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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 to 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.
Support 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 Viloria (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 im-
portant piece of their identity. Some publicly push bound-
aries about sex and gender (and even sexuality) by, for ex-
ample, doing public talks about their experiences on radio
and television shows. This is not to suggest that individu-
als 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 prob-
lematic to frame the use of PGD as “morally permissible”
in addressing—or worse, avoiding—the problems associat-
ed 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 sex-
ual 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 fur-
ther 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 neg-
atively affected. Because Sparrow explained these nega-
tive social consequences, there is no point in repeating
them here. Instead, I proceed directly to examine the di-
versity 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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