

What's in a Name?

The Controversy over "Disorders of Sex Development"

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For a decade now, the two of us have taken a critical stance toward the medical treatment of children with intersex conditions. While clinicians have been overwhelmingly focused on how to turn children with intersex conditions into “normal” boys and girls, we have asked why bodies that violate gender rules require treatment at all, and we argued that it was the cultural need for a coherent gender—a single and true sex, if you will—that drove what was often unethical treatment of these children and adolescents. Intersex, as we understood it, was largely a problem of *meaning* rather than of medicine: the gender-atypical features associated with intersex conditions have been misconstrued as requiring intervention. So in 2006, when the U.S. and European endocrinological societies published a consensus statement announcing a significant change in nomenclature for those born with atypical sex anatomy, whereby variations on the term “hermaphrodite” and “intersex” would be replaced by the term “Disorders of Sex Development,” or DSD, we were faced with the question of the meaning of this new terminology and how to understand its implications for the treatment of intersex conditions.¹

Controversy erupted almost immediately over the new nomenclature. The arguments for and against the shift echoed our own internal grappling with this terminology: did it reinforce the tendency to view gender-atypical bodies

as pathological, or could it mark an important advance in the treatment of the underlying conditions so frequently associated with gender-atypical bodies? To what extent should we support and make use of the term in our ongoing critical work? One of us initially eschewed it, feeling it left intersex conditions fully medicalized.² But our experience with parents and doctors also led us to acknowledge the limitations of the current labels, whose mere utterance could be fighting words. Struggling with the host of competing stakes, we finally found ourselves in a curious and at times uncomfortable position: critics of medicalization arguing in favor of its benefits.

Tracing the history of the terminology applied to those with atypical sex anatomy reveals how these conditions have been narrowly cast as problems of gender to the neglect of broader health concerns and of the well-being of affected individuals. By raising the possibility of rethinking what counts as a medical concern, the new terminology can help to refocus medical care on lifelong health; it could thus not only contribute to improving medical care but also to promoting attention to affected individuals' quality of life.

Development of Terminology

For centuries, people with atypical sex anatomy have been labeled hermaphrodite.³ By the late nineteenth century, a consensus emerged in medicine that gonadal histology was the most reliable marker of a person's “true sex” and that there were three classificatory types of hermaphroditism: male pseudohermaphroditism, female pseudohermaphroditism, and true hermaphroditism.⁴ People diagnosed with one of the forms of pseudohermaphroditism were those with either ovarian or testicular tissue whose phenotypes contradicted their “true sex” indicated by their gonads. Individuals possessing both ovarian and testicular tissue (either as one ovary and one testis, or as what is called an ovotestis) were considered true hermaphrodites. Since the nineteenth century hermaphroditism was not only understood as a disorder but referred to a problematic type of person—a connection that would prove important in contemporary debates and in our own thinking.⁵

The term intersex has a more recent history. It was first applied to sexual ambiguity in moths in the early twentieth century.⁶ Clinicians gradually adopted the term to refer to sexual ambiguity in humans, but its use over the intervening century has been inconsistent and variable.⁷ Despite a few isolated instances referring to intersex as a diagnosis (notably, an article by David Williams in 1952), clinicians have not viewed it as a diagnostic term.⁸ Rather, much like hermaphrodite, intersex is an umbrella term that medicine adopted to refer to a range of conditions in which sex development is atypical.

During the second half of the twentieth century, as medical techniques were refined and medical specialization became more defined, diagnostic terms proliferated and were mapped onto the earlier hermaphrodite taxonomy. Thus, an-

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drogen insensitivity syndrome, for example, was understood more generally as a case of male pseudohermaphroditism.⁹ By the end of the twentieth century, intersex was widely used in the medical literature as a synonym for hermaphrodite, and the older taxonomy based on hermaphroditism and the newer diagnoses of specific conditions coexisted, if at times uneasily. Despite the variability of the terms, one thing remained consistent: intersex was understood to denote kinds of people who violated prevailing cultural understandings of male and female bodies, and for whom physicians sought to provide a coherent gender.

The use of the term intersex became newly contentious beginning in the 1990s, when activists appropriated the term for their own use. Newly politicized and no longer restricted to medicine, intersex came to mean many things to different people, fueling widespread disagreement over what diagnoses—and thus who—counted as intersex. Because activists were interested in bringing together people who shared similar treatment and life experiences, they made use of the term intersex to refer to any condition in which reproductive or sexual anatomy does not conform to typical understandings of male and female. Thus, they often included conditions such as Turner syndrome and hypospadias that clinicians would not locate within the older taxonomy.¹⁰ Some activists further embraced intersex as an identity, likening it to any of a number of other categories of gender identity that one can claim.

The expansion of conditions considered intersex drew criticism from clinicians and parents, among others, who variously felt the term intersex referred only to conditions for which genitalia are “ambiguous,” or only to those conditions for which chromosomal type and phenotype are discordant. Still others held that the term did not refer to conditions in which the genitals may be atypical but for which the brain has had gender-typical hormonal exposure.¹¹ Moreover, many people—and perhaps the majority of parents of people affected with these conditions—resisted the imputation of identity associated with intersex. Not surprisingly, many parents and clinicians found the term’s connotation that the affected person is neither male nor female (or is both male and female) deeply objectionable. They felt it did not apply to those conditions for which gender assignment is straightforward or to those people who had undergone genital surgery (whose “intersexuality” had been “corrected”). The term intersex has been viewed as stigmatizing by many doctors and parents and by some of the individuals who have these conditions. For this

reason, doctors have largely avoided using the term in the clinical setting despite its widespread use in the medical literature over the last fifty years.¹²

Over time, people began to recognize a need to change aspects of medical care provided to people with intersex conditions, such as adopting a more cautious approach to genital surgery and providing psychosocial support for families. As this trend took hold, and as activists and advocates became increasingly interested in working in partnership with parents and doctors toward this end, it became clear that the existing nomenclature—and particularly the term intersex—presented a barrier to conversation, collaboration, and, hence, the im-

provement of care. Many took intersex to be a politicized term identified with radical gender activists who advocated deferral of sex assignment and opposed early genital or gonadal surgeries. Perhaps most importantly, advocates for improved care—who were trying to convey the message that questions of gender should not be the primary focus of medical care—came to believe that the term intersex actually reinforced and refocused conversations on those very questions.¹³

Implications of Continuing Medicalization

The new nomenclature aims to circumvent the fraught history of the terms hermaphrodite and intersex. The use of these terms to identify kinds of people, rather than individuals with conditions that could have profound health consequences, is not only inconsistent with contemporary medical nomenclature but appears to have helped shape unethical aspects of treatment characterizing medical management since at least the 1950s.¹⁴ Resistance to the term has come most forcefully from those who experience the introduction of DSD as yet another instance of medical “pathologization” of their bodies and their selves.¹⁵ David Cameron’s powerful and succinct declaration—“I am a person, not a disorder”—encapsulates the aim of intersex activism since its beginning.¹⁶ Cameron’s is an entirely apt response to the position that intersex conditions can be corrected or ameliorated through cosmetic genital surgery, hormone replacement, and secrecy about bodily traits and their treatment—a position that was intended to minimize the shame and stigma associated with gender-atypical bodies but that effectively promoted shame and stigma. If DSD merely replaces intersex, then it serves only to reinforce a history of medicalization that has brought much physical and emotional pain. For those who have refused to identify as intersex, however,

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the term DSD brings a welcome clarification that theirs is a medical condition, not an identity.

Both the resistance to and the enthusiastic embrace of the new nomenclature underscore the fact that intersex conditions have been understood for more than half a century as “disorders like no other.”¹⁷ Doctors have thereby justified treatment of these conditions in ways that defy accepted medical practice and that violate long-established principles of bioethics. The shift from variations on hermaphroditism and intersex to DSD and clinically specific diagnoses may be understood not as a politically correct attempt to replace stigmatized terms with less stigmatized terms, but as an effort to replace terminology that has shaped harmful treatment practices with terminology consistent with medicine that, however problematically, regards all deviations from a norm it itself defines as being “disorders.”

In place of the pathologizing language of disorder, some have suggested the terms “variation” or “divergence.”¹⁸ These alternatives rightly indicate that differences of anatomy should be regarded no differently than other inconsequential anatomical differences—eye color, for example. Although these alternatives are intended to depathologize gender atypicality, their narrow concern with establishing atypical anatomy as acceptable continues to mark differences of gender and genitalia as the primary problem of intersex conditions. This strategy may trivialize the genuine medical needs of those with atypical anatomies, whether in the neonatal period (as with congenital adrenal hyperplasia) or across the lifespan (as with many other conditions). It may also privilege anatomical difference over and against these needs. The new nomenclature brings with it the possibility of focusing on genuine medical needs while—and this must be the ongoing challenge—understanding different anatomies that are symptomatic of these conditions as mere variations. Viewed in this way, the change in nomenclature offers the possibility that intersex conditions can be transformed from “disorders like no other” to “disorders like many others,” and so must be treated both clinically and ethically in ways that are consistent with other medical conditions.

Identity and Disorder

Perhaps ironically, what makes intersex conditions like no other is that they have been treated, both by physicians aiming to “correct” them and by activists resisting these same practices, as an issue of identity. If the change in nomenclature can promote the important development of attention to the genuine medical issues associated with intersex conditions and so displace the concerns with gender identity, then intersex can be counted among the many disorders for which the terms “normal” and “abnormal” are taken to mark differences—some consequential, others less so—in the functioning of human bodies.

Changing the nomenclature is not a panacea: there remain significant problems in lumping together widely disparate conditions whose only common feature is that they produce

gender-atypical phenotypes. Thus, the introduction of DSD marks another moment in the history of medicalizing bodies that defy the norms of so-called natural sex development. Debate over the nomenclature has focused overwhelmingly on how best to characterize an umbrella term for these conditions, but this focus is misplaced. The critical move is the recommendation that DSD be used together with a system based on *clinically descriptive* terms—for example, “androgen insensitivity syndrome” and “congenital adrenal hyperplasia.”¹⁹ It would be naive to think that the change in nomenclature can destigmatize gender atypicality. It is the latter shift—that is, a focus on the specific disorders in question—that holds immediate promise for demedicalizing aspects of the condition that have been improperly pathologized.

Despite the rancor provoked by the debate over the new nomenclature, we should not lose sight of the fact that almost everyone involved in this discussion would agree on matters concerning care for those diagnosed with intersex conditions. That there are grave problems with the history of treatment, and an urgent need to secure appropriate medical care both in the neonatal period and across the lifespan, is uncontroversial. We must grant that while there is no terminology that can eradicate the stigma of atypical anatomies, nomenclature that situates conditions in the “usual” way of medicine—as matters of health rather than identity—can certainly help to correct many of the gross wrongs of the past.

1. P.A. Lee et al., “Consensus Statement on Management of Intersex Disorders, International Consensus Conference on Intersex,” *Pediatrics* 118, no. 2 (2006): e488-500.

2. K. Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Durham, N.C.: Duke University Press, 2008).

3. L. Daston and K. Park, “The Hermaphrodite and the Orders of Nature: Sexual Ambiguity in Early Modern France,” *GLQ: A Journal of Gay and Lesbian Studies* 1 (1995): 419-38; A. Dreger, *Hermaphrodites and the Medical Invention of Sex* (Cambridge, Mass.: Harvard University Press, 1998).

4. Dreger, *Hermaphrodites and the Medical Invention of Sex*.

5. *Ibid.*

6. R. Goldschmidt, “Intersexuality and the Endocrine Aspect of Sex,” *Endocrinology* 1 (1917): 433-56.

7. The term “intersex” had been in use for some time but had been used to refer to what today we would understand as homosexuality and bisexuality.

8. D.I. Williams, “The Diagnosis of Intersex,” *British Medical Journal* 1, no. 4771 (1952): 1264-70. “Intersex” occurs nowhere in ICD9 or ICD10, the current and forthcoming versions of the International Statistical Classification of Diseases and Related Health Problems. Rather, “752.7 Indeterminate sex and pseudohermaphroditism” is an umbrella classification.

9. By the end of the twentieth century, dozens of diagnoses were classed in the hermaphrodite taxonomy; see M.M. Grumbach, F.A. Conte, and I.A. Hughes, “Disorders of Sex Differentiation,” *Williams Textbook of Endocrinology*, tenth ed., ed. P.R. Larsen et al. (Philadelphia, Penn.: W.B. Saunders, 2002).

10. Intersex Society of North America, “Frequently Asked Questions: What Is Intersex?” http://www.isna.org/faq/what_is_intersex; accessed March 26, 2008.

11. W.G. Reiner, "Gender Identity and Sex-of-Rearing in Children with Disorders of Sexual Differentiation," *Journal of Pediatric Endocrinology and Metabolism* 18, no. 6 (2005): 549-53.

12. S. Kessler, *Lessons from the Intersexed* (New Brunswick, N.J.: Rutgers University Press, 1998); Karkazis, *Fixing Sex*.

13. The change in nomenclature emerged out of a confluence of events occurring in 2005. In response to the controversy provoked by the use of the term intersex, the Intersex Society of North America (ISNA), an advocacy group, argued for new terminology that it sought to introduce in parent handbooks and clinical guidelines it was preparing (see also A. Dreger et al., "Changing the Nomenclature/Taxonomy for Intersex: A Scientific and Clinical Rationale," *Journal of Pediatric Endocrinology and Metabolism* 18 (2005): 729-33). During this same period, the U.S. and European endocrinological societies convened a meeting to revisit the standard of care for intersex, providing an opportunity for advocates of the change in nomenclature to argue for a formal change and for announcing it in a consensus statement. When those at the meeting settled on "Disorders of Sex Development," ISNA followed that usage for the handbook (see Consortium on the Management of Disorders of Sex Development, "Clinical Guidelines for the Management of Disorders of Sex Development in Childhood," 2006, www.dsdguidelines.org/clinical, and "Handbook for Parents," 2006, www.dsdguidelines.org/parents).

14. Kessler, *Lessons from the Intersexed*; Karkazis, *Fixing Sex*.

15. See letters to the editor in response to the consensus statement published by the Consortium on the Management of Disorders of Sex Development, <http://adc.bmj.com/cgi/eletters/adc.2006.098319v1>.

16. D. Cameron, personal communication to Katrina Karkazis.

17. E. Feder, "Imperatives of Normality: From 'Intersex' to 'Disorders of Sex Development,'" *GLQ: A Journal of Gay and Lesbian Studies*, forthcoming.

18. M. Diamond and H.G. Beh, "Variations of Sex Development instead of Disorders of Sex Development," letter to the editor, *British Medical Journal* (2006), <http://adc.bmj.com/cgi/eletters/adc.2006.098319v1#2460>; E. Reis, "Divergence or Disorder? The Politics of Naming Intersex," *Perspectives in Biology and Medicine* 50, no. 4 (2007): 535-43.

19. I.A. Hughes et al., "Consensus Statement on Management of Intersex Disorders," *Archives of Disease in Childhood* 91, no. 7 (2006): 554-63.

Web of Care: *How Will the Electronic Medical Record Change Medicine?*

BY JOSEPH J. FINS

Several weeks ago, fifteen of my primary care-internist colleagues and I sat in a midtown skyscraper in a classroom fitted with a laptop computer for each of us. Coffee cups in hand, we embarked upon a two-hour class—the first installment of a ten-hour course—to learn to use a multispecialty electronic medical record (EMR).

The EMR our medical center has decided to launch is elegant, with lots of pop-ups, color-coding, and an amazing ability to collect and generate data. Our instructors pointed out that the new system was more than just a computer to write notes or order prescriptions. Our practice has had *that* capability for years.

No, this new system was different. It was a medical information superhighway. It connected you with colleagues throughout the medical center by means of a shared medical record. Between sips of coffee, we were told of the new system's capabilities: If you want to know about your patient's last visit to the urologist or send a pre-op clearance note to his cardiac surgeon, your colleague is but a click away. Order a drug that is incompatible with the patient's medication list, and the EMR will warn you away from your choice and steer you clear of a pharmacologic mismatch. Beyond its capability to promote safety, it also can facilitate outcomes research.

Although I was none too thrilled to trudge downtown for training, I must admit that typing up a mock patient visit on the computer was fun. Since it is not altogether different from ordering a book on Amazon or searching UpToDate for medical information, it was not entirely unfamiliar, but it was still

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