

DIVERGENCE OR DISORDER?

the politics of naming intersex

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ABSTRACT The conditions once known under the umbrella terms *intersex* and *hermaphroditism* are now generally being called *disorders of sex development* in medical settings. The terms might seem synonymous, but in fact there are significant differences with controversial consequences. *Hermaphroditism*, an older term that can still be found in many medical writings, is vague, demeaning, and sensationalistic, conjuring mythic images of monsters and freaks. In the 1990s, activists advocated *intersex* to describe discordance between the multiple components of sex anatomy, but that word alienated many parents of affected children, as it suggests a self-conscious alternative gender identity and sexuality. *Disorders of sex development* also refers to intersex, but it deemphasizes the identity politics and sexual connotations associated with *intersex*, avoids the degradation associated with *hermaphrodite*, and instead highlights the underlying genetic or endocrine factors that cause prenatal sex development to take an unusual path. I argue that using *disorder* is problematic, because it implies medical conditions in need of repair, when some intersex anatomies, though atypical, do not necessarily need surgical or hormonal correction. I advocate a less pathologizing new term, *divergence of sex development*, that might reduce some of the conflict over nomenclature and satisfy intersex people, their parents, and their doctors.

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AS A HISTORIAN, I AM ACCUSTOMED to thinking about change over time, and I know that change often happens slowly. Not so with the recent nomenclature shift in the world of intersex. Many of the conditions previously grouped under the broad categories of “hermaphroditism” and “intersex” are now generally being called *disorders of sex development* (DSDs) in medical settings. The new term was agreed upon in October 2005 at a conference hosted by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology (hereafter called the Chicago Conference) and is quickly becoming ubiquitous (Hughes et al. 2005). Though participants at the Chicago Conference reached the decision to change the nomenclature by consensus, it has not been universally embraced. Each of these three terms—*hermaphrodite*, *intersex*, and *disorders of sex development*—is controversial and divisive. In this paper I explain the ongoing debate and suggest a new term, *divergence of sex development*, that might reduce some of the conflict and satisfy intersex people, their parents, and physicians.

How to name a diverse set of conditions involving aspects of external genitalia, sex chromosomes, internal reproductive anatomy, and gender identity raises political as well as medical questions. The choice of nomenclature influences not only how doctors interpret medical situations but, equally as important, how parents view their affected children, how intersex people understand themselves, and how others not directly involved in medical settings—such as gender and legal scholars, historians, and media commentators—conceive of and theorize about gender, sex, and the body.

The three terms might seem synonymous but in fact there are significant differences with controversial consequences. *Hermaphrodite* and *hermaphroditism* are older words that can still be found in medical writings, but they are vague, demeaning, and sensationalistic. Those with gender atypical anatomy used to be called hermaphrodites, and beginning in the 19th century, doctors termed a sweeping variety of related medical conditions hermaphroditism (Dreger 1998; Matta 2005; Reis 2005). The word *hermaphrodite* conjures images of mythical creatures, perhaps even monsters and freaks, and so it is not surprising that people would want to avoid this aspersion. Historically, *hermaphrodite* has been one of the more neutral descriptors; derogatory terms such as *freak of nature*, *hybrid*, *impostor*, *sexual pervert*, and *unfortunate creature* pervade early medical literature. In an 1842 article on malformations of the male sexual organs, for example, one doctor referred to “these mortifying and disgusting imperfections” (Mettauer 1842, p. 43).

Starting in the early 1990s, activists instead advocated *intersex* (first introduced by biologist Richard Goldschmidt in 1917) to describe the set of conditions previously called hermaphroditism—namely discordance between the multiple components of sex anatomy (internal reproductive organs, external genitalia, and sex chromosomes). The Intersex Society of North America (ISNA), founded by Cheryl Chase, sought to lift the stigma perpetuated by negative labeling and sup-

ported individuals and groups with diverse congenital conditions that fall under this rubric, including (but not limited to) hypospadias, Turner's syndrome, congenital adrenal hyperplasia, androgen insensitivity syndrome, 5 alpha-reductase deficiency, and sex chromosome mosaicism. Even while most often using *intersex* to refer to themselves, some of these early activists also consciously reclaimed the term *hermaphrodite*, co-opting the negative label in a bold effort to call attention to their concerns and to dispel pathological connotations associated with their conditions (Chase 1998; *Hermaphrodites Speak!* 1996). *Intersex* thus took on a political valence, as activists proudly sported T-shirts that proclaimed themselves "Hermaphrodites with Attitude" and, wearing these shirts, protested at medical conferences against stigmatization and unnecessary infant genital surgeries (Preves 2004).

Some parents, though, were uncomfortable with the *intersex* label for their affected children. To them, *intersex* meant a third gender, something in-between male and female. They wanted to see their newborn babies as girls or boys, not as *intersex*. Even though *intersex* activists advocate raising children as girls or boys rather than in a third, in-between category, some parents found the label as frightening, off-putting, and freakish as *hermaphrodite*. Dr. Arlene Baratz (2006), for example, has affirmed that, as a parent of a daughter with androgen insensitivity syndrome, she was "shocked and unnerved" when she first confronted the words *intersex* and *pseudohermaphrodite*. She has said that other parents in her support group have rejected the *intersex* label because of its implications. Others have associated the word *intersex* with sexuality, eroticism, or sexual orientation and have had trouble reconciling their child's anatomical condition with thoughts of his/her future sexual activities (Dreger and Herndon n.d.).

For their part, doctors have never fully incorporated *intersex* into their vocabulary, and so the word has suffered from a lack of specificity in the medical world. There has never been agreement on what *intersex* means or on what conditions constitute *intersex*. Lacking a suitable alternative, many physicians still use (at least until very recently) the 19th-century terms based on *hermaphrodite*, including *male pseudohermaphrodite* (characterized by ambiguous external genitalia with male gonads), *female pseudohermaphrodite* (ambiguous external genitalia with female gonads), and *true hermaphrodite* (having both testicular and ovarian tissue regardless of external characteristics). The term *hermaphrodite* thus has continued to humiliate some patients and embarrass some parents. Some physicians have tried using the *hermaphrodite* label in their medical records but avoided saying the word in front of children or parents, for fear it would cause alarm and harm, leading to an awkward penumbra of secrecy and shame surrounding these conditions (Dreger 2005).

Supporters of the alternative term *disorders of sex development* believe it deemphasizes the identity politics and sexual connotations associated with *intersex* and the degradation associated with *hermaphrodite* and instead draws attention to the underlying genetic or endocrine factors which cause prenatal sex development

to take an unusual path. Many proponents of the name change believe that using *DSD* has the potential to create better medical care for affected children and their families because it avoids sensationalizing health conditions, allowing doctors to focus solely on therapeutic issues (Vilain et al. 2007). Of course, each specific condition has its own terminology and its own protocol, but thinking across diagnoses has advantages, including the potential for encouraging clinicians to collaborate in multidisciplinary teams when working with patients faced with similar medical and psychosocial needs.

The 2005 Chicago Conference, composed of 50 invited international experts in the field (principally MDs), included only two intersex adults and no parents of affected children.¹ Despite its limitation in this regard, however, the conference was itself pathbreaking, specifically because intersex adults were included in the policy-making process at all. Participants came to other important agreements beside the name change, including the need for more open communication between doctors, patients, and families, and a more conservative approach to surgery. Perhaps most importantly, the consensus statement acknowledged that there is little evidence that infant genital surgery does what it has been assumed to do: improve attachment between child and parents, ease parental distress about atypical genitals, ensure gender identity development in accordance with the assigned gender, or eliminate the intersex condition.

The term *disorders of sex development* may promise clarity for doctors who diagnose patients with such conditions and provide some relief for parents of children born with such conditions, but it has produced considerable rancor among some adults who identify as intersex. Specifically, their problem is with the word *disorder*. The disability rights movement has taught us that atypicality does not necessarily mean disordered. Doesn't *disorder* imply that something is seriously wrong and needs to be corrected?

If using the word *disorder* connotes a need for repair, then this new nomenclature contradicts one of intersex activism's central tenets: that unusual sex anatomy does *not* inevitably require surgical or hormonal correction. ISNA (the primary activist organization) advocates eliminating infant or childhood genital surgical procedures other than those that are life-saving, such as necessary repair in cases of bladder exstrophy or surgeries to ensure adequate voiding. The so-called normalizing genital surgery that most infants born with unusual genitals endure does not "cure" the intersex condition and is often simply cosmetic. In fact, allegedly "corrective" surgery sometimes does more harm than good, sometimes causing incontinence and permanent loss of sexual sensation. As Alice Dreger (2004a), past chair of the Board of Directors of ISNA, put it, "Why perform irreversible surgeries that risk sensation, fertility, continence, comfort, and life without a medical reason?" Using the word *disorder* elides a crucial point that

¹Cheryl Chase of ISNA and Barbara Thomas of the German group XY-Frauen were the two intersex adults who attended (Thomas 2006).

some of these surgeries, such as clitoral recession, have primarily social rather than medical goals. As Suzanne Kessler (1998) declared, “gender ambiguity is ‘corrected,’ not because it is threatening to the infant’s life, but because it is threatening to the infant’s culture” (p. 32).

More broadly, should we think of intersex bodies as disordered when they actually are more common than most people think? Since at least 1 out of every 2,000 babies is born with such anatomy, perhaps it makes more sense to think of this phenomenon as part of the natural, albeit unusual, spectrum of human conformation.² The label *disordered* marks an individual as patently impaired, a body that needs to be poked and prodded until it fits neatly into the recognizable binary categories of female and male (Holmes 2002). Using the word *disorder* thus contradicts a central precept of disability politics, that physical difference need not be seen as inherently insufficient or defective (Thomson 1997).

The idea that culture, rather than the body, needs to be changed has informed feminist scholars in addition to disability theorists (Dreger 2004b). The notion that biological sex may not be as rigidly binary as conventionally thought has appealed particularly to academic feminists (Butler 2001; Dreger 2004c; Hird 2000; Holmes 2000; Morland 2001). In turn, some intersex people have benefited from the feminist understanding of the complicated relationship between gender and sex. Some have corroborated the feminist supposition that we should think of sex, like gender, on a continuum, as something more flexible than strictly female or male. Some have felt more comfortable identifying not solely as female or as male, but as intersexed, with a combination of physical and behavioral characteristics (Cameron 2006; *Yellow for Hermaphrodites* 2004). From the perspective of sexual politics, then, shifting from *intersex* to *disorders of sex development* represents a denial of a core feminist and intersex-activist principle regarding the fluidity of sex and gender.

Suspicion among intersex activists about the medical management of intersex is based on their knowledge of the long, painful history of doctors’ approach to intersex people. Ever since the early 19th century, when doctors began to professionalize and publish their cases in medical journals, we can trace not only their cruelly judgmental descriptors of these conditions and people, but the damaging therapeutic treatment they have dispensed as well. The ways in which intersex bodies have been scrutinized and pathologized have been negative, harmful, and based, not on medical necessity but on social anxieties about marriage, heterosexuality, and the insistence on normative bodies (Matta 2005; Reis

²The figures on the incidence of intersex range widely, depending on which conditions one includes in the calculation. One incident in 2000 births represents a moderately inclusive estimate. Estimators who are more selective in determining what characteristics qualify as intersex put the figure at 1 in 5,000. Researchers at Brown University recently stated that the frequency of people receiving “corrective” genital surgery is between 1 and 2 per 1,000 live births. The Chicago Conference put the figure at 1 in 4,500. See Blackless et al. 2000; Fausto-Sterling 2000; Hughes et al. 2005; Sax 2002.

2005). The prevention of homosexuality has long motivated surgical and non-surgical sex assignment in this country, for example, and even today the use of the prenatal drug dexamethasone as a treatment for congenital adrenal hyperplasia may be linked to its deterrence (Casper and Muse 2006; Meyer-Bahlburg 1999; Sytsma 2006).³ Those with atypical genital anatomies have had their bodies reshaped and sculpted to look (and presumably act) more typical, even though evidence suggests that many of those who have undergone such life-altering surgeries have not had more successful outcomes and happier lives than those who have avoided surgery (Dreger 1999; Morland 2005; Reis 2005).

This long history of strife is one reason some intersex activists are wary of having a new, medicalizing term thrust upon them. At a recent ISNA-sponsored symposium, embedded in the annual Gay and Lesbian Medical Association meeting in October 2006, Peter Trinkle, the board president of Bodies Like Ours, an intersex educational and peer support organization, voiced complaints from a wide spectrum of intersex activists who contend that the new term further stigmatizes and pathologizes their lives. Using *disorders of sex development*, Trinkle argued, suggests that the ends of sexual development should be “normal” male or female bodies, whereas the term *intersex* seems to imply and accept biological diversity. Many worry that promoting the use of pathologizing medical terminology will overshadow the political progress and advances in gender and disability theory that have been gained since the early 1990s (see Dreger and Herdon n.d.).

Where does this leave us? Some intersex people (though not all) do not want their conditions to be pathologized as “disorders.” Parents of affected children do not want them to be considered “abnormal,” or intersexed. They want “normal” girls and boys. For their part, doctors want to provide the best care possible, and, ironically, in their world labeling something a “disorder” normalizes it. Doctors (and insurance companies) understand disorders.

Hence the dilemma: whose naming should/will prevail?

Another way of posing this question is: whose needs should be met? Most speakers at ISNA’s 2006 symposium—including doctors, social workers, therapists, intersex adults, and parents—agreed that using the term *DSD*, despite its limitations, would likely benefit infants and children. Indeed, in 2005 an independent group of intersex people, parents, and clinicians organized by Dreger as ISNA’s Director of Medical Education and known as the Consortium on Disorders of Sex Development, used the term *DSD* in their novel clinical guidelines and parents’ handbook, because they believed it would advance “patient-centered care” (Consortium on Disorders of Sex Development 2006). If it takes using this new term to get medical professionals to listen to what activists want,

³According to Meyer-Bahlburg (1999), dexamethasone is thought to “reduce the degree of genital masculinization (with all its implications) in female newborns with classical CAH.” The “implications” are spelled out in the article: body image problems, lack of maternal feeling, and lesbianism.

then perhaps the end justifies the means. Most of the authors of the Consortium's two books hold this pragmatic position, though even in that group, three of the contributors objected to the use of the word *disorder* and added disclaimers to the Consortium Web site.

By adopting the term *disorders of sex development*, and granting doctors the power to do the naming, do we, in fact, give disproportionate control to the medical establishment? I think we do, even though using *DSD* in the medical arena does not preclude intersex people from claiming the term *intersex* for themselves, as adults. One speaker at the 2006 ISNA symposium who has androgen insensitivity syndrome explained that she used to recoil from the *intersex* label because she thought it was just a euphemism for *hermaphrodite*. Now that *DSD* is available, she is better able to incorporate intersex into her identity; consequently, she thinks of herself as a woman who is intersexed because she has a *DSD*.

My suggestion is to retain the acronym *DSD*, but have it stand for "divergence of sex development." *Divergence of sex development* would be less pathologizing than *disorder of sex development* and yet would satisfy those who want to minimize the emphasis on genitals, gender identity, and sexual orientation that the *intersex* label may encourage. Using *divergence*, intersex people would not be labeled as being in a physical state absolutely in need of repair. *Variations of sex development* has been suggested for the same non-stigmatizing reason, but the term has been objected to because *VSD* is already a medical acronym (for ventricular septal defect) and also because a simple variation might downplay the seriousness of some intersex conditions such as congenital adrenal hyperplasia (Diamond and Beh 2006; Elford 2006).

The *divergence of sex development* designation would neither prohibit medical intervention nor inevitably demand it. *Divergence* still implies a departure from a typical developmental path but in terms of incidence, the word is consistent with reality. As with any divergence, doctors would be compelled to see if there was a serious underlying organic health problem requiring intercession and then, using the same principles of medical ethics applied to other conditions, make therapeutic choices accordingly, without imparting a sense of stigma or shame to patients or parents.

While the term *intersex* can still be a useful political expression for adults, using *divergence of sex development* in the medical sphere would allow physicians to see intersex issues in all their complexity, and that is in everyone's best interest. I am not so unrealistic as to think that change among doctors or insurance companies (who might only pay for treatment of "disorders") will come easily. At the minimum, however, the new term could sensitize clinicians to the implications of the language they use. With non-stigmatizing, non-correction-demanding nomenclature, doctors, therapists, and parents can assess those affected more responsibly and ethically—the desired goal in this, and indeed in any, medical situation.

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