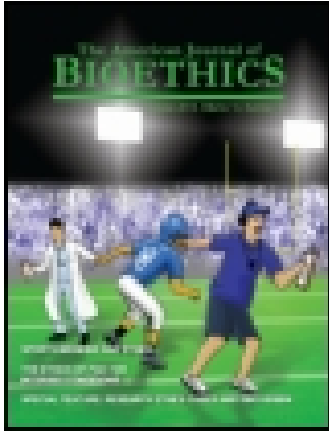


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Gender Eugenics Between Medicine, Culture, and Society

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refer to a biological “standard”, or, rather, to a state of non-problematic health, as we have termed it? On one hand, Sparrow seems to agree with the biostatistical theory (BST) on human health, developed by Boorse (1997), which views disease as a malfunction or limitation of normal individual functioning, that in some objective and empirical way impedes crucial biological abilities such as survival and reproduction. Following Boorse, Sparrow identifies between being healthy with being “normal.” On the other hand, however, Sparrow seems to defend a holistic theory (HT) of human health, inasmuch as his arguments to defend the use of PGD to select against the birth of an intersex child also include aspects like personal goals and subjective well-being. In contrast to BST, a holistic theory of health is not primarily driven by the aim of restoring biological functions, since it is the welfare of an individual, his or her subjective understanding of quality of life, that is of most concern. Indeed, for a position such as Sparrow’s, the concept of health developed by Lennart Nordenfelt might be a better reference than normal species functioning, for some of his arguments seem to imply similar ideas. Nordenfelt’s (2007) account considers health as “the ability, given standard circumstances, to reach all his or her vital goals.” In Nordenfelt’s view, the main reason to seek medical help lies in the recognition of a particular situation as personally problematic and avoidable, but not because that situation diminishes survival or other biological functions. Applied to the medical avoidance of intersex individuals: If an intersex condition is not regarded as problematic per se, as Sparrow claims, then we think that the justification for using PGD should continue taking the welfare of a child as the major moral

justification, rather than an account of “normal” sexual anatomy. ■

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In his article, Sparrow (2013) presents a vivid scenario of the “normalizing power” of preimplantation genetic diagnosis (PGD) through its selective capacities applied against inter-

sex conditions. From this application of PGD, he develops an argument in which a social ethic against discrimination and in favor of diversity can be outweighed by an individ-

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ualistic, parental ethic. Although fully relevant, this possibility described by Sparrow would benefit from relying on clearer definitions, from more appropriate examples, and from taking into account the social construction of disease, illness, gender, sex, and the relationship between them. We adopt a critical bioethics and anthropological stance, to argue that this parental ethic of choice cannot be dissociated from the medical, social, and cultural contexts in which it is shaped. This perspective leads us to suggest that resorting to “cosmetic” selection in the case of intersex conditions cannot be as easily justified as Sparrow argues.

At first, as Sparrow pointed out, it may be hard to clearly differentiate a cosmetic “social” condition from a serious “medical” condition that could require recourse to a medical intervention. It is unrealistic to believe that we could draw a consensual line between what is serious and what is not. For parents, the conception of seriousness will be different according to their own perceptions and ability to cope with a genetic condition and all that it involves (Scott et al. 2007).

However fundamental the parental perspective may be, the responsibility of such a decision has to be shared by many parties. Sparrow’s argument ignores the fact that PGD must generally be accompanied by genetic counseling. Some studies have pointed out that genetic counseling helps many parents come to terms with conditions and deem them acceptable, when they were initially thought to be problematic. Although there are still pregnancies that are interrupted after sex chromosome abnormalities are detected, after adequate counseling, it seems that the majority of parents do pursue the pregnancy (Pieters et al. 2011). This main feature of PGD may be nondirective and informative, and at the same time give prospective parents the relevant medical information they’ll need to consider the implications of their decision.

The two diseases used as main examples in Sparrow’s article are, in this sense, problematic because of their radically different phenotypic manifestations. The phenotype of the complete androgen insensitivity syndrome (AIS), an X-linked disease caused by mutations of the androgen receptor, does not have any sex ambiguity and corresponds to the phenotype of a “normal” woman. Therefore, usually the diagnosis is made during adolescence because of primary amenorrhea. The suffering associated with AIS is not “cosmetic” and not related to any sex ambiguity but is mainly associated with infertility, incapacity to become pregnant and carry a pregnancy to term. This may suggest that the main motivation to select against an intersex condition, in the case of AIS, is not abnormal genitalia but fertility issues. Congenital adrenal hyperplasia (CAH), however, may have greater medical repercussions, including sex ambiguity. CAH includes several rare autosomal recessive diseases resulting from mutations of gene coding for enzymes mediating the biochemical steps of production of the different steroid hormones from cholesterol by the adrenal glands (steroidogenesis) (Lin-Su et al. 2007). Therefore, CAH includes a very heterogeneous group of diseases and the majority of affected individuals do not show sex ambiguity. Indeed, the children with milder forms may not have any

clinical manifestations; all boys will have normal genitals at birth and only girls with more severe forms may have abnormal genitals at birth. We underline that dexamethasone is a safe and effective prenatal treatment to prevent the virilization of a female affected with CAH (Lin-Su et al. 2007) In conclusion, PGD is hardly justifiable for known familial AIS and CAH.

From a larger perspective, as PGD is a costly technique with a success rate of about 30% (Ferraretti et al. 2012), the possibility of its use for cosmetic purposes may depend on the social organization of the service provision. Because of ethical reasons or limited resources, jurisdiction with public coverage of PGD may be less interested in offering this technology for cosmetic purposes. Consequently, the accessibility to such a reproductive option may also be limited to permissive jurisdiction or jurisdiction without any laws on PGD (Soini 2007). For the people living in countries under such jurisdictions, the use of PGD for cosmetic reasons may only be accessible to wealthy couples through a two-tier system or with cross-border reproductive care, producing class medicine (Hudson and Culley 2011).

We must also consider that gender problems may result from parental decisions. Being uncertain about the sex of a newborn is one of the most agonizing situations for parents. This is a possibility with CAH, but not with complete AIS. This situation often prompts parents to quickly decide the sex of their newborn, potentially causing subsequent gender problems. The reasons for the parents’ decision might not be based on rational grounds. Usually, parents will want to avoid reliving the same situation and will, if possible, request PGD to prevent another case in their next newborn.

Adding to the confusion between medical and social/cosmetic conditions, Sparrow rapidly pushes aside the distinction between social gender and biological sex. The possibility that sex development disorders (SDD) produce specific genders can hardly be asserted. Also considering the diversity of phenotypes associated with intersex conditions, we can seriously doubt the deterministic association of sex and gender and its operationalization through PGD.

Sparrow’s argument is intended to make sense in a society with a strong belief about gender normativity. In the cultural environments where appearance, seduction, and sexual attraction are highly important for social achievement, an “abnormal” sex development could be perceived as a serious disability. However, concluding that intersex conditions are a source of discrimination may not be true in all contexts. There are groups where the social categories of gender are flexible, simultaneous, interchangeable, and inclusive (Boellstorff 2007; Nanda 2000). There are also cultures in which social roles are dissociated from sex, and where gender identities are constructed through a process of soul reincarnation. In all cases, the social construction of gender invites us to take into account the diversity of strategies that are used to follow or to subvert genders.

Social reactions may also have political implications that go beyond the hereditary case of intersex conditions. Sparrow considers that because intersex conditions have a rather

rare prevalence and because PGD is not widely used due to financial, technical, and logistical reasons, PGD will not affect as many people as it would if it were used to select against homosexual or non-white people. The limited scope of PGD for intersex conditions may be criticized on different grounds. First, reflecting on the title of the article, we may ask, which gender would be the target of eugenics? Because of the heterogeneity of the phenotypes, the prevalence, and the penetrance of the conditions under the “umbrella” of intersex—or preferably of sex development disorders (SDD)—we have serious doubts about a common isomorphism of gender and genetic, gonadic, genital sexes for intersex conditions. Moreover, if we consider that gender has no specific substance and that it is a construct that is simply performed in one’s daily routine (Butler 1990), we may find a greater political community of people who do not fit under the categories of men or women, independently of their genitalia. At last, we can add that genetic conditions may engage larger groups of people than what is implied by the prevalence of the conditions. The biosocialities of SDD may reach relatives with a family history of the conditions (Rabinow 1999). In that sense, the parental ethics of choice will have to justify its discriminatory agenda in the political arena.

To conclude, we wanted to demonstrate through this commentary that the “cosmetic” use of PGD for intersex conditions has medical, social, and cultural implications that, to a certain extent, concern more than just those whom Sparrow calls “social policymakers.” Empirical work still needs to be done to know whether it is possible to give a greater legitimacy to such a conception. One of the strengths of Sparrow’s article is that he presents the hybridity of intersex conditions playing out in both the social and medical fields. Sparrow’s insight is that such a condition may incarnate the next paradigmatic use of PGD. In a near future, new technological developments like noninvasive genetic screening that will easily and massively detect intersex

conditions may grant greater relevance to this seemingly marginal reflection. ■

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