

Genes, identity, and the “expressivist critique”

Dr Rob Sparrow, Centre for Human Bioethics, Monash University.

(This is a “pre-press” version of this paper, which appeared in Loane Skene and Janna Thompson (eds), *The Sorting Society*, Cambridge: Cambridge University Press, 2008, pp. 111-132. Please cite that version.)

Introduction

Technologies such as prenatal testing, combined with the option of abortion, and preimplantation genetic diagnosis now give prospective parents unprecedented power to choose the genetics of their children. In effect, they allow parents to sort embryos according to whether they have desirable or undesirable genes. A society in which such technologies become widespread—as they have in many industrialised nations already—might be thought of as a “sorting society”.¹ This description, however, immediately draws attention to another, more disturbing, potential in these technologies. Critics of the sorting society worry that it involves choosing between different “sorts” of people, deciding who will be born on the basis of a belief that some sorts of people are better than others.

The shameful historical legacy of racial eugenics has meant that there is little open enthusiasm for using modern technologies of genetic selection to select for (supposed) racial traits. While technologies enabling sex selection have been widely adopted to that purpose, their use in this fashion has, I think, as least as many critics as admirers amongst those writing about the ethics of this practice. Instead, these sorting technologies have been taken up and defended most enthusiastically in the service of the goal of preventing the birth of children who might suffer from various disabilities. As a result, it has been critics from within the disability community who have thought hardest about—and have raised some of the most forceful objections to—the development of the sorting society. Critics including Adrienne Asch (1988; 2000), Susan Wendell (1996), Marsha Saxton (1997), and Deborah Kaplan (1993) have argued that in using technologies of genetic selection to ensure that children are not born with disabilities we may express a disrespectful attitude towards existing persons with disabilities.

In this paper, I explore this “expressivist critique” (Buchanan, 1996; Parens & Asch, 2000). I begin by setting out the expressivist critique and then highlighting, through an

¹ The most powerful of these technologies, preimplantation genetic diagnosis, remains a comparatively rare phenomenon largely because it requires conception to occur via *in vitro* fertilisation. However, various forms of prenatal screening, with the option of termination, are now a routine part of antenatal care in much of the industrialised world.

investigation of an influential objection to this critique, the ways in which both critics and proponents of the use of technologies of genetic selection negotiate a difficult set of dilemmas surrounding the relationship between genes and identity. I suggest that we may be able to advance the debate about these technologies by becoming more aware of the ways in which this debate is itself in part a political contestation over this relationship (Stainton, 2003). Ultimately, I will argue, the real force of the expressivist objection lies in its capacity to draw our attention to *political* questions about the role of the state and about relationships between different social groups rather than between parents and prospective children. That is to say, crucial issues, when evaluating the force of this criticism, turn out to be: the nature of the institutions which determine how decisions about prenatal selection are made; and how we think of each other, that is, what we take to be the defining characteristics of human beings. Paradoxically, arguments about the ethics of the “sorting society”, both supportive and critical, are an important arena in which these institutions and these ideas about identity are contested and shaped. An increased awareness of the reflexive nature of the process of debating these issues may assist us in better negotiating them.

The expressivist critique

An important criticism of the project of the “sorting society” derives from a concern that selecting against embryos with genetic disorders, or terminating pregnancies on the basis that they are likely to result in the birth of a child with a disability, expresses morally reprehensible negative attitudes towards people with disabilities. There are in fact two different messages that the decision to choose one embryo over another might be taken to express (Buchanan et al., 2000, p. 265).² First, the decision to terminate a pregnancy—or not to select an embryo for implantation—on the basis of a diagnosis of a genetic condition contributing to a disability, might be thought to send a message along the lines of “it would have been better if you had never been born” (Davis, 1987; Kaplan, 1993; Wendell, 1996, pp. 83, 153-154; Saxton, 1997). Second, the decision to choose an embryo which is more likely to become a child without a disability rather than one which might develop into a child with a disability might be thought to imply that those doing the selection believe that people without disabilities are superior to those with disabilities (Buchanan et al., 2000, p. 265). The use of technologies of genetic selection to prevent disability may therefore convey both a message of superiority over, and of lack of respect for, those living with disabilities.

This objection has been dismissed by many philosophers who have examined the topic on the basis of a distinction between (dis)respect for persons and our attitudes towards disability (Buchanan et al., 2000, pp. 276-281; Steinbock, 2000). A desire that a child not be born with an disability which could be avoided through the use of a technology of genetic selection need not express any attitude towards existing persons with disabilities.

² In what follows I will, for the most part, restrict my discussion to the use of the technology of preimplantation genetic diagnosis to this end in order to avoid the complexities arising from the psychological and physical trauma to the mother which may result from terminating a pregnancy.

Parents may simply believe that is better to be born without a disability rather than with a disability, without having any feelings about the *worth* of the lives of those with disabilities. According to this way of thinking, choices made on the basis of beliefs about the negative impacts of disabilities need not express any message about the worth of the lives of those currently living with disabilities.

The question of what sort of actions and utterances express evaluative attitudes, what they express, and what determines this, is a complex and controversial one. I will return to this matter in a later section of the paper. First, however, I want to consider an argument which draws on the fact that both genetics and environment play a role in shaping the ultimate character of an organism in order to suggest that we are obligated to make use of technologies of genetic selection to improve the opportunities available to those who will be born. This argumentative strategy is a familiar one in debates about “liberal eugenics” (Agar, 2004; Nelson, 2000; Savulescu, 2001) but I want to rehearse it here because I think presenting it in the stages set out below can usefully illuminate just what is at stake in arguments about the ethics of the sorting society and, in particular, the way these arguments raise difficult philosophical and—I will argue—political questions about personal identity.

Genotype and phenotype

A compelling chain of analogies appears to demonstrate that an obligation to avoid—or even terminate—particular pregnancies on the basis of a diagnosis of a genetic disorder follows naturally from an obligation to treat injuries sustained after birth which we all ordinarily acknowledge (Buchanan et al., 2000, p. 267-276; Nelson, 2000; Steinbock, 2000).

Few would be prepared to argue that we should not use medical technology to heal and correct injuries or conditions which have occurred after birth. Yet the purpose of such interventions is to prevent a disability. In this case, however, it seems wildly implausible to suggest that we should not proceed with surgery because to do so would be to express a negative attitude towards people with disabilities. This argument would rule out any medical treatment of conditions which, if left untreated, might lead to disability. It seems clear in this case that, on the contrary, we are obligated to proceed with such surgery if it offers any chance of success.

If such post-natal surgery is acceptable, however, it is hard to see what would be wrong with surgery performed *in utero* to avoid a condition which might otherwise negatively affect the child. The only difference between such surgery and an operation performed postnatally to the same effect is a matter of a few weeks and the location of the child being operated upon. It is far from clear that these factors should make a difference in the ethics of the procedure.

Similarly, if surgery of this type is acceptable it is difficult to see what would be wrong with making use of a (hypothetical) somatic cell gene therapy to achieve the same effect (Buchanan et al., 2000, p. 275; Nelson, 2000). In theory, an efficient somatic cell gene therapy might introduce new genes into the somatic cells of the developing embryo to

correct for the effects of defective genes. In terms of its effects on the eventual capacities of the infant, this appears only to move the moment at which the condition is corrected a few months earlier in the course of the pregnancy.

However, at this point intuitions about any obligation to carry out such gene therapy begin to diverge. As I will discuss further below, rather than altering the capacities of the child that is eventually born, such gene therapy might be thought to result in the birth of a different child—with dramatic implications for the ethics of the procedure.

The intuition that genetic interventions may affect the identity of the child that will be born is, I think, even stronger in the case of a hypothetical *germ line* gene therapy. Such a therapy would introduce new genes, which would replace (or repair the effects of) the genes that would otherwise result in a disability, into the chromosomes of every cell in the developing embryo. The eventual presence of the new genes in the gametes of the developed infant mean that these changes could be passed on to future generations. As a result of such therapy, the embryo will now have a different genome.

This method of intervening to prevent a child being born with a disability can be described in two different ways. It can be described as altering the character of the (same) organism so as to change the phenotype of the infant (Harris, 1998, Chapter 3), which renders it analogous to the *in utero* surgery described above. However, because it involves altering the genome of the embryo, insofar as many people have the intuition that genetics play a role in individuating organisms and on the, not unreasonable, assumption that a different organism means a different person, germ line gene therapy might be argued to involve changing who will be born; that is, that this kind of intervention secures the birth of a different person (Zohar, 1991). This way of understanding this scenario suggests that it is more analogous to the case of preimplantation genetic diagnosis (PGD).

If germ line gene therapy is acceptable then it is difficult to see what would be wrong with using preimplantation genetic diagnosis (or prenatal testing and selective termination of pregnancy) instead, in order to ensure that the child which is born will have the appropriate genotype. Indeed, we could imagine that the genetic selection and the germ line gene therapy might lead to the birth of a child with the very same genome. That is, if we imagine a gene therapy which alters an embryo with a genotype, “A” (which includes a gene coding for a defective protein), so that it will instead have a revised genotype, “B” (which will lead to the embryo developing normally), then administering this gene therapy prevents a child being born with genotype A and instead ensures a child with genotype B will be born. The very same outcome could be achieved by employing PGD instead to choose between two embryos, one of which has genotype A and one of which has genotype B. In each case we have an action that determines the genetics of the child which will be born. However, whereas the gene therapy might be thought only to alter the character of the embryo, PGD seems to involve choosing a different organism—and therefore, presumably, a different person—to be born.

Because the phenotypic outcome at the end of all these interventions is the same it is, at first sight at least, difficult to explain what grounds we could have for accepting some of

them but not others. Indeed, given that most people accept that we are obligated to initiate surgery in the case of the accident immediately after birth, it is difficult to explain why we are not similarly obligated to use PGD (Buchanan et al., 2000, Chapter 6; Nelson, 2000; Savulescu, 2001).³

There are two obvious ways in which this conclusion may be resisted.

Firstly, it may be pointed out that when prenatal testing and selective abortion, or preimplantation genetic diagnosis, are employed to shape future persons this involves the destruction of the unwanted embryos, which is not the case with the other technologies. Yet many of those writers drawn to the expressivist objection deny that the termination of pregnancies (or the destruction of embryos) *per se* is morally problematic (Asch, 2000; Nelson, 2000, p. 270). This suggests that it is not the destruction of embryos itself that is the issue here but rather their destruction on the basis of a particular character trait. Thus Adrienne Asch (2000) has argued that it is the destruction of an embryo on the basis of a diagnosis of a genetic condition that might lead to a disability which communicates a negative attitude towards people with disabilities. When parents choose to terminate a pregnancy on basis of a diagnosis of a possible genetic disorder in the foetus or embryo, the developing life that they had previously celebrated and welcomed into their lives is instead suddenly and emphatically rejected. The extent to which any such attitude towards a potential life must extend to, or communicate something about attitudes towards, actual persons will be discussed further below.

Secondly, while all these interventions result in the child that is born having the same phenotype, PGD and (perhaps) germ line gene therapy (and perhaps even somatic cell gene therapy) achieve this by achieving the birth of a *different* child. One set of therapies improves the life of the child who is eventually born whereas the other set of interventions alter who comes to be born. Thus it might be argued that the use of these technologies involves asserting that one embryo is better than another and therefore, perhaps, that people of one sort are better than another (Buchanan et al., 2000, p. 264-274). Again, it is not implausible to suggest that there is something about a course of action which must necessarily alter the whole character of the future person, that is problematic in a way in which courses of action which merely alter one (or perhaps

³ Moreover, while I have sketched this argument in the context of the therapeutic intervention, a similar form of argument is possible in relation to the moral permissibility of—and perhaps even obligation to pursue—enhancements. That is, if we are willing to concede that it is morally permissible, or perhaps admirable, or perhaps even obligatory to provide a child with various benefits through a non-therapeutic environmental intervention such as vaccination, cosmetic surgery, or character-shaping education then, if we can similarly imagine that this result might be able to be achieved by intervention in utero, somatic cell gene therapy, germ line gene therapy, or preimplantation genetic diagnosis and selection amongst embryos, it seems that we should also hold that these interventions would also be morally permissible, admirable, or perhaps obligatory (Savulescu, 2001). To discuss the issues raised by the use of technologies of genetic selection to enhance human beings would take me too far from the main task of my argument, which is to interrogate the competing accounts of identity that underlie debates about their use to prevent disability. However, in so far as such accounts are also crucial to debates about human enhancement, I hope the discussion which follows will also illuminate those debates.

several) particular character traits are not. In particular, such action seems to involve a comparison between different persons (or, at least, embryos) that might need to be based on comparison between different sorts of lives (Stainton, 2003, p. 534).

The dangers of genetic determinism

However, in linking such decisions to attitudes towards persons with disabilities both these ways of resisting this chain of analogies seem to involve conceding that the identity of the person who would be born — what sort of person they are — will primarily be determined by their genetics (Nelson, 2000, p. 219). The expressivist critique therefore seems to involve a genetic determinism that has been widely criticised elsewhere in bioethics.

People are, as we must continually remind ourselves in debates about genetics, more than their genes. This is true as a matter of developmental biology. Genotype only produces phenotype in a given environment. Environmental conditions are thus equally important as genes in determining an organism's character (Rothman, 1998).⁴ However, more importantly, it is also true in relation to our duties to others. The respect we owe to other persons is owed to them regardless of their genetics. Whether or not a person has a genetic condition leading to disability is irrelevant to the moral respect that is owed to them. It seems odd, therefore, for critics writing from a disability perspective to choose genetics as what distinguishes one person from another.

Moreover, in suggesting that steps taken to reduce disability express disrespect for persons with disabilities, the expressivist critique seems to imply that persons with disabilities are essentially constituted by their *disabilities* (Nelson, 2000, p. 219; Stainton, 2003, p. 534). Consider the case of a couple who terminate a pregnancy because if they proceed with it, they would have four children, when they only intended to have three. In this case we are unlikely to conclude that they express a disrespectful attitude towards all those people who are the fourth child in the family (Buchanan, 1996; Nelson, 1998; Nelson, 2000). In order to establish that selection against embryos expresses disrespect for an existing group of people, it seems that we must hold that there is a certain sort of person who is characterised by sharing the trait on the basis of which the embryos are being selected against. Being a “fourth child” does not pick out a sort of person who might claim to be the object of disrespect or hostility expressed by parents who make such choices. For the expressivist critique to function, however, it must be the case that disability does (Press, 2000, p. 215). This claim is obviously problematic in the context of a critique from a disability rights movement that is elsewhere insistent that persons with disabilities are persons who happen to have disabilities rather than disabled persons (Nelson, 2000, p. 219).

⁴ This is not to say that, in relation to their causal role in producing any given variation in phenotype, genetics and the environment are equally important, only that without specifying both we cannot determine the phenotype of the organism at all.

The manner in which the expressivist critique relies on a perverse claim about the identity of people with disabilities is highlighted by Mary Ann Baily when she observes, of critics of the use of technologies of genetic selection to screen out disabilities, that,

Their picture is of a line of babies waiting to be born, and a quality control officer coming along and throwing “people like them” out of the line so they never make it to earth (Baily, 2000, p. 66).

That embryos might be “people like them” requires both that people with disabilities are appropriately interpellated with reference to their disabilities and that the character trait of “being a person with a disability” inheres in the genes (Press, 2000, p. 215).

However, it would be a mistake to think that it is only critics from the disability community who are inclined to individuate and draw conclusions about embryos—and therefore the beginnings of persons—on the basis of their genes. The advent of modern genetics has led to social discourses about identity becoming dominated by “gene talk” (Kitcher, 1996, Chapter 11). Since the discovery of DNA, race, sexuality, sex, and gender have been re-imagined as “genetic conditions” (Rothman, 1998). This process has accelerated further since the initiation and subsequent completion of the Human Genome Project.⁵ As a result, it is increasingly the case that a wide range of character traits are thought of as coded “in the genes” (Jennings, 2000). The use of preimplantation genetic diagnosis only makes sense if we can say something about the sort of life a person is likely to live purely on the basis of their genetics.

Moreover, I noted above that many people are inclined to think that preimplantation genetic diagnosis and perhaps germ line gene therapy result in a different person being born rather than just altering the character of the (same) person who is born. The temptation to link genetic identity and continuity to personal identity across the early stages of life is a product of our scientific understanding of the role played by genes in the development of an organism and our sense that the human organism begins at conception. Yet this way of individuating human lives has perverse and puzzling implications for the description and ethics of the use of technologies of genetic selection. It has the consequence, noted above, that technologies of genetic selection change who comes into existence rather than alter the character of any particular person (Parfit, 1984). As the persons who are brought into existence using these technologies would not have come into existence except for the use of these technologies they are unable to claim that they would have been either better or worse off if these technologies had been used otherwise (Glover, 2001).⁶ As a result, it seems that the use of these technologies does

⁵ Moreover, in other debates about bioethics, especially about new reproductive technologies, a good deal of weight is placed on genetic identity — especially genetic relatedness. In many moral—and legal— contexts genes determine whose children are whose; decisions about which embryos to implant, or bring to term, are regularly made on the basis that their genes determine key aspects of their identity (Alpern, 1992).

⁶ An important exception here is where decisions about genetic selection might lead to the birth of children with lives so filled with pain and suffering and devoid of potentially rewarding experiences as to be “not

not harm or benefit those who they affect most directly (Brock, 1995).⁷ This conclusion in turn renders it extremely difficult to provide an account of our obligations in relation to the use of these technologies (Brock, 1995; Cohen, 1996; Feinberg, 1987; Glover, 2001; McMahan, 2001; Steinbock & McClamrock, 1994; Strong, 2005).

Unfortunately, the obvious alternative way of thinking about these dilemmas, as involving changes in the situation of a person identified independently of their particular genetic makeup, is equally, if not more, problematic. Baily offers this alternative in a passage immediately following that quoted above.

My picture is of a “disembodied soul,” the essence of my yet-to-be-born child, waiting to be inserted into a baby shaped container, with me standing there to make sure my child’s soul gets into a well functioning container (Baily, 2000, p. 66) .

This way of thinking has the advantage of allowing us to talk of benefiting and harming particular individuals and therefore of grounding an obligation to use these technologies to promote the well-being of those people who are brought into existence. However, it has the obvious disadvantage of requiring an account of personal identity which is independent of any physical substrate. This is enough to render it unattractive to most contemporary thinkers.⁸

It is not just critics from the disability community, then, whose arguments run into trouble in the face of the notoriously difficult to set of problems in metaphysics and the philosophy of personal identity which surround choices concerning who comes into existence. The possibility that I wish to explore in the rest of this chapter is that, rather than wait for these problems to be solved before attempting to engage with the disability critique, we might make some tentative progress if we approach the question of the identity of persons and expressive content of various choices and policies as *political*

worth living”. In situations where it would be rational for the person who comes into existence to prefer to be dead, it seems that we *can* speak of harming someone in the act of bringing them into existence.

⁷ This way of understanding personal identity also appears to have strange implications for the ethics of our treatment of embryos. It looks as though on this account it is possible to benefit or harm embryos (and the individuals they will develop into) in morally significant ways but that it is not morally wrong to kill them. Actions which affect embryos which fall short of destroying the embryo must be evaluated in relation to the impacts they might have on the future well-being of the person this embryo will become. That is, the baseline for determining harm or benefit is the interests of the person who would have developed from an embryo if it retained the chromosomes it had at conception. However, actions which destroy an embryo and which therefore lead to another person being born, do not harm anyone. It seems, then, that we could inflict multiple successive harms on an embryo over an extended period with each action being morally wrong, except for the last one, which renders the embryo nonviable. That the last of a series of identical harmful actions should fail to be harmful because it proves fatal to the embryo is counter-intuitive to say the least.

⁸ Although a recent (2007) paper by Jeffrey Reiman in *Philosophy and Public Affairs* does seem to embrace this alternative.

issues. That is, as issues which are, at least in part, about contestation for power between different groups of people.

Eugenics, “old” and “new”

One important reason for interpreting the expressivist critique as, at least in part, a political concern for relationships between social groups is that doing so draws our attention to the morally disturbing similarities between the sorting society and the eugenic programs of the past.

There are, at least, three important similarities and one important dissimilarity between the “new eugenics” of the sorting society and the “old eugenics” of the 1930s.

The dissimilarity has been widely advertised and a number of writers have taken it to render the new eugenics fundamentally different from the old. Whereas the “old” eugenics made use of the coercive power of the state to enforce its eugenic agenda and deprived individuals of their human rights in doing so, the “new” eugenics is organised around the rhetoric of individual choice and respect for human rights, and abjures the use of the coercive powers of the state (Agar, 2004, pp. 5-6; Buchanan et al., 2000, pp. 55-60; Savulescu, 2001; Silver 1999, p. 255; Wikler, 1999). Given that the most obvious and dramatic atrocities associated with the old eugenics were for the most part carried out using the coercive powers of the state, this is an important difference.

However, although the new eugenics disavows the coercion and state planning of the old eugenics, it shares with it a deep seated belief that genes matter. The project of the sorting society remains “eugenic”—concerned with ensuring that children are of “good birth”. In so far as it relies on technologies of genetic diagnosis to attempt to secure this goal, the sorting society requires that we can make plausible assumptions about the sorts of lives people are likely to have on the basis of their genes. It requires both that we can sort embryos and that we can distinguish between the different sorts of people they are likely to become.

It is also equally true of the new genetics as of the old that some sorts of people will not be chosen to be brought into the world once the use of technologies of genetic selection becomes widespread. Indeed, the effect of the widespread adoption of the new eugenics is likely to produce similar outcomes to those that were the goal of the old eugenics. It is embryos that might have become “less than perfect” children that will be selected for termination or that will not be implanted. Children that might once have been born with a disability, or born female, or born with any of a range of character traits deemed to be socially undesirable, will cease to appear in the world. In their place will be born children who are strong and healthy, good-looking, male, and who have all the marks of local privilege.

The history of the use of these technologies to this date supports these predictions. In societies where daughters are considered less valuable than sons their use has led to less girls and more boys being born (Oomman & Ganatra, 2002). The range of conditions tested for has increased, as has the number of diagnoses which have been used to justify

selecting another embryo. Moreover, arguments are beginning to appear in both the scientific and philosophical literature that we are obligated to use these technologies to produce children who will have the “best possible” lives (Savulescu, 2001). That is to say, that the distinction between therapeutic and non-therapeutic uses of these technologies is already being blurred in the philosophical literature. One suspects it is only a matter of time before wealthy couples began using these technologies to ensure that their child has “superior genes” (Silver, 1999).

In part, this pattern of likely outcomes is a function of the pre-existing preferences of parents. That is, these technologies are likely to be taken up to prevent the birth of children with character traits that are currently socially disvalued and/or to ensure the birth of children with traits that are considered to be valuable. However, the existence of technologies of genetic selection also plays a significant role in *shaping* these preferences. Once these technologies become available it becomes more difficult for parents to refuse them, or to choose to make the “less popular” choice and proceed with a pregnancy that may lead to the birth of a child with a disability, because the consequences of making various choices depend in part on the aggregation of the choices of others in similar circumstances. For instance, if other parents make use of a technology of genetic selection to prevent the birth of children with a particular condition then the availability of social and medical support services to support children with that condition will decrease as a result of demand for these services being reduced (Asch & Geller, 1996, p. 325). In this fashion, the technologies which make possible the sorting society condition their own use. Indeed, many critics have expressed concern that the existence of these technologies will establish a “genetic rat race” which will effectively force people to adopt them or else risk that their children will be left behind in competition for scarce social goods.

However, it is more than the sum of the individual choices of parents, or even “market forces”, which leads to the use of these technologies to select in favour of certain sorts of people. The idea that it is rational to prefer some sorts of children to others is built into the very foundations of the sorting society. As Nancy Press (2000) has remarked, it is the choices “made available” which reveal the attitudes driving the new eugenics. While programs of genetic screening and testing are usually established and defended on the basis of offering choice to parents, it is clear that they would not exist except for the belief that having such a choice is important *because* there are *good reasons* to prefer a child *without* a disability. That is, the justification for the dedication of resources to making such a choice possible relies implicitly on the notion that many people would wish to exercise such a choice in a particular direction. Governments do not, after all, typically fund research into screening technologies in order to allow people to choose the colour of their children’s eyes, or hair colour, or to allow them to try to have children with particularly shapely elbows. This suggests that while the coercive powers of the state are not mobilised by the new eugenics, other aspects of the state are. The state which rules the sorting society is not “neutral” on the question of what sorts of people should be born. In providing funding for the development of some tests and not others, and in funding public access to a limited range of tests, the state necessarily reveals beliefs about which choices are worth having, and in turn which conditions one would be

justified in choosing against (Jennings, 2000; Press, 2000, p. 231). In this way, the new eugenics will still involve state policy about what sorts of people there should be.

Indeed, such policy is often explicit—or, at least, easily discernible—in the justifications given in various bureaucratic debates about whether to support routine genetic screening for particular conditions. When costing various programs, government agencies typically compare the amount of money it will cost the government to make a screening technology available to a certain cohort of parents with the amount of money which would be saved by eliminating the need to provide medical care and social services to those people who might otherwise be born with the condition the test is designed to diagnose (Press, 2000, p. 221-223). If the state program will save more money than it will cost then the argument that it should be funded becomes straightforward. The justification of the policy therefore essentially refers to how many births/lives it will prevent.

An important lesson to be drawn from a political concern with power and structure about the sorting society, then, is that the expressivist critique may be especially strong when it is directed towards applications of technologies of genetic selection that are socially sanctioned and state funded (Press, 2000).

A much criticised feature of the expressivist critique is that it sometimes seems to rely on an assumption about the motivations of individual parents, when they decide to terminate a pregnancy on the basis of a diagnosis of a possible disability, or to choose one embryo over another on the same basis (Nelson, 2000). That is, in some formulations of this critique, it appears as though the sentiment the parents' actions express is the attitude that they (must) have towards persons with disabilities (Buchanan, 1996). However, as I observed earlier, parents making decisions about which embryo to choose may not be thinking about the worth of the lives of anyone at all (Steinbock, 2000). Instead, they may simply be trying to secure for their children certain ordinary human capacities, the absence of which does not render a life not worth living but can make achieving various social and economic goods much more difficult. In so far as they think about the “worth” of various lives at all—perhaps because they have been exposed to the expressivist critique—they may, in fact, affirm the equal worth of all human lives. Thus, if the expressivist critique relies upon facts about the actual intentions of parents making these sorts of decisions, it may apply only rarely (Buchanan, 1996). Furthermore, the decisions of individual couples have only an infinitesimal effect on the relations that exist between those social groups whose members might claim to have an interest in their decisions. As a result, it is difficult to see how either the expressive content or the consequences of their decisions could justify the interference with the liberty of the parents which would be involved in preventing them from acting on their decision.

However, the situation is quite different when we are considering the expressive content of government policies. These policies often reveal motivations and intentions which are formed only fleetingly, if at all, in the course of the deliberations of individual parents. As I argued above, even if the choice as to how to act on a test result is left up to prospective parents, the justification of the policy that makes it available refers to the expectation that this choice will often be made in a certain way. Moreover, these policies

will have a dramatic impact on relations between people with disabilities and people without disabilities. While the choices of individuals will have only a marginal effect on what sort of people will exist in the future, the consequences of adopting various policies about researching, funding, or introducing screening programmes may very well include ensuring that certain sorts of people will disappear from the community over the course of a few generations. The argument that various applications of technologies of genetic selection express something is therefore much stronger when it is policies are rather than individual choices which are being considered for their expressive content.

This last observation draws our attention to a third similarity between the old and the new eugenics, which is less often remarked upon, which is that the new eugenics, like the old, overwhelmingly involves one sort of people making decisions which primarily affect another. The old eugenics involved those who believed themselves to be genetically superior making decisions about those they believed to be “unfit”. In the new eugenics, it is, by and large, persons without disabilities who make decisions about funding research and programmes of genetic screening, whereas it is persons with disabilities who feel threatened by them and whose communities may well disappear as a result of them.

The significance of this fact for debates about technologies of genetic selection is hinted at by an otherwise puzzling feature of the expressivist critique. One of the many striking things about the expressivist critique is how weak the conclusion of the argument is, given its apparent ambition initially and also the strength of the claims made in the course of the argument. If it really were the case that those making the expressivist critique believed that the use of technologies of genetic selection to select against the birth of persons with disabilities was motivated by, and expressed, a profound lack of respect for a significant portion of the population, one might expect them to go on to mount an argument against the use of these technologies in this fashion altogether. Instead, the usual conclusion of the “expressivist critique” is only that parents should be exposed to the opinions and experiences of those with the disability they are concerned about, or those caring for them, before making their decision (Asch, 1988, pp. 89-92; Kaplan, 1993). That is, what is ultimately contested in this argument is the process whereby these decisions are made, and who makes them, rather than the content of the decisions. The negative attitudes towards people with disabilities that the use of technologies of genetic selection expresses are expressed not so much by the decisions that are actually made but by the fact that people with disabilities are not included in the decision-making about their use. It is the relation between groups of people within a generation, between people with disabilities and people without disabilities, that is crucial here, rather than the relationship between parents and their (possible) future children.

The expressivist critique revisited

This way of understanding what is at stake in debates about technologies of genetic selection cannot avoid the problematic implication, noted above, that people with disabilities are, apparently, according to this way of thinking, essentially constituted by their disabilities. Why should people with disabilities or—perhaps the more politically urgent question—people without disabilities care about what happens to a social group defined by disability unless membership of this group marks something deep and

important about those within it? In many other policy debates people with disabilities are often insistent that they should *not* be characterised as “disabled persons” and that a properly inclusive society would *not* single out people with disabilities for special treatment (Asch, 1988). The apparent tension between these claims can be at least partially reconciled if we recognize them both as being understandable responses to a political dilemma that confronts members of marginalised social groups across a broader range of issues. In order to see how this might be the case, it will help to first consider an analogy that is often referred to in the course of the expressivist critique between selecting against disability and selecting against race or sex (Asch, 1988, pp. 85-6; Wendell, 1996, p. 81).

I noted above that sorting embryos according to their sex or “race” has far fewer defenders than selection on the basis of possible disability. As critics from the disability community have rightly pointed out, if the technologies of the sorting society were used primarily to select on the basis of skin colour, for instance, we would think that this is likely both to reflect and to express racism (Asch, 1988, pp. 85-6; Wendell, 1996, p. 81). In particular, any state funded screening programme in Europe, the United States, the United Kingdom, or Australia designed to allow parents the option of terminating pregnancies likely to lead to the birth of dark-skinned children would rightly be condemned as racist. Similarly, it is clearly the case that the use of sex selection technologies to select against the birth of female children in India, Bangladesh, and China is a sexist practice (Oomman & Ganatra, 2002). This remains true even if the intentions of a particular parent are not the product of gender hierarchy.

There are, I think, at least two good reasons why our intuitions should be so much clearer in these cases.

Firstly, it is much more widely recognized in relation to racism and sexism that what a person’s actions “express” cannot be entirely determined by them nor settled by referring to their intentions (Nelson, 2000). Instead, because meaning is social, the expressive content of our utterances and our actions is determined by what other people will understand of them. This means that our utterances and actions may even have expressive content contrary to that which we intend. Genetic selection on the basis of race (or sex) is racist (or sexist) because it is continuous with and perpetuates historical patterns of oppression on the basis of race (or sex) even where the intentions of parents are beneficent. The social context of these decisions over determines their content.⁹

⁹ This remains true even if it is also true that people born with dark skin face substantial disadvantages in the society in which the decision takes place. More controversially, I believe it may be true even if a concern for skin colour was motivated by a purely “medical” concern for the connection between skin pigmentation, exposure to UV radiation in sunlight, and vitamin D deficiency. The history of racism makes any use of medical technology to alter the composition of racial groups extremely problematic. Resistance to this conclusion stems largely, I believe, from the idea that racism is primarily a matter of intention. My contention here is precisely that actions, especially actions by institutions, can have a political character, which is not a function of the intentions behind them but rather of their nature and consequences viewed in a historical context.

Secondly, the doubt canvassed above, about whether such uses of these technologies are directed towards and affect a certain “sort” of person, does not arise here. Race and sex are social categories which structure contemporary societies to such an extent that we cannot help but acknowledge the different sorts of people which exist either side of the divisions they establish.

Thus what makes the idea that selection on the basis of sex or race is sorting persons more immediately obvious than the case of selection on the basis of disability is that the majority of the community is more committed to these categories as describing socially important phenomena (This is also why “disability” in turn marks out a—more or less—distinct social group in a way that being the youngest child in the family does not (Asch, 2000; Wendell, 1996; Stainton, 2003).) Moreover, because of the prevalence and influence of “gene talk” in modern societies, in part as a consequence of the development of technologies of genetic selection, these social identities include a genetic component. That is, we imagine them to be “in the genes”.¹⁰ As a result, sorting *embryos* on the basis of sex or (putative) race can also be understood as distinguishing between different sorts of persons. Because the social practices and institutions organised around the categories of race and sex have real social force, changes in the relations between these groups are likely to be important to those within them. Selecting future persons on the basis of race or sex clearly will have such an effect and is therefore politically and ethically controversial.

This remains true even if, in more philosophical and reflective moments, we acknowledge that these distinctions are often arbitrary and morally pernicious. Morally pernicious systems of discrimination can have real social effects which extend over long period of histories and across a wide range of social institutions. These systems both rely upon and produce discriminatory social categories, such as race, caste, and social class. These categories become categories of social organisation with very real effects on the shape of society and the lives of those within them. As a result they become terms with genuine reference to classes of people. Yet at another level they remain founded on fictions.

Social policy—and criticism—in relation to inequalities of this sort confronts a dilemma. In order to identify and remedy those injustices that we wish to address we must formulate policy in terms of these categories (Minow, 1990; Wendell, 1996; Young, 1990). However, doing so strengthens the very categories which constitute and sustain these unjust social relations. If, alternatively, we try to prefigure the future of just social relations between persons that we desire, and formulate policy in terms which do not presume these categories, then there is a very real risk that we will be unable to address existing injustices.

¹⁰ We can intuitively understand the idea of selecting on the basis of race even though race is not a category with any real genetic (indeed, scientific) basis. While traits which are associated with racial stereotypes, such as skin, eye, and hair colour, and facial bone structure, undoubtedly have a genetic basis, “race”—a social category—does not.

The dilemma facing those who would put forward the expressivist critique of the use of technologies of genetic selection to prevent the birth of persons with disabilities is therefore an instance of a dilemma facing members of oppressed and socially marginalised groups more generally: how to negotiate the troubled waters of identity politics in a society shaped by existing and historical injustices? This dilemma perhaps presents itself with extra urgency in the debate about selection on the basis of *disability* because this category appears, at least at times, on both sides of the debate as primarily “genetic”. Both critics and advocates of technologies of genetic selection are often committed to the implication that some genetic conditions are constitutive; they determine what “sort” of person someone is. Equally well, both critics and advocates have strong reasons to deny that the identity of a future person is coded in the genes of each embryo. In some circumstances then both sides of these debates imply that our genes make us who we are, whereas in others they are quick to insist that it is environment and society that determine what sort of person embryos become.

The unresolved tension in these discussions of the relation between genetics and identity, should, I believe, be understood as reflecting this same dilemma. The question “How much are we constituted by our genes?” is—at least when we are discussing the ethics of the use of genetic technologies—as much a question of politics and sociology as it is a question of biology, ontogeny, psychology, or metaphysics. It is social understandings that determine which conditions are contingent to, and which are constitutive of, personal identity. What sorts of social identity have a genetic component is itself a matter of political contestation. Genetic technologies and the debate surrounding them therefore play a central role in determining what the relationship is between genes and persons. This means that both critics and advocates of technologies of genetic selection have reason to be more careful about the implications of their arguments for the relationship between genes and identity and therefore for the force of the expressivist objection. The contentious analogy between sorting embryos on the basis of disability and on the basis of sex or race may have more to teach us, then, about the ethics of the sorting society than simply lending intuitive support to the expressivist critique. It may be that further insights into, and progress in, the debate about the sorting society could be achieved by looking more closely at debates about multicultural and identity politics (Stainton, 2003; Wendell, 1996; Young, 1990). However, this project would be a larger task than I could hope to achieve here.

Conclusion

I must acknowledge that my discussion in this chapter has stopped short of an evaluation of the expressivist critique. I have tried to show how this critique is more challenging if understood as a critique of existing relations between social groups. I have also tried to show how the process of contesting these relations is itself implicated in the construction of a social identity around disability which itself is part of what is being contested.

However, I have not tried to settle the ethics or the politics of the construction of such an identity. Constructing a social identity and community is not without its costs, especially when such construction occurs around an already existing identity that has been, for the most part, shaped by the responses of others and which has, in many circumstances,

appeared largely as an obstacle to respect for the rights of persons with disabilities. However, in the first instance at least, judgements about the consequences and relative merits of various political strategies in relation to identity are best made by those who are more likely to find themselves identifying or being identified with the group whose members will be most affected. For this reason, as a person who does not identify as a person with a disability, I have hesitated to enter into a debate about whether people with disabilities might be better off denying or affirming this label.

Nor have I tried to determine whether the expressivist critique succeeds in establishing an all-things-considered objection to the use of technologies of genetic selection to select against the birth of persons with disabilities. Key questions here will obviously be whether a concern for relations between social groups can justify the restriction of individual liberty imposed by preventing prospective parents from using these technologies as they wish; and, how any such concern weighs in relation to any duties of procreative beneficence—to promote the well-being of those we bring into the world—that we acknowledge.¹¹ However, in so far as I have resiled from evaluating the force of arguments derived from a concern for relations between particular social groups I am equally unable to resolve these further questions. Moreover, the interpretation of the expressivist critique I have been advocating suggests that the answer to these questions is sensitive to social context. That is, the force of the expressivist critique will depend on facts about the extent to which people identify themselves and others as being certain “sorts” of people in the societies which are considering the ethics of genetic selection (Stainton, 2003, p. 537).

Nonetheless, I hope that the interpretation of the expressivist critique I have offered here may usefully contribute to the larger project of evaluating the critique. Unless philosophers endeavour first to understand why this critique seems compelling to those who advance it, we are unlikely to convince them that we have considered it adequately. My examination of an influential objection to the expressivist critique, based on a series of analogies between ordinary therapeutic and selective genetic interventions, has highlighted the way in both critics and proponents of the use of technologies of genetic selection must negotiate a difficult set of dilemmas surrounding the relationship between genes and identity. Paying attention to the political dimensions of this negotiation lends strength to the expressivist critique in three ways. Firstly, it highlights important continuities and similarities between the “old” and the “new” eugenics, in particular, that the state which governs the modern sorting society is not neutral about the sorts of people who will be born in the future. Secondly, it draws our attention to the fact that the policies which the state adopts concerning the use of technologies of genetic selection express attitudes towards persons with disabilities which plausibly may be morally evaluated. Thirdly, it shows how the expressive content of these policies may be as much a function of the relations between the people who determine the policies as it is about

¹¹ It seems highly unlikely, for instance, that such concern should prevent us from making use of screening technologies for the purpose of preventing the birth of children who would have “a life not worth living” such that it would be rational for them to prefer to be dead.

their content. These lessons suggest that the expressivist critique may have more force and substance than is often appreciated.

Finally, acknowledging the crucial role of claims about identity in debates about the ethics of the sorting society allows us to acknowledge the high degree of reflexivity in the expressivist critique and in responses to it. Contributions to these debates inevitably help constitute our understandings of the relation between genetics and identity at the same time as they contest these understandings. This suggests that there may yet remain lessons to be learnt about the ethics of the sorting society from other debates about relationships between different sorts of people (Connolly, 1991; Minow, 1990; Stainton, 2003; Young, 1990).¹²

¹² I would like to thank Justin Oakley, Jacqui Broad, Debra Dudek, Toby Handfield, and Emilio Mora for helpful comments and discussion over the course of the development of this paper.

References

- Agar, Nicholas. 2004. *Liberal Eugenics: In Defence of Human Enhancement*. Oxford: Blackwell.
- Alpern, K. D. 1992. Genetic Puzzles and Stork Stories. In *The Ethics of Reproductive Technology*, edited by K. D. Alpern. Oxford: Oxford University Press.
- Asch, Adrienne. 1988. Reproductive Technology and Disability. In *Reproductive Laws for the 1990s*, edited by S. Cohen and N. Taub. Clifton N.J.: Humana Press.
- Asch, Adrienne. 2000. Why I Haven't Changed My Mind about Prenatal Diagnosis: Reflections and Refinements. In *Prenatal Testing and Disability Rights*, edited by E. Parens and A. Asch. Washington, D.C.: Georgetown University Press.
- Asch, Adrienne, and Gail Geller. 1996. Feminism, Bioethics, and Genetics. In *Feminism and Bioethics: Beyond Reproduction*, edited by S. Wolf. New York and Oxford: Oxford University Press.
- Baily, Mary Ann 2000. Why I Had Amniocentesis. In *Prenatal Testing and Disability Rights*, edited by E. Parens and A. Asch. Washington, D.C.: Georgetown University Press.
- Brock, Dan. 1995. The Non Identity Problem and Genetic Harms – the Case of Wrongful Handicaps. *Bioethics* 9 (3/4):269-275.
- Buchanan, Allen. 1996. Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion. *Social Philosophy and Policy* 13 (1):18-46.
- Buchanan, Allen, Dan W. Brock, Norman Daniels, and Daniel Wikler. 2000. *From Chance to Choice*. Cambridge: Cambridge University Press.
- Cohen, Cynthia B. 1996. "Give Me Children or I Shall Die!" New Reproductive Technologies and Harm to Children. *Hastings Center Report* 26(2):19-27.
- Connolly, William E. 1991. *Identity/Difference: Democratic Negotiations of Political Paradox*. Ithaca: Cornell University Press.
- Davis, Alison. 1987. Women with Disabilities: Abortion and Liberation. *Disability, Handicap & Society* 2 (3):275-84.
- Feinberg, Joel. 1987. Wrongful Life and the Counterfactual Element in Harming. *Social Philosophy & Policy* 4(1):145-78.
- Glover, Jonathon. 2001. Future People, Disability, and Screening. In *Bioethics*, edited by John Harris. Oxford: Oxford University Press, 429-44.

- Harris, John. 1998. *Clones, Genes and Immortality: Ethics and the Genetic Revolution*. Oxford: Oxford University Press.
- Jennings, Bruce. 2000. Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability In *Prenatal Testing and Disability Rights*, edited by E. Parens and A. Asch. Washington, D.C.: Georgetown University Press.
- Kaplan, Deborah. 1993. Prenatal Screening and its Impact on Persons with Disabilities. *Clinical Obstetrics and Gynecology* 36 (3):605-612.
- Kitcher, Philip. 1996. *The Lives to Come: The Genetic Revolution and Human Possibilities*. New York: Simon and Schuster.
- Minow, Martha. 1990. *Making All The Difference: Inclusion, Exclusion and American Law*. Ithaca: Cornell University Press.
- Nelson, James Lindemann. 1998. The Meaning of the Act: Reflections on the Expressive Force of Reproductive Decision Making and Policies. *Kennedy Institute of Ethics Journal* 8 (2):165-182.
- Nelson, James Lindemann. 2000. Prenatal Diagnosis, Personal Identity, and Disability. *Kennedy Institute of Ethics Journal* 10 (3 (September)):213-228.
- McMahan, Jeff. 2001. Wrongful Life: Paradoxes in the Morality of Causing People to Exist. In *Bioethics*, edited by John Harris. Oxford: Oxford University Press, 445-75.
- Oomman, Nandini, and Bela R. Ganatra. 2002. Sex Selection: The Systematic Elimination of Girls. *Reproductive Health Matters* 10 (19):184-197.
- Parfit, Derek. 1984. *Reasons and Persons*. Oxford: Clarendon Press.
- Parens, Eric, and Adrienne Asch. 1999. The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations. *The Hastings Centre Report* 29 (5):1-22.
- Parens, Eric, and Adrienne Asch, eds. 2000. *Prenatal Testing and Disability Rights*. Washington, D.C.: Georgetown University Press.
- Press, Nancy. 2000. Assessing the Expressive Character of Prenatal Testing: The Choices Made or the Choices Made Available? In *Prenatal Testing and Disability Rights*, edited by E. Parens and A. Asch. Washington, D.C.: Georgetown University Press.
- Reiman, Jeffrey. 2007. Being Fair to Future People: The Non-Identity Problem in the Original Position. *Philosophy & Public Affairs* 35 (1):69-92.
- Rothman, Barbara Katz. 1998. *Genetic maps and human imaginations : the limits of science in understanding who we are*. New York: Norton & Co.

- Savulescu, Julian. 2001. Procreative Beneficence: Why we should select the best children. *Bioethics* 15 (5):413-426.
- Saxton, Marsha. 1997. Disability Rights and Selective Abortion. In *Abortion Wars: A Half Century of Struggle*, edited by R. Solinger. Berkeley and Los Angeles: University of California Press.
- Silver, Lee M. 1999. *Remaking Eden: Cloning, Genetic Engineering and the Future of Human Kind*. London: Pheonix.
- Stainton, T. 2003. Identity, difference and the ethical politics of prenatal testing. *Journal of Intellectual Disability Research* 47 (7):533-539.
- Steinbock, Bonnie. 2000. Disability, Prenatal Testing, and Selective Abortion. In *Prenatal Testing and Disability Rights*, edited by E. Parens and A. Asch. Washington, D.C.: Georgetown University Press.
- Steinbock, Bonnie, & McClamrock, Ron. 1994. When Is Birth Unfair to the Child? *Hastings Center Report* 24:15-21.
- Strong, Carson. 2005. Harming by Conceiving: a Review of Misconceptions and a New Analysis. *Journal of Medicine and Philosophy* 30:491-516.
- Wendell, Susan. 1996. *The Rejected Body*. New York: Routledge.
- Wikler, Daniel. 1999. Can we learn from eugenics? *Journal of Medical Ethics* 25 (2):183-194.
- Young, Iris Marion. 1990. *Justice and the Politics of Difference*. Princeton, New Jersey: Princeton University Press.
- Zohar, N. J. 1991. Prospects for “genetic therapy”—Can a person benefit from being altered? *Bioethics* 5 (4):275-88.