

# Introduction

## Straddling Past, Present and Future

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Why bring together a group of essays from an international group of scholars to examine the issue of *intersex* precisely when ‘DSD’ is being promoted<sup>1</sup> as the most appropriate way to refer to and to think about what has been medically identified as ‘intersex’ throughout much of the twentieth century, and popularly recognized under the latter umbrella term since the 1993 establishment of the now defunct Intersex Society of North America (ISNA) and the concomitant development of the contemporary intersex movement? Does the titling of this collection not belie a lack of awareness on the part of the editor that ‘intersex’ is no longer the appropriate term through which to apprehend and understand the identification of bodies that are neither discretely male nor discretely female? Is the collection not terribly out of date even before arriving on the shelves, and perhaps radically off the plot as well?

In response to these troubling worries, this collection asserts that we (whether we are scholars, intersexed persons, activists or some combination of these three) are not yet done with ‘intersex’, even as we seek to turn a critical gaze on ‘intersex’. The implicit imperative in the title of this collection is that it is too soon to accept the language of *disorder* wholesale and that, in fact, a critical value remains in the use, deployment, recognition and interrogation of ‘intersex’. What is critical about intersex? What does it mean to think about intersex critically? If there are limits to the ability of some stakeholders, especially parents, to work comfortably with the description of their children’s conditions as forms of intersex, does that mean there is no value left for the term? It is in a reflective and reflexive mode that this volume addresses these very questions, and does so from the starting assertion that there is, indeed, some critical utility, vigour and power left in the deployment of the term ‘intersex’. The essays in this collection speak to these questions through epistemological and theoretical lenses and are

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1 See Consortium 2006a and 2006b, originally published through ISNA and now available from the Accord Alliance, following the closure of ISNA and its reconstitution in 2007 under a new mandate as the Accord Alliance.

grouped into three sections: ‘Medical Practices/Colonial Practices’, ‘Challenges to Identity Claims’ and ‘Refiguring the Human’.

*Critical Intersex* challenges the primarily North American and liberal humanist paradigm of intersex identity politics and clinical practices by explicitly adopting ‘queer interventions’ to further discussion on an ontological phenomenon that can never be reduced to a pure, embodied state, nor to a simple cultural rendering in which ‘intersex’ is whatever we want it to be. Instead, this collection understands that ‘intersex’ is not one but many sites of contested being, temporally sutured to biomedical, political and social imperatives in play in each moment. ‘Intersex’ then, is hailed by specific and competing interests, and is a sign constantly under erasure, whose significance always carries the trace of an agenda from somewhere *else*.

### Reflecting Backward

From its development as a term in 1917 by the biologist Richard Goldschmidt (Reis 2007: 536) until the early 1990s, ‘intersex’ existed as a diagnostic label and epistemological category that circulated only inside the confines of academic bio-medicine; it did not enter into use in conversations between clinicians and their patients or their care-givers. Rather, the language of the clinic was—and remains, for the most part, as we shall see—evasive, and spoke of sex development, undifferentiated gonads and incomplete sex:

Most doctors believe that an intersexual child is ‘really’ a boy or a girl. [John] Money, and others trained in his approach, specifically ban the word *hermaphrodite* from use in conversation with the parents. Instead, doctors use more specific medical terminology—such as ‘sex chromosome anomalies,’ ‘gonadal anomalies,’ and ‘external organ anomalies’—that indicate that intersex children are just unusual in some aspect of their physiology, *not* that they constitute a category other than male or female. (Fausto-Sterling 2000: 51)

Medical records, by contrast, listed more specific information about discrete characteristics to transfer information only from one specialist to another in consultation with each other, using labels such as ‘male pseudo-hermaphrodite’, ‘female pseudo-hermaphrodite’ and ‘true hermaphrodite’, or ‘isolated micro penis’ and ‘isolated clitoromegaly’ to denote intersex phenotypes. As Alice Dreger’s research has demonstrated, use of the ‘true hermaphrodite’ designation was deliberately rare, as the point of the ‘pseudo’ designation was to maintain the view that, in the end, every human being has only one ‘true sex’ and that the expertise of biomedicine could be relied upon to secure a sex that the lay observer found elusive. Furthermore, because clinicians thought it absurd to

continue to refer to a ‘pseudo’ condition when they had rejected the existence of the absolute condition, use of terms rooted in the concept of hermaphroditism appear progressively less frequently in the clinical literature (Dreger 1998: 154–6). ‘Intersex’, however, has retained some of the lack of clarity of meaning that plagued ‘hermaphroditism’ which, according to Elizabeth Reis (2007), explains why the increasing use of ‘intersex’ did not mean that physicians ever completely abandoned their use of ‘hermaphrodite’ (537).

At the same time that ‘intersex’ and ‘hermaphroditism’ co-existed as vague umbrella terms, research on underlying diagnoses thought to cause a particular intersex phenotype resulted in specific diagnostic categories. Congenital adrenal hyperplasia (CAH) and androgen insensitivity syndrome (AIS), for example, describe atypical adrenal, hormonal and genetic functions thought to result in the development of intersex features. Importantly, however, the underlying features of adrenal, hormonal and genetic function do not always result in the development of a visually ambiguous sex, and so the diagnostic language cannot be said to refer in any precise way to what the public now popularly understands by the term ‘intersex’: that is, a body that confounds in some way the visible, physical features thought to be exclusively of one sex or the other. For clinicians interested in securing the *true sex* of their patients, the lack of a precise referent remained beside the point; after all, the goal was not to illuminate the existence of intersex, but to erase it altogether. Furthermore, Kessler’s research on the development of standard practice from the 1960s through to 1990 demonstrates that the issue of narrative credibility appears to be the *defining* concern of the standards for practice that arose following Money’s treatment paradigm:

The doctors interviewed concur with the argument that gender be assigned immediately, decisively, irreversibly, and that professional opinions be presented in a clear and unambiguous way. The psychoendocrinologist said that when doctors make a statement about the infant, they should ‘stick to it.’ The urologist said, ‘If you make a statement that later has to be disclaimed or discredited you’ve weakened your credibility.’ A gender assignment made decisively, unambiguously, and irrevocably contributes ... to the general impression that the infant’s true, natural ‘sex’ has been discovered, and that something that was there all along has been found. It also serves to maintain the credibility of the medical profession, reassure the parents and reflexively substantiate Money and Ehrhardt’s theory. (Kessler 1990: 8)

Neither ‘intersex’ nor any variation of ‘hermaphrodite’ would enter into language for communication information about infants so apprehended in the diagnostic practice, and as we can see, a central worry among the experts was that use of such language would only confuse the issue, confuse parents, and undermine a course of action meant to *reveal* (rather than to produce) the ‘true

sex' of the child. As this collection's essays by Ulrike Klöppel and Angela Kolbe show, language shifts are central to the discursive functions of law to describe, elide, erase and produce particular subject positions but not others.

In 1993 'intersex' spread beyond its cloistered use in diagnostic practice when bo laurent/Cheryl Chase's<sup>2</sup> letter responding to Anne Fausto-Sterling's (1993) article 'The Five Sexes' was published in *The Sciences* magazine. Fausto-Sterling's article and laurent/Chase's subsequent reply marked the first introduction of the language of 'intersex' to a broader public. It turned out to be an historically pivotal introduction that hailed a number of others who would go on to be important players in the development of the contemporary intersex movement.<sup>3</sup> In those early days, however, 'intersex' had not yet become a mobilizing nodal point for a community of people. Intersex was then still a scientific *object*, albeit one on its way to becoming a culturally salient category with a particular set of cultural characteristics, and it was in that configuration that I began to study intersex and to participate in the founding of the contemporary intersex movement.

In my scholarly and activist work, largely following Kessler's (1990) observations that parents had to be actively *taught* by doctors to perceive sexual ambiguity in their infants, I argued that the management of both the children's bodies and the language to describe them secured the position of doctors as the arbiters of knowledge, and helped to maintain the coherence of the standard sex categories: male and female.<sup>4</sup> In a similar vein, but accounting for the wresting away of meaning and control from its medical/clinical articulation point, laurent/Chase writes of the decision to adopt 'intersex' as the term under which the new movement would organize:

I did possess the rudimentary knowledge that the gay rights movement had gathered momentum only when it could effectively deny that homosexuality was sick or inferior and assert to the contrary that 'gay is good.' As impossible as it then seemed, I pledged similarly to affirm that 'intersex is good,' that the body I was born with was not diseased, only different. (Chase 1998: 195)

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2 From 1993 to 2007, bo laurent produced most of her activist work under the name 'Cheryl Chase' but was published under the name 'bo laurent' in more academic venues dating back to the mid-1990s. In 2007 laurent came out publicly as one and the same with 'Cheryl Chase'. I have been aware of the pseudonymous use of 'Cheryl Chase' since we met by phone in 1993. I have combined the name 'laurent/Chase' here to avoid confusing readers.

3 I include here in no particular order: Kiira Triea, Gaby Tako, David Cameron, Sherri Groveman, Max Beck, Angela Moreno-Lippert, Heidi Walcutt, Hida Valeria, Mani-Bruce Mitchell, Heike Boedekker and Diane Marie Anger.

4 See Holmes 1994, 1998, 2000.

The mobilization of ISNA in particular—and of those who would come to the more broadly defined movement—around the term ‘intersex’ was then very much a search for autonomous self-identification, a reclamation and wresting away of meaning and power from medicine, and the terms under and through which intersex would signify. In short, the movement’s trajectory was away from a stigmatizing and medicalized view and toward a valuing of embodied difference.

This collection is organized in part around the idea that in the immediate present and future, the initial goals that inhere in the reclamation of intersex as a viable identity and not as a medical pathology retains an unfinished and valid critical edge. The collection also aims, however, to maintain a critical stance toward the use—past, present, and future—of ‘intersex’.

## **Moving Forward**

By engaging in a critique of the dominant paradigms internal to the contemporary intellectual and activist intersex movement, the three sections of this collection compel current historical, activist and theoretical and interdisciplinary work on human intersexuality to move forward, and to interrogate the dispassionate gaze of scientific, clinical practice by turning that gaze back upon itself. Fully aware of the recommendation to take up the use of DSD language in place of intersex, certain chapters take up questions of language and identity and the politics of diagnostic practice, and so it is that even this collection of essays moves outside of the strict confines of intersex as a mobilizing category. The nine essays collected here produce a *queer intervention* that questions not only the trajectory of current medical practice and research, but also the hegemonized identity politic of liberal activism. The broad range of issues the collection addresses includes the perception, structure and social positioning of intersex beyond the confines of a U.S. context, the mobilization of identities and epistemologies around the presuppositions of clinical language, and the potential for subverting the power of clinical language, diverting its trajectory away from the normative.

On the point of diverting the trajectory, this organizing principle for this collection benefits from taking heed generally of Robert McRuer’s (2006) imperative for ‘crip theory [to] conjure up the disability to come ... and in the interest of another future altogether, we should not as this point avoid considering the ways in which disability studies is haunted’ (200). The nascent field of intersex studies is not precisely the same as disability studies, and I do not mean to conflate the two here, but intersex studies draws as much from the impulses, theoretical frameworks and critical lenses of disability studies as from the development of queer theory/studies and gender studies informed by

feminist theory. What I take as a guiding point from McRuer is the idea that the terrain of intersex studies is also haunted and haunting. In the context of the clinic where parents confront the unexpected, there is a gender haunting that conjures up all the performative efforts required to shore up the traditional sex/gender divide, and which repeatedly collapses inward when we feel ourselves to have ‘failed’ at what was supposed to come naturally. For those of us who have rejected assertions regarding the naturalness of sex, and its effect as gender, such collapsing may become a welcome part of the performance, or even a logical impossibility in the face of a more fluid conceptualization of sex/gender. That is, when all things are possible and welcome, the idea of a collapse ceases to make sense.

However, this queer embrace of fluidity is not (yet) the context in which most parents of intersexed children first encounter intersex. Rather, they encounter it in the context of diagnosis: the pointing out of a flaw, an error, perhaps—it is implied—arriving through some heritable genetic ‘defect’ not expressed in the parents, but present nonetheless. Parents and families of intersexed children confront a world informed by the premise of defect, not of neutral variation. Even the conciliatory ‘DSD’ nomenclature speaks to problems and defects: *disorders* that can be managed, fixed, and brought into line with the expected rather than the unexpected. Much like McRuer’s (2006: 203–4) image of disabled bodies made disposable by the neoliberal goals of such global bodies as the United Nations, the future of intersex itself is haunted by the probability that if we do not maintain a critical framework, intersex will not simply be under erasure but will be done away with altogether. This collection, then, conjures intersex yet to come, even as the clinical environment repeats in a new guise its nineteenth-century assertion that intersex/hermaphroditism does not really exist, as we see in the recommended assurances to give to parents of a child with a ‘DSD’:

Q: Is my child a boy or a girl?

A: Your question is very important. We wish we could tell you right at this minute, but we really can’t tell yet. We will have more information after we conduct some tests. It’s hard for parents to wait for these test results so we will try to update you every day, and you can call [give contact person’s name] at anytime. Although your baby has a condition you probably haven’t heard much about, it isn’t that uncommon. We’ve encountered this before, and we’ll help you through this time of confusion. As soon as the tests are completed, we will be able to talk with you about the gender in which it makes most sense to raise your child, and we’ll give you a lot more information, too, since quite a lot is known about these variations and we are learning more each day. (Consortium 2006a: 37)

This rather long proposed answer to a hypothetical question from parents makes no mention of either DSD or intersex, but promises to deliver an appropriately and singly gendered child as quickly as possible. What is troubling here that the ‘not yet’ I invoked earlier in reference to the absence of a general embrace of a queer(ed) embrace of gender fluidity becomes a discursively effected ‘not ever’ that, in the context of the clinic, obviates the necessity of accepting a broader range of human states than ‘boy’ and ‘girl’ can accommodate.

If we are ‘post-intersex’, it is not to the language of disorders of sex development (DSD) that I sought for this collection to move. Instead of adopting the language of disorder and its concomitant medical management, I want us to consider adopting as a positive identifier/sign the ‘ambi’ in the ‘ambiguous’ character of intersex, and the *intersex* as interjection, as interlocutor, and as many simultaneous interstices (of embodiment, gender, inter-subjectivity, interdependent deferral of meaning, etc). It is an *inter* I aim to use to disrupt the male/female sex binary upon which the (hetero)sexual difference model is built (Angelides 1995). I have long argued that it is precisely because its disruptive potential has been grasped only too well by those who diagnose it that intersex has been made to disappear so thoroughly through material and medical discursive practices such as those identified in Morland’s paper in this collection. Changing the nomenclature to ‘DSD’ and withholding ‘cosmetic’ surgeries does not change the fundamental medical insistence/assurance that the intersexed child really does have one true sex, and is not *actually* intersexed at all. That is, we can all rest assured that in the end an intersex child’s disorder can be managed and made orderly. But can it? Does it? And why ought intersex fade? Why not rethink intersex along similar lines to those Angelides proposes in considering bisexuality, so that we can welcome ‘subject positions without borders’ (38).

This collection in no way seeks to resolve the controversy of the adoption of DSD language, nor the concomitant abandonment of ‘intersex’, but holds at its centre a premise that work that is informed by the terms of the modern intersex movement is far from complete. Moreover, the essays collected here hold ‘intersex’ in a critical and interrogative relationship to the thinking developed in the pages that follow. ‘Intersex’ then, is not a final term, nor the most appropriate term, but a powerful term whose historical, social and political import remains *critical* as a tool for interrogating heteronormative and bio-normative presuppositions about proper embodiment. Intersex also remains a *critical* site for our interrogation of the limits of its ability to speak of and to the experiences of self of those so labelled, and a *critical* site for the examination of scholarship on intersexuality. In a conversation that embraces the tools and political power of queer theory, *Critical Intersex* brings together research from an up-and-coming generation (Eckert, Van Heesch, Malatino, Spurgas, Kolbe and Klöppel) with more established scholars in the field of intersex studies

(Roen, Morland, Cornwall). Not all of the papers would embrace wholesale the manner in which I have characterized the hazards of the turn toward ‘DSD’ and away from ‘intersex’, but all have come together around the term ‘intersex’, seeing in it a still-useful conceptual tool, and a field of studies that must bear critical interrogation if it is to continue to develop into the future.

The collection opens with Katrina Roen’s development of the concept of *embodied becoming*, a perspective she deploys to interrogate the medical colonization of intersexed bodies, and the resulting sense of a ‘surgical self’ that many intersexed persons develop out of their experiences of medicalization. At the centre of Roen’s concern is the medical construction of anxious parents and vulnerable patients, and Roen launches an empirically based argument to demonstrate that these anxious and vulnerable states are a discursive effect of the clinical encounters, and not of intersexuality itself. It is to the production of a fear of difference and of a desire for sameness that Roen directs our thinking on the manner in which ‘cosmetic surgery’ to ‘correct’ intersex is encouraged, justified and enforced. Our bodies, argues Roen, are made and remade over time, yet surgery to ‘correct’ intersex approaches bodies as though they were objects, constant and unchanging, and intersexed persons who were treated as though their bodies were just things will be faced with ‘a project of reclaiming, recapturing and re-memembering that which is lost’ (p. 19). In her final pages, Roen demonstrates the particularly fraught character of this reclamation project precisely because the colonization of the intersexed child’s body, unlike the usual modes of embodied becoming which entail a sense of control over one’s becoming, has robbed the later adult of a sense of self free from feelings of shame and monstrosity.

Lena Eckert’s work draws our attention back to one of the benchmark bodies of cross-disciplinary work on intersex—the cooperation of Gilbert Herdt with Robert Stoller (1985) and the work of Imperato-McGinley et al. (1974)—and Eckert examines the implications of the close relationship between medical specialists’ priorities and anthropological priorities for epistemological questions in fieldwork and in clinical practice with intersexed children.

Hilary Malatino’s chapter, the final contribution in the first section, also directs our attention to power and colonization as it operates in scientific disciplines focused on the appearance/development of *monstrous bodies*. Malatino’s work asks us to examine the standard scientific orderings of gender, of sex and of those monstrous bodies that defy traditional categorization in the binary logic of gender. Working principally through the theoretical apparatus supplied by Kristeva’s (1980) understanding of the symbolic power of those states apprehended as ‘abject’, Malatino situates the monstrous/intersex body in the larger context of scientific efforts to rationalize the meat of bodies into the proper constraints of the social. Malatino explains the taxonomic fascination with bodies that refute ‘bio-logic’ and directs our attention to discourses that

determine who will receive and who will be denied ‘human rights’. Yet it is not toward an expanded vision of what counts as properly human that Malatino guides readers; instead, it is toward a timely (re)consideration of a queered human (Giffney and Hird 2008), contesting the tendency of various essentialist and constructivist arguments to leave intact common Enlightenment-era presuppositions about the necessary alignment of gender with ‘human’ subjectivity (p. 74).

Part II opens with Alyson Spurgas’s interrogation of the increasingly powerful language of ‘disorder’ in the debate over the supplanting of ‘intersex’ by ‘DSD’ in the clinical environment. Spurgas draws our attention back to the early enthusiasm of intersex activism in the 1990s for an allied cooperation with various queer and LGBT communities and strategies, and moves from that history to a discussion of contemporary disagreement among various intersex activists, support groups and allies over the recommendations of the DSD Consortium that lean away from queer identity politics and toward a model of ‘biomedical citizenship’. Spurgas’s use of biosociality as a primary conceptual tool functions to ground the discussion at the intersection of discursive/clinical requirements for the recognition of a valid self, and rhetorical constructions of sexed selfhood that come out of queer and normate orientations.

Margriet van Heesch argues that the relationship between knowing and telling requires, after the diagnosis and concomitant erasure of intersex difference, that patients must actively *unknow* their own statuses as intersexed persons. As van Heesch explains it, the requirement for this unknowing results largely from the dominance of the Western simplification of ‘sex’ into the simple sum of biological building blocks: genes, chromosomes, gonads and hormones. Women with XY chromosomes, she argues, are forced into a position of unknowing because for the most part they lack access to a language of sex that would admit its multiply contingent character. This unknowing is the cost paid in a system that demands that the underlying features of intersex be erased from the official record, and that takes no notice of the imprint of diagnostic and clinical practice on the bodies and psyches of those apprehended as intersexed secondary to AIS.

Chapters 6 and 7 round out Part II of the collection with subtle discussions of contemporary German law and concerns about gender-based rights. Each chapter takes up in its own way the tensions between intersexuality and transsexuality and claims for rights recognitions, and both also examine the overlap in reasons for the denial of rights and recognitions for intersex and transsex persons. These essays are among very few that specifically address intersex from a contemporary legal perspective, and as such they contribute enormously to the expansion of work on international legal considerations. Angela Kolbe argues that the failure in German law to recognize intersex as a valid subject category aligns with the generally accepted common wisdom that

there are only two sexes. Kolbe makes the point that in the absence of a larger awareness of intersexuality, the law is neither subject to change nor likely to act as a vehicle for change. Kolbe's essay provides readers with an account of historical developments that wrote 'hermaphrodites' out of nineteenth-century German law in a manner similar to that in nineteenth-century French law (Dreger 1998), but it points out that legal recognition is not always liberating. Kolbe argues that legal recognition can function to delineate 'illegitimate' categories, and that historical recognition for 'hermaphrodites' included the threat of death as punishment for switching sex-role behaviours once s/he had taken an oath to live as one sex or the other. Kolbe asks why the state ought to have any interest at all in the genitals or in the sex-roles of its citizens, and argues that for purposes of tracking the activities of citizens there are many more efficient means at the disposal of the state. Kolbe therefore launches a discussion of alternative means of thinking about subjecthood through the lenses of both provisionality and the abolishment of sex categories.

Ulrike Klöppel, by contrast, directs our attention to nineteenth-century attempts to distinguish sex characteristics and in so doing launches an important critique of Alice Dreger's assertion that modern conceptualizations of intersex relied on a paradigm shift that Dreger refers to as 'the age of gonads' (1998). Klöppel shows that, in fact, far from accepting the idea that gonads were the seat and root of sex, sex researchers in the nineteenth and early twentieth century thought gonads themselves to be the result of some 'other developmental impulses that were pre-determined at the time of fertilization' (p. 173). Moreover, Klöppel argues, biomedical research into sex can be understood as informed by an appreciation for the fact that neither gonads nor hormones nor chromosomes could be said to be the seat of sex, and that indeed, any assertion that strict sex dimorphism is a biological given is unsustainable in the face of the biological evidence. It is against this biomedical set of recognitions that Klöppel launches her argument regarding the persistent cultural assertion that there are (and must be) only two sexes, and develops a critical assessment of the legal consequences of such assertions in the post-war German context.

Part III of the collection opens with Iain Morland's chapter 'Between Critique and Reform', and takes up the very particular mandate I referred to in the opening pages of this introduction: to move the study of intersex beyond the current confines that pit personal testimony against clinical claims to impartiality, and to move away from relying on a simplified version of ethics in which identity claims trump all. Morland specifically rejects the liberal humanist claims regarding autonomy and bodily integrity that have characterized much current activist scholarship on intersex (including claims that appear in certain of Morland's own previous publications, for example, Morland 2006).

The final chapter in the collection, Susannah Cornwall's 'Theologies of Resistance' reads current controversies regarding intersex through a lens shaped by liberation theologies. Cornwall's work pragmatically acknowledges the shift toward the implementation of DSD language and so refers to intersex/DSD in much of the discussion, but also turns a critical eye toward the limits of the shift, especially for its failures to adequately disrupt dominant paradigms of the sex/gender *order*. Cornwall considers intersex *vis-à-vis* contemporary disability studies and draws our attention quite productively toward Shelley Tremain's (2006) argument that the distinction between impairment and disability is a flawed one that fails to understand that there is no body prior to cultural inscription.

Historical, activist, and theoretical work on human intersexuality has reached a point where, in order to mature, it needs to critique its own dominant paradigms. It is just such a critique that this collection launches, and as the editor, I hope that this collection will mark only a beginning point out of which many trajectories may develop for the continued critical engagement with the questions the collection raises.

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