

# GENDER EUGENICS? THE ETHICS OF PGD FOR INTERSEX CONDITIONS

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## **Abstract:**

This paper discusses the ethics of the use of Preimplantation Genetic Diagnosis (PGD) to prevent the birth of children with intersex conditions/disorders of sex development (DSDs), such as Congenital Adrenal Hyperplasia (CAH) and Androgen Insensitivity Syndrome (AIS). While paediatric surgeries performed on children with ambiguous genitalia have been the topic of intense bioethical controversy there has been almost no discussion to date of the ethics of the use of PGD to reduce the prevalence of these conditions. I suggest that PGD for those conditions that involve serious medical risks for those born with them is morally permissible and that PGD for other “cosmetic” variations in sexual anatomy is more defensible than might first appear. However, importantly, the arguments that establish the latter claim have radical and disturbing implications for our attitude towards diversity more generally.

**Keywords:** intersex; DSDs; PGD; ethics; eugenics; gender; genetics.

## GENDER EUGENICS? THE ETHICS OF PGD FOR INTERSEX CONDITIONS

Is it a boy or a girl? This is often the first question people ask when they learn of the birth of a child. It is a poorly kept secret amongst the medical — and bioethical — community that these options do not exhaust the alternatives (Dreger 1998a and 1998b). A small percentage of children are born with anatomies that are not easily categorised as either male or female.

While some authors have argued that the existence of such “intersex conditions” demonstrates that there are more than two human sexes and that we should therefore be more accepting of variations of sexual anatomy (Fausto-Sterling 2000; Hester 2004; Kessler 1998), historically, medical science has responded to the possibility of a child being born with an intersex condition as though it were an emergency.<sup>1</sup> Today, confronted with the spectre of intersex, modern medicine makes choices available to parents and physicians at three different points in the course of pregnancy and infancy: at birth; during pregnancy; and, at — or shortly after — conception.<sup>2</sup> Notoriously, if a child is diagnosed with an intersex condition at birth, parents may face difficult decisions about assigning a social gender and also about various forms of surgery that may be advertised to them as increasing the probability that their child will grow up happy and secure in his/her assigned gender (Dreger 1999; Gillam *et al.* 2010). If an intersex condition is detected while the child is still in the womb, through prenatal tests such as amniocentesis or chorionic villus sampling, then parents may be offered various therapies intended to mitigate the effects of the condition (Nimkarn and New 2007). Finally, where a family history of intersex births exists, parents may be offered the choice of conceiving via *In Vitro* Fertilisation (IVF) in order that they might then use Preimplantation Genetic Diagnosis (PGD) to avoid the birth of an intersex child (Amor 2012).

In this paper, I want to focus on the ethics of the last of these alternatives. There are a number of reasons for this choice. First, the ethics of the appropriate medical response to the birth of children with intersex conditions has been extensively explored elsewhere, with the result that there is an emerging consensus on this topic (Lee *et al.* 2006). Similarly, the ethics of prenatal “treatment” of intersex conditions, in particular of Congenital Adrenal Hyperplasia (CAH) through the administration of dexamethasone, is also the topic of an existing literature (Dreger *et al.* 2012; Nimkarn and New 2007). Second — and more importantly — neither of what are perhaps the two main issues in the ethics of the surgical treatment of children born with intersex disorders — the essentially experimental nature of the surgeries and the impact of the experience of surgery on the welfare of the child — arise in the context of PGD. Thus, the existing more-or-less consensus on the treatment of children born with intersex conditions underdetermines the ethics of the use of PGD. Third, to my knowledge there has been very little

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<sup>1</sup> What were once described as “intersex conditions” have recently been reclassified as “disorders of sex development” (Dreger *et al.* 2005; Houk *et al.* 2006). I prefer the previous term, which I will use here, in so far as it allows more conceptual space for understanding these anatomical variations as points on a wider spectrum of sexual diversity rather than as — by definition — disorders of “normal” anatomical development.

<sup>2</sup> I will use the language of choice here in order to highlight the formal possibility, at least, of different decisions being made by different parents. However, it is worth noting that both the ways in which these choices are structured and presented and other powerful social and psychological pressures call into question the extent to which parents really have the opportunity to determine for themselves what to do in these situations.

written on *this* topic, despite the fact that PGD is already being used to prevent the birth of children with both CAH and Androgen Insensitivity Syndrome (AIS) (Amor 2012, 205-206). The practical question of what parents and policy makers should do as more and more information becomes available about the genetics of intersex is largely unaddressed by bioethicists.<sup>3</sup> Fourth – and perhaps most importantly – in the context of intersex conditions, PGD threatens to become a form of “gender eugenics”, wherein advanced medical technology is deployed to prop up hetero-sexism by preventing the birth of those with non-normative anatomies (Holmes 2008). This disturbing prospect requires us to think hard about the nature and significance of human variation and our willingness to embrace the use of medical technology to prevent the birth of those whose biology may-or-may-not be “pathological”. Finally, as my discussion below demonstrates, PGD for intersex conditions raises a set of complex and interrelated questions about disability, the concept of the normal, and the appropriate response to social norms in decision-making about the best interests of children. My hope, then, is that thinking through the ethics of PGD for intersex conditions may also shed light on the ethics of PGD more generally.

I begin, in Section I, with a brief discussion of the genetics of intersex conditions in order to establish what is and is not possible when it comes to PGD for these conditions. I argue there is a realistic possibility of using PGD to prevent the birth of intersex children in an important range of cases. I then outline, in Section II, two key aspects of the ethics of PGD that will play an important role later in the argument. The question of the ethics of PGD for intersex conditions is difficult at least in part because the ethics of PGD itself is still poorly understood. In Section III, I set out a number of hypothetical uses of PGD, which may serve as useful comparison cases for thinking about the ethics of PGD for intersex. Section IV introduces and then problematises a distinction between “medical” and “social” aspects of intersex, which has played a central role in discussions of the ethics of surgical treatment of intersex conditions in infants and that might be thought to be useful in the context of a debate about the ethics of PGD. Section V examines the ethics of PGD for intersex in the context of the comparison cases. I suggest that PGD for those conditions that involve serious medical risks for those born with them is morally permissible and that PGD for other “cosmetic” variations in sexual anatomy is more defensible than might first appear. However, importantly, the arguments that establish the latter claim have radical and disturbing implications for our attitude towards diversity more generally. In Section VI, I offer some final reflections on the relation between PGD for intersex and other uses of PGD, and on the difference between ethics and public policy in relation to genetic selection. While there may be good public policy reasons to reject PGD for variations in sexual anatomy that do not in themselves involve risks to the physical health of those who evidence them, the question of the ethics of parental choices in relation to PGD for these — and other — forms of human variation remains surprisingly open.

## I. THE GENETICS OF INTERSEX

“Intersex” is an umbrella term to refer to a range of different conditions that result in individuals being born with non-normative sexual morphologies (Intersex Society of North America 2008; Kessler 1998). These conditions may involve variations in any or all of an individual’s chromosomal sex, genital-anatomical sex, gonadal sex, “hormonal” sex, and gender

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<sup>3</sup> The only discussion of which I am aware occurs in the course of Holmes (2008).

identification. Some of these conditions are extremely rare, while others are merely very uncommon. Some individuals born intersex — for instance, those with a chromosomal sex different to their anatomical sex, or with some forms of mosaicism, or mild gonadal dysgenesis — may never become aware of their condition. In others cases, the anatomical variation may be obvious at birth or become obvious during adolescence. In some cases, these conditions are life-threatening.

Whether it will be possible to use PGD to prevent — or ensure — the birth of a child with an intersex condition will depend on the particular condition involved and its aetiology (Amor 2012).<sup>4</sup> There are a number of different causes of intersex conditions, not all of them genetic and many of them poorly understood. Some intersex births are the result of perturbations in the normal course of embryonic development due to environmental conditions such as maternal tumours or the fusing of two early-stage embryos: PGD will not be possible in such cases (Kolon 2008, 174; Amor 2012). Chromosomal variations, such as Klinefelter syndrome, may also arise spontaneously as a result of random errors in the process of chromosomal division during the formation of the germ cells or in the early cell-divisions after fertilisation (Lanfranco *et al.* 2004). In the absence of a family history of intersex births, there would be little cause to undergo PGD to screen for these conditions.<sup>5</sup> Finally, even if there is a family history of intersex births, affected individuals — who might otherwise be interested in using PGD — may be unable to reproduce using their own gametes and thus, again, the question of PGD will not arise.

However, a significant number of the causes of intersex conditions *are* heritable and are therefore, theoretically at least, amenable to detection through PGD (Amor 2012).<sup>6</sup> In rare cases Turners syndrome runs in families and unaffected individuals may therefore have cause to undertake PGD. Both AIS and CAH, which together account for a sizeable percentage of intersex births, have a genetic cause and therefore could be avoided in many cases through the use of PGD (Amor 2012).<sup>7</sup> PGD has been used successfully by parents with family histories of CAH to avoid transmitting the condition to their children (Altarescu *et al.* 2011; Christofidou *et al.* 2009; van de Velde *et al.* 1999) and its use has also been reported for AIS (Harper *et al.* 2010, Supplementary Table IV; van Rij *et al.* 2011, 1820; Ye *et al.* 2012).<sup>8</sup> Various other rare causes of intersex births may also be amenable to “treatment” via PGD.

Because PGD is a complex and expensive medical procedure and because it requires IVF, which does not guarantee a successful pregnancy, it is unlikely that couples will undertake it unless they are concerned to prevent their child being affected by some specific condition. It is not, therefore, a panacea to the “problem” of intersex. Nevertheless, PGD has several advantages over “corrective” surgery if parents are concerned to raise a child with normal sexual anatomy. It is not an experimental technology in the way in which surgeries carried out on intersex

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<sup>4</sup> My thanks to David Amor of Victorian Clinical Genetic Services for correspondence on this topic.

<sup>5</sup> It is worth noting, however, that karyotyping of embryos during IVF in order to maximise the chance of a successful pregnancy, as is increasingly routine, will effectively screen out these conditions in a much larger range of circumstances (Verlinsky *et al.* 2005).

<sup>6</sup> Rosario (2009) provides a useful account of (some of) the genetics of intersex, which is amenable to understanding by the layperson. See also Vilain (2006), and White and Sinclair (2012).

<sup>7</sup> My thanks to Garry Warne, Honorary Professorial Associate, Department of Paediatrics, University of Melbourne, for correspondence on this topic.

<sup>8</sup> My thanks to Luk Rombauts at Monash IVF for correspondence on this topic.

infants often are (Diamond 1999).<sup>9</sup> Whereas surgery may fail to produce a body of the nominated sex, children born after PGD will almost always be born with the desired chromosomal, endocrinological, and anatomical sex.<sup>10</sup> Questions about the possibility of surgical and/or psychological harms to the individual being “treated,” which loom so large in the context of the debate about surgery for intersex conditions— do not arise in the context of genetic selection.<sup>11</sup> Finally, in so far as we are all born with genomes that we have not chosen, it makes little sense to worry about whether the person born as a result of PGD consented to the treatment.

## II. THE ETHICS OF PREIMPLANTATION GENETIC DIAGNOSIS

The ethics of preimplantation genetic diagnosis more generally has been extensively discussed elsewhere. There are two – contradictory – lessons from this broader enquiry, in particular, that will be relevant to my discussion here.

First, PGD is what has become known, in debates around philosopher Derek Parfit’s work (Parfit 1984), as “non-person-affecting”. That is to say, because embryo selection determines *who* will be born there is no individual who is directly harmed or benefited by this technology.<sup>12</sup> Assessments of harm or benefit require that we can compare an individual’s welfare with what it would have been had they not been harmed or benefited. This counterfactual fails in PGD. Had parents not used the technology or had they selected another embryo, it would *not* be the case that any particular individual would have been better or worse off: rather another individual would have been born in place of the individual who was actually born (Brock 1995; Parfit 1984, 352-379). This peculiar feature of PGD explains why the ethics of its use remains so controversial: it is difficult to know how to think about the ethics of a technology that can prevent children being born with severe and life threatening illnesses yet that arguably fails to provide any benefit to those people who actually are born as a result of the use of the technology.

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<sup>9</sup> In fact, PGD, like IVF, is experimental in so far as — given that the oldest child born of IVF is currently in her mid-30s — we do not know what its impact might be on the health of those conceived using this technology over the course of their lifetimes (For a recent survey of the parlous state of knowledge about the risks involved in assisted reproductive technologies, see Allen *et al.* (2006)). Nevertheless, it remains true that PGD involves few (as yet) identifiable risks for the child and that PGD for intersex conditions is no more or less risky than PGD for other conditions.

<sup>10</sup> Various technical limitations of existing PGD protocols mean that there is a very small chance that an embryo with non-desired genetics may nevertheless be implanted. Similarly, there will be a small chance that an intersex birth may arise due to perturbations in the normal course of embryonic development even after implementation of an embryo without genetic factors contributing to intersex. Finally, PGD cannot, of course, guarantee the *gender* of the child, understood as the social performance and recognition of sexual identity – as gender variation may occur in the absence of an intersex condition or, indeed, any genetic determinants.

<sup>11</sup> IVF — and therefore PGD — does involve risks of both physical and psychological harms to the woman undergoing the procedure. However, these are generally held to be minor and certainly to be within the range where the patients consent is sufficient to establish that it is ethical to proceed.

<sup>12</sup> Of course, it is possible that the use (and especially the widespread use) of PGD will lead to *indirect* harms to various people, including parents, the broader society, and other people with the condition being selected against. The import of (some of these) will be discussed below.

Second, although it is hard to fully characterise their import, our responses to circumstances in which environmental influences, such as pollution, disease, or —more positively—education impact on the welfare of children appear to have implications for the ethics of PGD. An organism’s phenotype — what it is like — is the result of both its genetics *and* its environment (Kitcher 1996, 245-269). The impact of genetic variations depends upon the environment and the impact of environmental differences depends upon an organism’s genetics. When it comes to the impact on the life of a child, it is hard to see why it should matter whether we understand the cause of a condition as genetic or environmental: what matters is its implications for the well-being of the child (Harris 2007, 1-2). Thus, for instance, if we believe it to be permissible to select for a deaf child, because there is nothing wrong with being deaf, then it appears we should also hold it to be permissible for parents to surgically deafen an infant under appropriate anaesthesia (Brock 2005). Conversely, if we think that deafening a hearing child would be impermissible — for instance, because it would restrict the opportunities available to them — then it would appear problematic to deliberately select a child with genes that predisposed them towards deafness (Harris 2000).

These two considerations pull in different directions when it comes to the ethics of the use of PGD to prevent the birth of children with conditions that are thought to impact negatively on the well-being of those affected. The environmental analogy gives us strong reasons to select against such conditions but the non-person-affecting nature of the decision suggest that we do not harm anyone if we fail to act on those reasons (Savulescu 2002).

### III. COMPARISON CASES?

It will be useful to frame my discussion of the ethics of PGD for intersex by attempting to locate this procedure in relation to a number of other hypothetical uses of PGD. These (imagined) cases are: the use of PGD to select against dark skin colour in the children of mixed race couples; the use of PGD to select against (hypothetical) genes for same-sex attractedness;<sup>13</sup> selection against a gene associated with a failure to develop legs; use of PGD to prevent deafness; and, the use of PGD to eliminate port-wine stains (nevus flammeus).<sup>14</sup>

In at least two of these cases (skin colour, same-sex attractedness), it is reasonably well accepted that the use of a selection technology would clearly be unethical – although my discussion will, inevitably, cast doubt on the foundations of this consensus. In another two cases (deafness, “leglessness”), selection is more controversial but is nevertheless still widely endorsed; again I will problematise the arguments that have been used to motivate this *status quo*. I have included the remaining case (port-wine stains) to serve as a mediating case between the other two pairs.

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<sup>13</sup> I have chosen this admittedly clumsy formulation in order to mitigate (valid) criticisms that the social category “homosexual” is too sensitive to history, culture, and social context to be capable of being correlated with any gene or set of genes.

<sup>14</sup> While nothing in the argument that follows turns on the question of whether these sorts of choices will ever be possible, the latter three of these cases at least are more plausible than might first appear. For identification of a gene associated with port-wine stains, see Eerola *et al.* (2003). For discussion of the likely future impact of genetic testing for deafness on Deaf culture, see Dillehay and Arnos (2006), and Sparrow (2010).

Naïvely, the difference between these two groups of two cases each, where a rough consensus exists, is that in the first two cases, the problem selection attempts to “cure” is purely “social” in character, whereas in the latter two cases, it is largely “medical.” Deafness and leglessness are deviations from species-typical functioning, which will raise barriers and reduce opportunities for those affected in a wide range of environments.<sup>15</sup> Selection against these traits looks to be justified by concern for the life prospects of the future child. On the other hand, same-sex attractedness and dark skin colour, are part of the normal range of human variation and only problematic in societies structured by systematic social injustice. Selection on the basis of these traits appears straightforwardly homophobic and racist.

Of course, the distinction between social and medical problems is notoriously problematic.

As disability advocates have argued, medical problems have a social component so that what appears as a problem in one social setting may be insignificant or even beneficial in another. Whether or not having legs, for instance, will restrict an individual’s opportunities and reduce their welfare will depend to a large degree on the extent to which the built environment is constructed to include or exclude them (Oliver 2009).

Equally well, however, the implications for the welfare of children of being born same-sex attracted in homophobic societies, or with dark skin in racist societies, are real and entirely independent of parental wishes in this matter.<sup>16</sup> The impact on the welfare of the child is not necessarily any less just because the markers of their difference are “merely” social. Indeed, the experience of racism, homophobia, and other forms of discrimination is associated with significant healthcare impacts according to ordinary measures of life-expectancy, morbidity, and social and psychological well-being (Barnes *et al.* 2008; Diaz *et al.* 2001; Meyer 2003; Pascoe and Smart Richman 2009; Shavers *et al.* 2012). Thus, to the extent that one is motivated by concern for the welfare of one’s child it is irrelevant whether they will suffer reduced welfare as a result of the interaction of their genetics with the natural or social environments. This is most obvious in relation to port-wine stains, which is why this condition is such a difficult case for the ethics of PGD. To go through life with such a birthmark is to be — quite literally — marked out for attention, much of it negative or critical or overly sympathetic or otherwise painful and annoying. The fact that children born with these marks may suffer real social and psychological harms over their life-course would seem to justify parents wanting to treat or

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<sup>15</sup> This claim is less controversial — although not entirely uncontroversial — when the medical condition genetic selection is intended to avoid is cystic fibrosis, Huntingtons disease, or a predisposition to breast cancer. I have deliberately chosen the examples of leglessness and deafness instead to foreground both that this claim *is* controversial in the light of the powerful critiques of the “medical model” by disability activists (Oliver 2009) and also the role played by the ideas of welfare and opportunities in assessing the claim (Savulescu *et al.* 2011).

<sup>16</sup> The claim that individuals who are same-sex-attracted in homophobic societies or who are born with dark skin in racist societies have lives that – on average — go worse than those of heterosexuals or lighter skinned individuals in the same societies is a confronting one. Nevertheless, it is a necessary consequence of the idea that homophobia and racism are oppressive. If racism and homophobia did not harm those who are their victims and reduce the opportunities of their targets then they would not be as morally objectionable as they are. Indeed, were such forms of discrimination truly harmless it is not clear that there would be anything wrong with them. The tempting thought that even purely “symbolic” discrimination is wrong arguably rests on the implicit recognition that in practice alleged instances of such always turn out to generate real harms.

avoid the condition even granted that these harms are (also) the result of the bigotry of others (Lanigan and Cotterill 1989; Madera and Hebl 2012; Masnari *et al.* 2013; Picardi *et al.* 2008).

Problematising the distinction between social and natural disadvantage therefore does not itself necessarily lead to the conclusion that we should be more reluctant to embrace the use of PGD: pending an alternative account of how we should delineate the appropriate use of PGD, it lends equal force to the claim that we should endorse its use more widely.

#### IV. TWO ASPECTS OF INTERSEX

Interestingly, the literature on the appropriate “therapeutic” response to intersex conditions in children also begins with – although it also challenges – a distinction between the appropriate response to medical and social issues.

##### “MEDICAL” INTERSEX

Even the most trenchant critics of surgeries on intersexed infants typically admit that some intersex conditions are not plausibly conceptualised as mere variations from a statistical norm but are rather harmful states requiring medical intervention (Dreger 1998b, 30; Kessler 1998, 14; Chase 1999, 453). For instance, the “salt wasting” version of CAH can be fatal in affected individuals who do not receive appropriate endocrinological treatment (White and Speiser 2000). Some children born intersex come into the world with abnormalities in the structure and location of the urethra that are likely to cause ongoing health problems unless corrected surgically (Nabhan and Eugster 2007).<sup>17</sup> Although the timing of surgery to address the issue remains controversial, the presence of internal testes in individuals with AIS produces an increased risk of testicular cancer (Cools *et al.* 2006). Other, still more uncommon, intersex conditions may involve various health problems for those born with them.

It is rare that surgery can make a positive contribution to an intersexed child’s ability to become a genetic or gestational parent, so the question of whether an inability to reproduce is a pathological aspect of intersex does not usually arise in this context. However, many intersex conditions result in affected individuals being unable to become a genetic parent and/or to become pregnant. Moreover, it is arguable that the presence of genitals, gonads, and a reproductive tract sufficient to allow (for the appropriate portion of an adult life) genetic fatherhood in a male, and gestation and genetic motherhood in a woman, should be seen as part of normal human health.<sup>18</sup> PGD *could* ensure that children are born healthy in this regard.

Finally – and more controversially – to the extent that medicine relies upon an account of the normal anatomy and physiology of male and female bodies, then significant variations from these norms may appear as deformities, the avoidance or repair of which might justify medical interventions.

##### “SOCIAL” INTERSEX

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<sup>17</sup> My thanks to Garry Warne for drawing my attention to this source. That there is a medical grounds for surgery in some cases is not to deny that surgery to treat hypospadias may often be essentially cosmetic.

<sup>18</sup> See Sparrow (2008a) for a discussion of the sexed nature of the concept of reproductive health.



On the other hand, many of the surgeries that have historically been performed on intersexed infants appear to be essentially cosmetic and motivated by a social anxiety about atypical genitalia (Crouch 1998; Dreger 1998b; Kessler 1998). A male child born with a small penis — or a female child with a large clitoris — may be perfectly healthy. Indeed, as long as a child’s genitals allow urination and do not render pleasure and/or (perhaps) reproduction impossible there would seem to be no medical grounds to operate to “normalise” any genitalia. If children are at risk of psychological harms from being teased or persecuted for having “different” genitals, this is clearly a social problem.

## PROBLEMATISING THE DISTINCTION

Unsurprisingly, the distinction between social and medical problems is no less problematic in the case of intersex than it is in the larger debate about disability (Murray 2009).

In the context of PGD, the availability of endocrinological treatments for CAH and surgery to repair the urethra can themselves be understood as features of the social environment such that being born with the condition does not lead to morbidity in that particular (social) environment. Strictly speaking, infertility is a property of couples – a social relationship – rather than of individuals and thus infertility treatment is often treatment of a social problem.<sup>19</sup> Moreover, many persons with intersex conditions who are unable to become genetic or gestational parents are nonetheless capable of becoming parents using donor gametes or surrogate mothers or by adopting children. To the extent that these options are held to be less desirable than becoming a parent via “natural” reproduction, this is a matter of social expectations. Finally, a more radical critique insists that the medical profession’s assumption that children should have “a sex” is itself a matter of social expectations (Hester 2004).

On the other hand, while the empirical claim that children born with ambiguous genitalia suffer consequent social and psychological harms may be controversial, it is also plausible (Elliot 1998; Warne and Bhatia 2006) and — if true — might justify PGD out of concern for the welfare of future child. Importantly, there is a sense in which three of the key “biological functions” of the genitals are already social. If we think of “healthy” genitalia as granting the capacity for intercourse leading to reproduction, eliciting sexual attraction in mates, and providing pleasure, then relations with other people are essential to the first two of these and will often be central to the third.<sup>20</sup> Genitals that don’t “fit” with the genitals of other people, that fail to elicit desire in one’s sexual partners, and/or render pleasure difficult to achieve in the prevailing social circumstances (which include access – or lack of access – to vibrators and/or other sex toys) are arguably functionally deficient. Establishing that the difficulties associated with being born intersex are a function of social context would not therefore in itself rule out their being the appropriate objects of medical intervention.

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<sup>19</sup> Thus, for instance, Murphy (2001) canvases the possibility that lesbian couples might be thought of as suffering from a sort of “relational infertility”. However, I say “often” here because in some cases individuals may be incapable of reproducing with any other individual, which does encourage the thought that these individuals are infertile in themselves.

<sup>20</sup> Compare the account of the “functionality” of sexual anatomy provided Kipnis and Diamond (1998), which emphasises the capacity to have (heterosexual?) sexual intercourse regardless of whether this leads to either pleasure or reproduction.

## V. GENDER EUGENICS?

The conclusions we reach about the ethics of use of PGD to select against intersex conditions will depend upon where we think the condition is situated in relation to the spectrum of comparison cases outlined in Section III above.

It seems likely that some intersex conditions should properly be thought of as analogous to leglessness or deafness – that is, as medical conditions that significantly restrict an affected individual’s welfare and opportunities in the range of environments that it is reasonable to expect them to encounter. In such cases, PGD to avoid the condition is morally permissible — and perhaps even morally required (Harris 2001).

Some may be tempted to argue, as per the “disability critique” of prenatal testing (Asch 1988 and 2000; Wendell 1996; Saxton 1997; Kaplan 1993), that selection is morally problematic even in these cases.<sup>21</sup> However, the environmental analogy foregrounds the implausible nature of the claim that such intersex conditions should be thought of as “mere variations” rather than harmful deviations from species-typical functioning. If an environmental condition, such as an infectious disease, was going to produce a potentially fatal endocrine disorder, or create the need for surgery to reduce the risk of urinary tract infections, unless the disease is treated, few would hold that we have little reason to treat the disease. This suggests that we have similarly strong reasons to use genetic technologies to avoid the birth of children with the salt-wasting version of CAH (for example) or with anatomies that require surgery in order to reduce the risk of urinary tract infections.

It is tempting, however, to think that the ethics of selecting against other intersex conditions, which do not in themselves involve risks to the physical health of those who are born with them, is more appropriately understood on the model of selecting on the basis of race or same-sex attractedness.<sup>22</sup> Along, I think, with many others, I have a very strong intuition that selection on the basis of the physical traits associated with race would be racist and that a selection on the basis of sexual preference would be homophobic — and that both would be *prima facie* immoral. Any attempt to guarantee that children are born clearly male or female, where there is no medical indication against the alternative, would implicate those involved in a hostility to diversity that reflects poorly on them (Holmes 2008, 178-9) and would arguably open the floodgates to other entirely cosmetic uses of PGD.

Yet there remain a number of complexities and possible objections to these claims, which are deserving of consideration at this point.

First, the conclusion that it is immoral to select on the basis of race or same-sex attractedness out of a concern for the future well-being of one’s child is less well-founded than might first

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<sup>21</sup> I have myself argued that funding research to develop the technology to make such testing possible should be more problematic than is generally recognised, in Sparrow (2008b).

<sup>22</sup> I am presuming here that it will be possible in the future to distinguish, in the course of PGD, between conditions that are likely to have severe medical consequences for those born with them and those that are not. This may be optimistic, in which case selection against genes for intersex conditions is likely to be justified in a wider range of cases by a concern to avoid the birth of children with severe medical conditions. Regardless, investigation of the ethics of PGD for merely “cosmetic” intersex conditions remains of considerable theoretical interest.

appear. Granted, a *social policy* of selecting on these bases would be immoral in so far as it would represent a failure to address the social injustices that generate these inequalities in expected welfare by an institution (the state) with the power to address them. Yet each couple has only a limited power to combat the racism and homophobia that are likely to impact on their child's welfare regardless of their choices about what sort of child to have. Moreover, any particular couples' choice about whether to have a child who will suffer from the effects of racism (or homophobia) will not make the difference between a racist (or homophobic) society and a society without racism (or homophobia). Finally, concerned parents can continue to combat these injustices regardless of their reproductive decision. Thus, the reproductive choice that parents face is whether *their* child should suffer reduced welfare as a result of social injustices. It is far from clear that it would be morally blameworthy for parents to decide to prevent this. Indeed, arguing that parents should choose a child that is likely to suffer as a result of injustice, for the sake of the political project of combating such injustices, seems to demand that parents should sacrifice the interests of their children for the sake of the larger social good (Sparrow 2011). Pending a convincing account of parental obligations in reproductive decisions in the context of injustice, then, even if the harms associated with being born intersex are entirely a product of a hostile social environment, we might still hold that parents have good reason to select against genes for intersex conditions.

Second, there are some important *disanalogies* between intersex conditions and race and sexual preferences.<sup>23</sup> The relative infrequency of intersex conditions differentiates them from race and sexual preference and the ability of many intersex individuals to "pass" as one or other of the conventional genders also differentiates intersex from race.<sup>24</sup> For both these reasons, it is more plausible to divorce decisions about intersex conditions from the concerns about culture and identity that dominate discussions of these other cases. A child born with dark skin may suffer as a result of racism but also has the opportunity to gain strength from the identification as black, from the example of other black role models, and from participation in the black community. Being black opens some doors even if others are closed due to racism. Similarly, persons who are same-sex-attracted will usually have access to a community of other same-sex-attracted persons.<sup>25</sup> These communities defined by race or sexual preference may then sustain and transmit a distinct set of cultural (or sub cultural) ideas and values. Except in very large cities, persons born intersex are likely to be one of only very few individuals with their particular form of embodiment. Even in large cities, intersexed persons may be effectively invisible to each other as well as to the larger community.<sup>26</sup> It is therefore much less plausible to object to a reduction in the number of children born intersex, as a result of PGD, on the grounds that this would jeopardise a distinctive "way of life" or "culture". "Political" critiques of such

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<sup>23</sup> Heyes (2006) offers a useful discussion of the dangers involved in treating racial and sexual difference as analogous.

<sup>24</sup> The precise figure for the percentage of births that involve intersex conditions is contested (Fausto-Sterling 2000; Sax 2002) but is small no matter which side of the dispute is correct.

<sup>25</sup> Where this is not the case, for instance in small country towns, the argument that selection against a gene for same-sex-attractedness would be justified by concern for the welfare of the child has more force.

<sup>26</sup> Historically, some intersex persons have formed political alliances with gay, lesbian, trans, and other queer activists. The advent of the Internet has, moreover, greatly facilitated the development of political constituencies and new identities amongst those who would otherwise be socially isolated. Nevertheless, it seems likely that for many intersex persons their condition will not form the basis of a political identification.

selection, of the sort I have advocated elsewhere (Sparrow 2008b), will consequently have that much less application.

Finally, even in this context, the environmental analogy has some force. If we are inclined to wince at stories of botched circumcisions, such as the operation that destroyed the penis of the infant who became famous as John/Joan under the subsequent ministrations of John Money, then this suggests that we would prefer male children to be born with penises rather than without. Similarly, if high levels of synthetic hormones in baby formula were leading to bottle-fed female infants being virilised, I suspect that most people would see this as regrettable.<sup>27</sup> If we think parents should act to prevent such environmental influences acting on their children, then it will be difficult to argue that they do not have reasons of similar force for using PGD to select against analogous conditions.

It is possible to reject the implications of the environmental analogy if one is willing to insist that being born with a condition differs significantly from acquiring it after birth. One route to this conclusion is to argue that environmental influences harm a child where genetic accident or selection does not, as the latter are “non-person-affecting”. An important corollary of this claim, however, is that there is no obligation to select against genes that predispose individuals to even severe conditions such as cystic fibrosis. The claim also risks a genetic essentialism that sits uneasily both with the science of ontogeny (Kitcher 1996, 239-269) and with arguments about the relations between genes and identity made elsewhere in the literature on disability (Saxton 2000, 160-16). Moreover, it is difficult to see why this essentially metaphysical distinction should be so important when what is at stake in both cases is a significant difference in the well-being of the affected individual.

Another – more radical – way to resist the argumentative force of the environmental analogy would be to affirm the analogy but deny that we should be concerned about the environmental cases: we really *shouldn't* care if our children become intersex as a result of environmental toxins. The key question in this context would seem to be the moral weight of “adaptive preferences.” Given time and a not-too-unforgiving social environment people will adjust to just about any change in their fortunes. A male child whose penis is amputated while they are an infant, or a female child who has been virilised as a result of exposure to hormones in the environment, is likely to grow up accepting their anatomy as a basic fact of their embodiment — as part of what makes them who they are. We might therefore conclude that such events do not harm them but simply change the person they become. Yet I still find it difficult to believe that parents should be indifferent to these sorts of influences on their child. This in turn suggests that parents would indeed be justified in using PGD to prevent these sorts of conditions.

Each of these objections challenges or undercuts the force of the intuition that it would be morally problematic to use PGD to eliminate those forms of intersex conditions that do not generate medical problems for those born with them. However, it is important to observe that these arguments would also justify the use of PGD to prevent the birth of children who would suffer discrimination on the basis of not being thought to be beautiful. Indeed, the first and the

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<sup>27</sup> The possibility that the presence of pesticides, estrogens, and other endocrine disrupting compounds in drinking water might be “feminising” men (or at least male gonads) has been subject of widespread controversy and intensive research. See, for instance, Falconer (2006), Harrison (2001), and Hayes *et al.* (2011).

third objection discussed above might also be used to defend selection on the basis of race or same-sex-attractedness.

## VI. FINAL REFLECTIONS

The idea that the development of PGD would lead to a world of “perfect babies” has been a long-standing trope in discussion of this technology. The rapid proliferation of conditions for which PGD is being used, its use to prevent the birth of children with predispositions to disease rather than with genetic disorders (Spits *et al.* 2007), and the contemporary philosophical enthusiasm for PGD for enhancement as well as therapy (Savulescu 2001; Harris 2007; Silver 1999) all serve to sustain and intensify this concern.

The prospect of PGD for intersex conditions is, I think, particularly disturbing in this context for two reasons.

First, sexual anatomy plays a key role in the organisation of gender and other aspects of human behaviour that are central to social life and individual well-being. Queer and intersex critics have called into question the extent to which sexual preference, gender, and anatomy necessarily map onto each other in simple ways (Butler 2004; Rosario 2009; Salamon 2010; Holmes 2008). Nevertheless, gender identity and psychological well-being are typically connected to the shape of one’s genitals in a way in which they are not — for instance — connected to the shape of one’s elbows. The demand for sex reassignment surgery by (some) transsexuals would not make sense if this were not the case. Similarly, without conceding a special role for genital anatomy in human psychology we would be unable to explain why thrusting a finger without consent into a woman’s vagina is an assault of a different nature to thrusting a finger into her ear and why sucking a man’s penis without his consent is different to sucking his finger. The project of normalising sexual anatomy therefore seems more fraught than that of normalising other aspects of human anatomy in so far as it would involve a reduction of diversity of a more significant kind.

Second, the prospect of PGD for intersex conditions that do not jeopardise the physical health of those born with them immediately highlights the possibility that the same arguments that might be used to justify selection against intersex conditions could also be used to justify selection against homosexuality, should genetic influences on same-sex-attractedness be identified. “Intersex” was after all originally a classification used to describe those whose *gender* and/or patterns of sexual *preferences* rather than anatomies could not easily be classified as male or female. For many critics, including myself, this is a line in the sand, which must not be crossed when it comes to the ethics of PGD. Selection on the basis of sexual anatomy seems to tread perilously close to this line.

Of course, the first of these thoughts cuts both ways. It is precisely because of the role that sexual anatomy plays in shaping identity that parents may wish to ensure that their children are born with “normal” sexual anatomy. The second of these observations highlights a cause for concern but falls well short of an argument to explain why selection on the basis of either sexual anatomy or sexual preference would be wrong.

Given the difficulty involved in explaining what would be wrong with parents choosing to use PGD to spare their children the harms of injustice and discrimination, it is, perhaps, some small

consolation that the ethics of PGD for intersex — as *per* other variations — is easier to resolve at the level of public policy than at the level of individual decisions. Social policymakers' decisions about acceptable uses of PGD will have consequences that individual couples' decisions will not. It is therefore more appropriate for them to take into account the loss of diversity that would ensue were they to licence various uses of PGD and thus (perhaps) to refuse to countenance them on that basis. Social policymakers also arguably have an obligation to promote an inclusive society, in which individuals with non-standard anatomies are able to participate in social, political, and economic life without suffering from discrimination. Support for PGD for some intersex conditions, genes for same-sex attractiveness, or for the physical markers of race, through provision of research funding, legislation to enable and facilitate it, and/or public subsidies would, it might be argued, constitute a dereliction of their duty to combat the discrimination and injustice that would drive the use of this technology. In so far as the private development and marketing of a technology of this sort inevitably relies on the existence of a larger legislative and regulatory context, it might also be argued a failure to prohibit such uses of PGD would also render policymakers complicit with it and thus represent a failure to combat discrimination and injustice appropriately.

These lines of argument suggest that the intuition that selection against non-standard variations of sexual anatomy would involve a morally reprehensible failure to respond appropriately to diversity can be rescued at the level of social policy at least. However, the ethics of parents deciding to normalise their children's anatomy using PGD remains more open at the end of my investigation than I had anticipated when I began it. PGD to select against genes for intersex conditions that involve serious medical harms can be justified by a concern for the well-being of the future child. PGD for merely cosmetic variations in sexual anatomy might also be justified on this basis. Arguing that parents should make decisions about their children's genes on the basis of concern for the sort of society that would result if the choice was universalised commits us to a form of eugenics that is equally — if not more — problematic as the social pressures that might motivate parents to want to spare their children the social consequences of being born with a non-standard sexual anatomy. Unlike surgery, PGD will not harm the child, nor is it plausible to object on the basis of the inability of the child to consent. Absent these objections, it is difficult to see what would be wrong with parents deciding to spare their children the social consequences of being born with a non-standard sexual anatomy. This is an uncomfortable conclusion because, as I noted above, the same considerations that argue for the moral permissibility of PGD for intersex conditions that do not threaten the physical health of individuals also bear on the ethics of PGD to select against other non-pathological human variations. The prospects of human diversity more generally, in the face of the normalising power of PGD, are therefore linked to the future of intersex.<sup>28</sup>

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