Bioethics and Human Rights. Available at: http://www.dpieurope.org/htm/bioethics/dpsngfullreport.htm; Purdy LM. Loving future people. In: Callahan JC, ed. *Reproduction, Ethics and the Law: Feminist Perspectives*. Bloomington: Indiana University Press; 1995:312; Stacey M. The new genetics: A feminist view. In: Marteau, Richards, eds. *The Troubled Helix*. Cambridge, U.K.: Cambridge University Press, 1996, at 343.
35. See note 26, Reinders 2000:55.
36. See note 26, Reinders 2000:55.
37. See note 26, Reinders 2000:56.
38. Edwards SD. Disability, identity and the "expressivist" objection. *Journal of Medical Ethics* 2004;30:418–20.
39. An intriguing discussion of Alzheimer's disease and continuity of identity has centered around the issue of advance directives. See, in particular, Dresser R. Advance directives, self-determination, and personal identity. In: Hacker C, Moseley R, Vawter DE, eds. *Advance Directives in Medicine*. New York: Praeger Publishers; 1989; Dresser R (with PJ Whitehouse). The incompetent patient on the slippery slope. *Hastings Center Report* 1994;24(4):6–12. See also Kuczewski M. Whose will is it, anyway? A discussion of advance directives, personal identity, and consensus in medical ethics. *Bioethics* 1994;8(1):27–48; Kuhse H. Some reflections on the problem of advance directives, personhood and personal identity. *Kennedy Institute of Ethics Journal* 1999;9(4):347–64.
40. See note 24, Nelson 2000:219. See also Walter Glannon's example of potentially identity-affecting gene therapy: *Genes and Future People: Philosophical Issues in Human Genetics*. Oxford: Westview Press; 2001:81–2.

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41. Following the logic of the Non-Identity Principle, and assuming that Dresser et al. are correct about the discontinuity of identity between those with and those without Alzheimer's, a somewhat more alarming prospect arises: that, in attempting to cure Alzheimer's, at least for those in the latter stages of the disease, we would in truth be seeking to replace one—existing—individual with a different, presently merely hypothetical one. If the discontinuity thesis is taken to its logical conclusion, would this amount to "killing" one human being in order that another might come into existence?
42. Dobson R. "Saviour sibling" is born after embryo selection in the United States. *British Medical Journal* 2003;326:1416.
43. "Because sex selection is banned in Britain, the couple paid an Italian clinic £30,000 for three attempts to conceive a girl but none was successful." Couple abandon battle for baby of their choice. *The Sunday Times*, Jan 23, 2005.
44. Approximately 69% of respondents to the HGC/HFEA Public Consultation on PGD agreed that PGD should be available only where there is a known family history of serious genetic disorder or to cases of aneuploidy. See note 8, Joint Working Group 2001:para. 16.
45. See note 22, Parens, Asch 2000:30–1.
46. See note 8, Joint Working Group 2001:Recommendation 11.
47. See note 26, Reinders 2000:64.
48. See Gavaghan C. "Designer donors"? Tissue-typing and the regulation of pre-implantation genetic diagnosis. [2004] 3 Web JCLI, at http://216.239.59.104/search?q=cache:6kase5MXEbsJ:webjcli.ncl.ac.uk/2004; Use of preimplantation diagnosis to produce tissue donors: An irreconcilable dichotomy? *Human Fertility* 2003;6:23–5.
49. Clarke A. Response to: "What counts as success in genetic counselling?" *Journal of Medical Ethics* 1993;19:47–9, at 48. See also Botkin J. "As the range of conditions for which we can test prenatally expands, society and the medical profession need to develop guidelines about which tests ought to be offered and which ought not to be." Fetal privacy and confidentiality. *Hastings Center Report* 1995;25(5):32–9, at 32.
50. It could be suggested that any ostensibly value-free approach would in reality be undermined by the fact that the overwhelming majority of PGD users would, in fact, use it to screen out "disabilities" and not more "frivolous" traits, still less to use it to screen *for* disability. My suggestion is that this need not undermine a genuine claim of state neutrality, any more than the constitutional commitments of the French and U.S. states to neutrality on the question of religion are undermined by the fact that, in practice, a substantial majority of their citizens use, and have always used, that freedom to practice as Christians.

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