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The Social Costs of Preempting Intersex Traits

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The Social Costs of Preempting Intersex Traits

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Is it “morally permissible” to use preimplantation genetic diagnosis (PGD)—genetic profiling of embryos prior to in vitro fertilization (IVF)—to select against intersex traits? Robert Sparrow (2013) presents a compelling argument centered on the claim that “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” (36). Although Sparrow is clear that the intellectual journey he takes us on begins with trepidation around the ethics of PGD for intersex traits, he leaves us concluding: “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” (36).

As a sociologist who is personally and professionally connected with the intersex community and the struggles that individuals with intersex traits face, I think it is necessary to revisit several of the assumptions that uphold this conclusion. First, Sparrow assumes the “reduction in the number of children born intersex” (35) would not harm diversity because the intersex community is invisible and/or nonexistent, unlike racial and sexual minority communities, when in fact its existence is evidence of sex variability that opens up new understandings of diversity. Second, Sparrow assumes that the social and psychological harm individuals with intersex traits express is due exclusively to a “hostile social environment,” when the pain and suffering originates with the medical treatment endured (i.e., irreversible surgical interventions and withholding diagnoses). Lastly, Sparrow assumes that there is a clear consensus about the extent and severity of the health risks associated with intersex traits, rather than accurately reflecting the actual inconsistent and limited evidence about these risks. In the sections that follow, I visit each of these assumptions in an effort to continue the dialogue about the ethics of PGD for intersex traits.

CHALLENGING BOUNDARIES

If PGD were regularly used to select against intersex traits, we would lose the natural diversity of sex variability under the guise that we are protecting individuals from harm. In actuality, what we are protecting are binary ideologies about sex and its presumed correlation with gender. This is sex (not “gender”) eugenics. Despite the fact that the distinction between sex and gender may not be pertinent or prevalent in mainstream philosophy, I find this distinction crucial in considering the ethics of using PGD to select against intersex traits. Sex is our social understanding of our biological disposition—for example our genital, gonadal, or chromosomal characteristics (Fausto-Sterling 2000). Gender, on the other hand, is a stratification system with consequences at the individual, interactional, and institutional levels of society (Risman 2004).

When Sparrow claims that it is “much less plausible to object to a reduction in the number of children born intersex [as opposed to objecting to a reduction in racial or sexual minorities], as a result of PGD, on the grounds that [it] would jeopardize a distinctive ‘way of life’ or ‘culture’” (35), I’m left wondering if he is at all familiar with the intersex community. Individuals with intersex traits force society to disentangle sex and gender, and in the process, open up new possibilities for embracing all sorts of human diversity. The recourse of using PGD to select against intersex traits would eventually lead to an obliteration of a community whose members take pride in their bodies and identities.

The intersex community is only “invisible” (Sparrow 2013) to those who choose to ignore it; thus, using PGD to select against intersex traits is not somehow different from selecting for race or sexuality (if that were a possibility). A simple Google search of “intersex” would lead one to many intersex organizations and support groups, including the United States’ AIS-DSD

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Support Group (<http://www.aisdsd.org>), Organisation Intersex International (<http://oiiinternational.com>), and the United Kingdom's Androgen Insensitivity Syndrome Support Group (<http://www.aissg.org>). Additionally, there are many individuals with intersex traits who are open about their experiences in ways that positively challenge sex, gender, and even sexuality binaries. Hida Vilorio (<http://hidaviloria.com>) is one example. More voices can be heard at The Interface Project (<http://www.interfaceproject.org>), an organization whose mission is to spread the message that "No Body is Shameful."

WHEN MEDICINE HARMS

It is the case that many individuals with intersex traits report substantial social and psychological harms tied to their "abnormalities." However, if one wishes to use the social and psychological harm argument to justify PGD to select against intersex traits, it is important to acknowledge that it is largely, albeit perhaps not exclusively, the medical field—not the intersex trait itself—that causes such stigmatization and creates the "hostile social environment." Historically, the medical profession unethically approached intersex traits. Many medical professionals withheld the intersex diagnosis from those being "treated" and forcefully insisted parents do the same. At the same time, medically unnecessary interventions—for example, irreversible surgeries—were being justified under the guise of normalizing one's body in ways assumed to be helpful rather than harmful (Karkazis 2008). Many individuals with intersex traits are understandably pained by how medical providers withheld and/or misrepresented their diagnosis (Holmes 2008a; Karkazis 2008; Preves 2003). When someone is lied to about one's diagnosis and learns that one's body was surgically altered because of a constructed "abnormality," how could we reasonably expect that person *not* to be harmed? Although contemporary intersex activism continues to challenge the practices and procedures of dominant intersex medical care, a colleague and I have argued that intersex traits continue to be presented to parents as medical emergencies in ways that establish and justify the need for medical interventions on healthy bodies (Davis and Murphy 2013). My research also shows that parents face substantial resistance from medical professionals when they question medical recommendations, perhaps offering an explanation for why irreversible surgeries continue (Davis 2011). If the intersex diagnosis were no longer withheld from individuals with intersex traits and medically unnecessary surgeries were postponed until these people were mature enough to make their own decisions (see Holmes 2008b), we might see a drastic decline in the social and psychological harms associated with intersex traits.

Because the medical profession, not the intersex trait itself, is a major source of the social and psychological harm that perpetuates intersex stigmatization and the "hostile social environment" that individuals with intersex traits encounter, justifying PGD by pointing to such

negative outcomes is ill-advised and a circular logic. If we are going to suggest that the use of PGD is "morally permissible"—which I personally wouldn't advise—we need to recognize that a major source of the shame and stigma individuals with intersex traits face originates in the medical profession.

A BLACK BOX OF RISKS

While Sparrow expresses hesitation in using PGD when the goal is to avoid "cosmetic variations" associated with intersex traits, he ultimately concludes that PGD "might also be justified" (36, emphasis added). I find this contradiction troubling. But what I find even more worrisome is the assumption that PGD "can be justified" when the trait "involve[s] serious medical harms" (Sparrow 2013, 36, emphasis added). This assumption takes for granted that we have reliable and valid evidence of the medical risks associated with intersex traits. In actuality, the risks associated with various intersex traits vary substantially from study to study, leaving us to act on (what might be misguided) predictions about health risks rather than scientific facts.

We know relatively little about the health risks associated with intersex traits. For example, depending on which study you consult, complete androgen insensitivity syndrome (CAIS) might pose a "serious medical harm" and thereby could justify, at least theoretically, the use of PGD to select against CAIS if such trait is detectable prior to IVF. However, there is no clear consensus on the malignancy risks associated with CAIS. For example, Dr. Rebecca Deans and colleagues analyzed 62 studies of malignancy risks associated with complete androgen insensitivity syndrome and found gonadal malignancy ranged from 0% to 22% (Deans et al. 2012). They concluded, "An accurate estimate for adult malignancy risk is unavailable" (Deans et al. 2012, 894). Congenital adrenal hyperplasia (CAH) is another condition that is often pointed to when one claims that intersex traits pose serious health risks. While some forms of CAH can be life-threatening if left untreated, it is also the case that there is a remarkable "range of severity" associated with CAH that can be minimized with appropriate medical care (Merke and Bornstein 2005, 2125). Given this inconsistent evidence of the health risks associated with intersex traits, we cannot point to them to justify the use of PGD in selecting against intersex traits.

INSIGHTS FROM WITHIN

When we begin to discuss the moral merits of using PGD to confront the problems associated with intersex traits, I fear we are missing an understanding of how individuals with intersex traits and their families experience these "disorders." Between October 2008 and April 2011, I conducted 65 interviews with individuals with intersex traits, parents of such individuals, medical professionals, and intersex advocates from across the United States. Among my major findings was that many people with intersex traits are

leading full and happy lives. In our community you will find an assortment of parents, partners, and folks with vibrant careers. Many have not allowed the shame and stigma to taint their lives. Others have made the intersex trait an important piece of their identity. Some publicly push boundaries about sex and gender (and even sexuality) by, for example, doing public talks about their experiences on radio and television shows. This is not to suggest that individuals with intersex traits have moved beyond the shame and stigma associated with intersex traits. However, what I've found in my research is that a major source of the social and psychological harm originates in the medical profession and could be prevented with open, honest, and accurate communication and information. I therefore find it problematic to frame the use of PGD as "morally permissible" in addressing—or worse, avoiding—the problems associated with intersex traits when the justifications provided rely on misinformed assumptions about the visibility of the intersex community and the boundaries it challenges, the origins and status of intersex shame and stigma, and the health risks associated with intersex traits. ■

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The Ethics of PGD for Intersex Conditions: Problems With the Diversity Argument

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In his well-crafted target article, Sparrow (2013) explored the issue of preimplantation genetic diagnosis (PGD) to avoid the birth of intersex children. After discussing a variety of arguments, he concluded: "It is difficult to see what would be wrong with parents deciding to spare their children the social consequences of being born with a nonstandard sexual anatomy" (36). Having seen that the case against PGD to avoid the birth of intersex children is difficult to make at the parental level, he suggested that the argument is more morally convincing at the level of public policy. According to Sparrow, society has an interest in diversity, using PGD to avoid the birth of intersex children decreases that diversity, and therefore it is morally justifiable to set public policies against it. I find this argument to be problematic.

Sparrow admits to the negative social consequences of being born with a nonstandard sexual anatomy, and further admits that these consequences are sufficiently severe so as to render parental concern and preventive actions (such as PGD) to be legitimate. Consequently, the gains to society based on the increased diversity that comes from more intersex individuals must be sufficiently large so as to outweigh the negative social consequences to those negatively affected. Because Sparrow explained these negative social consequences, there is no point in repeating them here. Instead, I proceed directly to examine the diversity gains that can be expected to accrue to society and attempt to determine whether they are sufficiently large so as to outweigh the negative social consequences

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