Exorcising Intersex and Crippling Compulsory Dyadism

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Abstract

Using hauntology as a linchpin, this dissertation explores the undertheorized connection between intersex and disability. Building on important feminist research in the fields of intersex, queer, disability, crip, and hauntology studies, I ask, how do we understand and reconcile the contested meanings, responses to, and effects of intersex? Intersex is “a perpetually shifting phantasm” (Holmes 2002: 175), yet intersex is typically represented and treated as innate disorder, disability, or disease by medical professionals. That said, many intersex people appear to distance from disability. By engaging intersex studies with feminist disability and crip theories, however, I demonstrate that an intersex politic and intersex studies must be rooted in a disability politic and disability studies.

Through a feminist disability and crip lens, I conduct a textual and critical discourse analysis of three case studies of interphobic violence or, what I term, “compulsory dyadism,” meaning the instituted cultural mandate that people cannot have intersex traits or house the “spectre of intersex” (Sparrow 2013: 29); such a spectre must be exorcised. The three case studies include nonconsensual medical interventions, sport sex testing, and employing reproductive technologies to select against intersex variations. My analyses of these case studies produce three important observations. First, intersex is presently and effectively being integrated into conventional notions of disability; second, ableist logics underpin interphobic violence; and third, compulsory dyadism is intertwined with, or is an iteration of, compulsory able-bodiedness. In recognizing this interconnection, theorizing intersex and disability together is not merely beneficial, doing so is necessary. Ultimately, my dissertation interrogates and extends questions of the ever-shifting categorization of body-minds, culturally mandated ways of being, and (the haunting effects of) pathologization. I apply pressure to the academic field of intersex studies as
well as intersex activist and advocate communities to center disability in discussions concerning intersex human rights and interphobia.
For Dana, who breaks and builds with me.
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# Table of Contents

Abstract.................................................................................................................................ii

Dedication...............................................................................................................................iv

Acknowledgements...............................................................................................................v

Introduction and Literature Review: Intersex and/as/is/with Disability.................................1

Chapter 1: Theoretical Framework and Methodology...............................................................28

Chapter 2: Intersex Mutilation: Medical Malpractice and Acquired Body-Mind Disabilities....69

Chapter 3: The Racialized Intersex Spectre: Sex and Dis/ability Segregation in Sport..........135

Chapter 4: Contemporary Eugenics: Preimplantation Genetic Diagnosis and Interphobia......199

Conclusion: “The Future is Intersex:” Combating Compulsory Dyadism and the Eradication of Intersex.......................................................................................................................265

Works Cited............................................................................................................................281
Introduction and Literature Review

Intersex and/as/is/with Disability

How do we understand intersex? As a medical(ized) phenomenon, a disorder or disability, a biological variation, an identity, a sexual minority, a subset of the queer community, as the third sex, as an “X” on certain people’s identification documents? These questions, or to use Donna Haraway’s terms “contests for meanings” (1991: 175; also see Haraway 1990), about the nature of intersex have been hotly debated within and between intersex activists and advocates, medical professionals, and scholars from a wide variety of disciplines. However, due to the tireless and successful labour performed by intersex activists and advocates as well as intersex studies scholars, these queries are entering into mainstream conversations like never before. In fact, intersex issues, interphobia (Costello 2010; Viloria 2015a),¹ and the Intersex Rights Movement have recently been referred to as the “next civil rights frontier” in the award-winning London-based magazine, Huck (Andrews 2017: n.p.; also see “Huck” n.d.). As conversations about intersex and intersex human rights become more mainstream, it is important to consistently reflect on how we understand intersex and what specific understandings accomplish politically.

This dissertation hopes to enter into and contribute to the conversations about the various contested meanings of intersex. Specifically, I place intersex studies in conversation with disability studies in order to see if, how, when, and why intersex and interphobia intersects with, or “folds” into (Clare [1999] 2009: 143; McRuer 2006: 71), disability and ableism. In other words, I ask: what is the political, discursive, and embodied connection between intersex and disability?

¹ Cary Gabriel Costello (2010) coined the term “interphobia” to describe the systemic violent discrimination against intersex people, people with intersex traits, and people thought to have intersex traits. Interphobia is another term for intersexphobia (see Viloria 2015a).
When speaking of making the political link between Deafness and disability in his book *Enforcing Normalcy: Disability, Deafness, and the Body*, Lennard J. Davis writes:

> [t]here has been too little examination of the connection between Deafness and disability. Because many Deaf activists have strongly defined themselves as a linguistic minority and not disabled, political bonds and political activity have been discouraged between the Deaf and people with disabilities. [...] I want to move through issues of Deafness to general statements about disability. While I understand that such a move will displease some in the Deaf community, I ask that they forbear in order to see what benefits, if any, may accrue from such a method. (L. Davis 1995: xix- xx).

L. Davis wrote of the possible link between Deafness and disability in the 1990s. During this time, in the attempt to resist pathologization as well as celebrate Deaf culture, the general sentiment within the Deaf community was, “We are Deaf,” a linguistic subgroup, “not disabled” (see McRuer 2006, 2013; L. Davis 1995; Kent 1997; Glendenning in Kent 1997; H. Davis and Silverman 1970; Cripps and Small n.d.; Markowicz and Woodward 1978). L. Davis’ request that readers refrain from immediate judgment was, therefore, quite bold. Critical projects like L. Davis’ (1995) that outlined overlaps between Deafness and disability and the advantages of these camps forming political bonds resulted in many (but not all) Deaf people “participating less in a refusal than in a public reinvention of disability” (McRuer 2006: 90; also see McRuer 2013: 377; Burch and Kafer eds. 2010; Shapiro 1994; Lane, Hoffmeister, and Bahan 1996; Golos, Moses, and Wolbers 2012; Erting et al. 1994; Stremlau ed. 2002; Goodstein ed. 2006; Haimowitz 1999; Padden and Humphries 2005; Sacks 1984; DeLuca et al. eds. 2008; Storbeck 2006; Bradford 2016; Deafstudent 2015; M. Jones 2002). Rather than “stigmaphobic distancing” from disability (McRuer 2006: 85), many Deaf people got involved in reinventing disability, resisting the medical model of disability that construes disabilities as innately undesirable and degenerate, and celebrating Deaf culture as well as disability. Put differently, the idea of, and identification with,
being a linguistic minority and disabled were no longer understood as mutually exclusive within
the Deaf community.

Similar to L. Davis’ acknowledgement in the 1990s that there was too little examination
of the relationship between Deafness and disability, at this particular moment as the Intersex
Rights Movement is deemed the “next civil rights frontier” (Andrews 2017: n.p.) and makes
significant human rights gains (Viloria 2017; G. Davis 2015a; Marchiano 2017; Dreger and
Herndon 2009; Crary 2017; Carpenter 2013b, 2015b; Lambda Legal 2016; Bennett-Smith 2015;
Crawford v. Medical University 2017; Albritton 2015; Baumgartner 2017; Tamar-Mattis 2015;
Ghorayshi 2015, 2017), analyzing the connection between intersex and disability will perhaps
result in some discontentment. Indeed, some intersex individuals distance themselves from
disability and/or reject disability. Some people with intersex traits view themselves as entirely
“normal.” Other intersex folks conceptualize themselves a sex/ual minority or the third sex, not
disabled, disordered, or diseased (G. Davis 2015a; S. Turner 1999). Although contested, some
intersex people align with LGBTQ(I) communities and view themselves as queer (Pagonis
2016b; Koyama 2006 n.d.; Cornwall 2009; Astorino 2013). Nevertheless, like L. Davis’ bold
request, I ask possible discontented readers to forbear in order to see what benefits emerge from
theorizing intersex and interphobia using a disability lens.

Many intersex studies scholars and activists rightly note that “compulsory
heterosexuality” (see Rich 1980, 2003; Butler [1990] 2006; McRuer 2006, 2013) and
queerphobia underpin interphobia (Holmes 2000; Kessler 1990, 1998; Dreger 2013; Sytsma
2006a; G. Davis 2015a; Karkazis 2008; Behrmann and Ravitsky 2013; Bastien Charlebois 2014).
That is, these scholars demonstrate that queerphobia and interphobia work together to enact
violence and re/produce the apparent normativity of heterosexuality, the sex and gender binaries,
and traditional gender roles. “Compulsory able-bodiedness” (McRuer 2013: 369) and ableism are also intertwined in this formula but has remained largely unexamined. Given that people with intersex traits who “fail” the sex binary are deemed disordered, disabled, or diseased (Holmes 2008, 2011; Mitra 2014a; Sparrow 2013; G. Davis 2015a) and are often subjected to unnecessary medical procedures to “cure” that which is supposedly out of order signals that exploring the connection between intersex and disability is vital. Combating ableism as well as interphobia and queerphobia must be central to struggles for intersex human rights.

Extending Iain Morland’s work in his article, “What can queer theory do for intersex?” (2009: 285), I explore what feminist disability and crip theories can do for intersex. Or, comparable to Robert McRuer’s question – “what might be gained by understanding ‘compulsory heterosexuality’ as a key concept in disability studies” (2013: 369) – I investigate what might be gained by understanding compulsory able-bodiedness as a key concept in intersex studies. My exploration demonstrates that feminist disability and crip theories nuance intersex studies analyses and ought to be integral to intersex human rights projects. The central argument of this dissertation is threefold: (1) given that intersex traits are constructed as disordered, disabled, or diseased by most authoritative medical professionals and many biomedical scholars, intersex is a disability issue – interphobia is underpinned by, intersects with, or is an iteration of ableism; (2) in order to combat the myriad ways interphobia manifests, intersex studies scholars and activists must not distance themselves from disability, but rather combat ableism; and (3) disability approaches to intersex – or cripping intersex studies – nuances our understanding of how interphobia is maintained, strengthens intersex human rights claims, and, broadly speaking, refines our theoretical understanding of the relationship between sex, gender, and disability. My project, therefore, contributes to the emerging literature that has begun to think through the
undertheorized connection between intersex and disability (see Koyama 2006; Spurgas 2009; Holmes 2008b, 2009, 2011; Cornwall 2013, 2015; Colligan 2004; Wilkerson 2012; Greenberg 2012a, 2012b). After conducting feminist disability and crip analyses of three different case studies of interphobic violence – nonconsensual medical interventions, sport sex testing, and employing reproductive technologies to select against intersex traits – I am convinced that an intersex politic and intersex studies must be rooted in a disability politic and disability studies (see Koyama 2006; Holmes 2008b, 2011).

Dis/association with Disability

Integrating disability into analyses about intersex issues may, at first blush, seem unproblematic. Indeed, prolific intersex studies scholar Morgan Holmes explains, “[i]ntersex studies draws as much from the impulses, theoretical frameworks and critical lens of disability studies [emphasis added] as from the development of queer theory/studies and gender studies informed by feminist theory” (2009: 5-6). And Holmes is correct. Some intersex studies scholars as well as activists enthusiastically and liberally draw from disability studies (see Holmes 2008b, 2011; Spurgas 2009; Koyama 2006; Wilkerson 2012; Menon 2011; Cornwall 2010, 2013, 2015; Colligan 2004). Yet, most intersex studies scholars or activists do not implicitly or explicitly engage with disability scholarship. This lack of engagement may be due to the fact that drawing from disability studies is contested. Susannah Cornwall (2013, 2015), Julie Greenberg (2012a, 2012b), Abby Wilkerson (2012), among others (Koyama 2006; Spurgas 2009; Holmes 2008b, 2009, 2011; Y. Menon 2011) theorize why this is the case, attempt to remedy rifts, and identify why drawing from disability studies is beneficial, indeed necessary.
One of the main points of contention concerns dis/association or, in other words, “stigmaphobic distancing” from disability (McRuer 2006: 85). “[G]iven cultural perceptions of disability as lack, loss, or pathology,” Wilkerson notes, “many intersex and transgender activists vehemently refuse any association with it” (2012: 185; also see Colligan 2004). Wilkerson’s observation is reflected in Georgiann Davis’ study regarding intersex people’s dis/identification with intersex and medical nomenclature, specifically the diagnostic term Disorders of Sex Development (DSD) (2014, 2015a). Many, but not all, intersex people reject discourses that frame intersex-as-disorder/disability/disease. For example, Millarca, a participant in G. Davis’ study, argues “DSD is not ... is not something a lot of people want to identify with ... nobody wants to be a disorder ... who wants to be a fucking disorder? ... I don’t” (qtd. by G. Davis 2014: 19; also see G. Davis 2015a; Briffa 2014; Cornwall 2013). In suggesting that nobody would want to be, be labelled as, or identify as (having) a disorder, Millarca’s statement, perhaps unwittingly, reproduces the cultural perception that disabilities are inherently inferior or

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2 For critical analyses of (the intersection of) disability and transness, see Alexandre Baril (2015a, 2015b).

3 In October 2005, fifty experts from various fields – urology, genetics, endocrinology, and gender studies – gathered to revise the medical treatment guidelines for intersex traits (Karkazis 2008; Greenberg 2012a). This meeting was the first (but not last) of its kind. The results of the meeting were published in the Archives of Disease in Childhood and were titled “Consensus Statement on Management of Intersex Disorders” (I. Hughes et al. 2006). In re/medicalizing fashion (G. Davis 2015a; Holmes 2011), “intersex” was replaced with the diagnostic phrase “Disorders of Sex Development” (DSD). The statement also claims that having intersex anatomy is not shameful, yet surgery, particularly for children assigned female, is still endorsed to “control the ‘sex’ of the body” (Karkazis 2008: 5). Furthermore, the statement claims that psychological care should be integral to treatment. The consensus statement has been met with a lot of warranted critique. According to many intersex studies scholars and activists, the statement “does not go far enough to curtail infant genital surgery” (Karkazis 2008: 83; also see G. Davis 2015a; Holmes 2011). The statement also reaffirmed that the medical community resists conceptualizing intersex as anything other than disordered or diseased pathology, as the journal’s title, Archives of Disease in Childhood, indicates.

4 Summarizing an interview with Marissa Adams, an intersex person, Nora Caplan-Bricker writes in The Washington Post, “After generations in the shadows, the Intersex Rights Movement has a message for the world: We aren’t disordered and we aren’t ashamed” (2017: n.p). This summary is misrepresentative of all intersex people. In fact, it is a bit misrepresentative of Adams own complicated relationship with the pathologization of her anatomical traits: “Adams embraces being intersex as part of her identity, but she’s still choosing to be a DSD patient – is it ever hard to reconcile those things? ‘I do embrace it,’ she [Adams] says, ‘and it is a part of my identity, but it still feels like a disorder to me in a way.’ [...] She can imagine someone growing up thinking about being intersex as ‘a normal part of them, not a thing you can fix,’ she says, but that wasn’t her experience. ‘I [Adams] think I feel that it’s a disorder because I was raised having my body corrected’” (Caplan-Bricker 2017: n.p.). That being said, the sentiment, “we aren’t disordered,” is promoted by many intersex people as a means to combat pathologization and is found in mainstream avenues, as is evident with this Washington Post article.
disadvantageous. In other words, even if Millarca does not personally maintain that disability is innately a deficit, the assertion distances intersex from disability, perhaps because “such an association” may “worsen” intersex people’s position (Cornwall 2013: 373).

Cornwall similarly draws readers’ attention to some intersex activists rejecting disability by quoting Organisation Intersex International (OII) Australia: “INTERSEX is not [emphasis in the original] a medical condition or a disorder or a disability or a pathology or a condition of any sort” (OII Australia qtd. by Cornwall 2013: 373). Also quoting this statement, Ethan Levine writes, “OII Australia stands radically opposed to the conflation of intersexuality with disability, declaring that ‘intersex is not a medical condition or a disorder or a disability or a pathology [sic]’ (OII Australia 2010, 3).’ On the other hand, Emi Koyama of the US-based Intersex Initiative engages actively with the social model of disability, situating intersex politics within and alongside radical disability politics (2006)” (2014: 186). In the attempt to resist medicalization and DSD terminology – nomenclature that “reinstitutionalises clinical power to delineate and silence those marked by the diagnosis” (Holmes 2011: 388; also see G. Davis 2015a) – the ableist notion that disabilities are inherently undesirable is implicitly reinforced. This disassociation rift must be attended to because it, even if only implicitly, reproduces the “cultural [perception] of disability as lack” (Wilkerson 2012: 185). Ensuring ableist ideologies do not underpin iterations of intersex identitarianism or rights claims ought to be important to human rights movements and scholarship.

Building on Yamuna Menon’s observations (2011), Cornwall explains, resisting association, whether it is intersex resisting association with disability or vice versa, “because they perceive that such an association would worsen their own position, then each group unwittingly perpetuates the characterization of the other as undesirable” (2013: 373). If (or
when) intersex studies scholars or activists refuse or neglect to engage with disability, they also deny themselves access to invaluable knowledge, philosophies, and methodologies that can help theorize and combat interphobia and medicalization. The sophisticated theorizations of interdependence that have emerged from disability studies and activism, for example, can improve the ways in which intersex projects theorize agency, self-determination, and intersex human rights (Wilkerson 2012: 184; also see Goble 2004). Moreover, forging an alliance with disability groups may “provide forums and methodologies by which non-queer-identifying intersexed people can share their experiences” (Cornwall 2009: 220), like, for example, experiences of medicalization and living with various traumatic outcomes created by medical interventions. Such outcomes, I postulate and explain below, are disabilities.

I must note, OII Australia’s statement – “INTERSEX is not [emphasis in the original] a medical condition or a disorder or a disability or a pathology or a condition of any sort” (OII Australia qtd. by Cornwall 2013: 373) – is no longer featured on the organization’s website.5 Intersex & Genderqueer Recognition Project’s website still references and seemingly supports this quotation (“Defining Intersex” n.d.).6 In addition to removing the assertion, Morgan Carpenter, intersex activist, consultant, and co-executive director of OII Australia, considered “[t]he intersex experience, and the intersex movement, has many intersectionalities with experiences of disability and the disability movement” (2012: n.p.). Carpenter notes, like people with disabilities, “[i]ntersex people are medicalised, stigmatised and suffer discrimination due to our [intersex people’s] distinctive biological characteristics” (2012: n.p.). Carpenter also explains that the World Health Organization’s (WHO) definition of disabilities “applies to intersex”

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5 A PDF file published by OII Australia with this statement is still available for download online (“What is Intersex?” 2010).
6 This quotation is also, interestingly enough, found in Australia’s Community Affairs References Committee’s published inquiry into The Involuntary or Coerced Sterilisation of People with Disabilities (Australia 2013).
(Carpenter 2012: n.p.), specifically the definition of impairments: “Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action” (“Disabilities” 2017: n.p.; also see Carpenter 2012: n.p.). In contrast to impairments, WHO’s definition continues, “participation restriction is a problem experienced by an individual in involvement in life situations. [...] Overcoming 7 the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers” (“Disabilities” 2017: n.p.; also see Carpenter 2012: n.p.).

According to Carpenter, WHO’s definition applies to intersex insofar as “the medical profession regards intersex people as having an impairment (‘disorder’) in the body function or structure, a ‘disorder of sex development’. These ‘disorders’ are regarded as impairments in our body structures (genitals, gonads, chromosomes) or functions (adrenal glands, gonads, or other glands)” (2012: n.p.; also see Sparrow 2013; Chapter 4). While the language of intersectionality is employed in Carpenter’s article, interphobia and ableism are not explicitly framed as fundamentally intertwined issues. They are framed as similar or comparable issues. It is important to highlight that, given the fact that intersex traits are construed as innate disabilities, the violence intersex people experience is fueled by interphobia and ableism. Carpenter has, on numerous occasions and forums, eloquently challenged essentializing narratives of intersex as disordered, abnormal, pathological. Nevertheless, drawing explicitly from disability theories that contest essentialist definitions (e.g. WHO’s definition of impairment) that place the “problem” of disability solely in people’s bodies would aid in the project of resisting pathologization and, in turn, unnecessary medical interventions (see Clare [1999] 2009, 2001, 2013, 2017; Omansky)


To elaborate, disability scholars’ critical examination of binaries, namely the innate impairment and environmental restriction dualism, and the dis/advantages of the social model of disability, coincide with intersex theorizing and intersex human rights projects (see Clare [1999] 2009, 2017; Shakespeare 2002, 2013; Oliver 1996, 2004; Crow 1992; S. Williams 1999; C. Thomas 1999, 2004; Swain et al. eds. [1993] 2004; Finkelstein 1988; Bury 1997; Tremain 2002). Such examinations also nuance and enrich intersex arguments concerning depathologization, medical interventions, and the social model. Take for instance, disability scholars’ theorization of the social model of disability. The social model of disability posits that the “problem” of disability is not in the body but rather in society’s ideologies and structures. Critically examining this theory, some disability scholars argue that the social model often neglects the fact that impairment (e.g. chronic pain) is “an important aspect of many people’s lived realities” (Shakespeare 2013: 217; also see Kafer 2013). Impairment may not always “be experienced as troublesome” or “disabling,” but recognizing that impairment sometimes is troublesome, even painful, is important (Stone 2008: 202). Moving beyond the social model, Alison Kafer proposes the “political/relational model” (2013: 4-10). Working within this model, disability and impairment are not conceptualized as separate from “social meanings and understandings” (2013: 7); and this model “is a direct refusal of the widespread depoliticization of disability” (2013: 8). Intersex studies scholars who integrate a critical social model or, better yet, Kafer’s political/relational model can, first, bolster anti-essentialist arguments about intersex traits as

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8 Shakespeare’s note can be read alongside Mollow and McRuer’s analysis of the problematic paradigmatic disabled person some disability scholars have unwittingly produced: “his or her body manifests visible difference; physical suffering is not a primary aspect of his or her experience; and he or she is not seeking cure or recovery” (2012: 12; also see Clare 2017).
innately wrong and abnormal. Second, doing so can reframe and politicize conversations about the impairing effects of unnecessary, nonconsensual medical procedures that many intersex people live with. And, third, acknowledging impairments can recalibrate folks’ relationships with people with intersex traits that cause impairments or disabilities (see G. Davis 2013; Fausto-Sterling 2000b). The fact that intersex traits themselves rarely cause pain, impairment, or health issues is often emphasized and used as evidence that medical interventions are unnecessary (see G. Davis 2013; Carpenter 2017a; Fausto-Sterling 2000b). Rather than minimize or ignore certain intersex people’s lived realities of living with impairments that stem from their anatomical traits, disability frameworks like the political/relational model (Kafer 2013) allow intersex studies scholars and activists to openly and unashamedly acknowledge that some intersex traits may cause impairing disabilities or health issues for certain people and some people may desire medical interventions to resolve or cure the impairment that limits their ability to comfortably move through the world (see Clare 2017; Kafer 2013). Arguing against nonconsensual interventions need not involve distancing from disability or ignoring impairments, even if uncommon.

All that being said, Carpenter’s (2012) consideration of disability gestures to a collaborative relationship between intersex and disability studies and activism. In fact, since the publication of the article (Carpenter 2012), OII Australia has voiced support for disability groups and their projects (Carpenter 2017a, 2017b). For example, OII Australia publicly endorsed the proposed list of changes prepared by Women with Disabilities Australia (WWDA) on behalf of Disabled People’s Organisation’s Australia (DPO Australia) (see “Submission: List of Issues” 2017). The list is to be adopted at the 18th session of the Committee on the Rights of Persons with Disabilities (14 August to 2 September 2018) to comply with the United Nations
Convention on the Rights of Persons with Disabilities (CRPD). In the document prepared by the WWDA, there is one mention of intersex under the “Respect for home and the family” section: “Please advise as to how the State party intends to address violations of sexual and reproductive rights of people with disability and people with intersex characteristics, including denial of rights to sexual and reproductive autonomy, self-determination and sexual expression” (Disabled People’s Organisations Australia 2017: 16). This statement implies that the WWDA and the DPO conceptualize intersex rights, and the denial of said rights, as a disability issue.

Furthermore, Carpenter recently suggested that intersex is a disability issue: “the framing of intersex variations using such terms [DSD] despite often only cosmetic (appearance ‘enhancing’) purposes for medical interventions makes them a matter of concern to the committee on the rights of persons with disabilities” (Carpenter 2017a: n.p.; also see Carpenter 2017b). Although Carpenter acknowledges that intersex is a disability issue because intersex is pathologized, this statement does not explicitly suggest that disability and ableism are intersex issues.

Ultimately, without fully acknowledging that interphobia and ableism are intertwined (not merely comparable issues), a crucial and detrimental distance between intersex and disability is maintained. By engaging with disability theories, intersex studies scholars and activists gain access to discourses and tools that effectively challenge conventional notions of dis/ability without distancing intersex from disability or definitively asserting intersex is (not) a disability. In other words, disability theories help intersex studies scholars and activists resist the medical model that aims to “cure” intersex without rejecting or disassociating from disability or reproducing ableist narratives.
Even though some intersex folks distance from disability, some disability studies scholars, typically without explanation, consider intersex a disability (see Garland-Thomson 2005, 2011; Snyder and Mitchell 2010; K. Hall 2011; Clare 2017). For instance, writing about the theoretical benefits of feminist disability studies, Rosemarie Garland-Thomson asserts, “[f]eminist disabilities studies acknowledges communities of all people based on shared disability experiences, and it recognizes the differences among the wide variety of stigmatized forms of embodiments that constitute disability in its broadest conceptualization – from blindness to intersex [emphasis added] to dyslexia” (2005: 1558; also see Garland-Thomson 2002, 2011). Likewise, speaking of nation states’ inability to grant full citizenship status to certain people with disabilities, Sharon L. Snyder and David T. Mitchell claim “intersexed peoples” have a disability that is “less easy to accommodate” into citizenship proper (2010: 119). Hence, intersex people experience “disability citizenship” (Snyder and Mitchell 2010; also see Altermark 2017; Erevelles 2011a, 2011b; Meekosha and Dowse 1997; S. Smith 2014; Ignagni et al. 2016; Darcy and Taylor 2009). Snyder and Mitchell conceptualize intersex as falling under the category disability and, therefore, construe intersex people’s inability to access full citizenship rights as disability citizenship. Scholars who theorize intersex people’s citizenship status, but do not integrate disability theory, use different language and theoretical tools. For example, sociologist and intersex studies scholar G. Davis employs the notion of “biological citizenship” (2015a: 8; also see N. Rose 2007; N. Rose and Novas 2005; Petryna 2002; Orsini 2008, 2009) to analyze the fact that intersex individuals are not rendered full citizens, as evidenced by, for instance, the fact that intersex people’s bodily integrity and self-determination are not legally protected. Emily Grabham, a feminist legal studies scholar, refers to intersex people’s limited access to citizenship
proper as “intersex citizenship” (2007). These discourses of intersex, disability, and biological citizenship are not necessarily mutually exclusive or distinct. In fact, braiding all of these theorizations together would provide a more nuanced picture of how intersex people’s citizenship, autonomy, and self-determination are denied and re/negotiated.

Some intersex people may be disconcerted by disability scholars presenting intersex as disability or presuming intersex traits are disabilities. Yet, including intersex in disability studies projects does not necessitate that intersex people identify with disability. Rather, including intersex signals to an openness and commitment to the porousness of disability experiences as well as disability as a cultural concept, creation, identity, and embodiment. I regard the inclusion of intersex in some disability literature – even if a brief mention – as a promising acknowledgement of the (ableist) oppression intersex people face, a form of oppression that goes largely unrecognized. Such inclusion also calls others to consider intersex as a disability issue.

Even though disability theories are not typically deployed in literature concerning intersex, some intersex studies scholars and intersex activists draw from disability studies and consider how these fields, activist movements, and embodied experiences can/do intersect and inform each other. Greenberg (2012a, 2012b), Cornwall (2009, 2010, 2015), Holmes (2008b, 2009, 2011), Y. Menon (2011), among others (Wilkerson 2012; Spurgas 2009; Koyama 2006; Colligan 2004), see the benefits of aligning intersex and disability. For instance, Greenberg (2012a, 2012b) explains, given that intersex is constructed by medical professionals as a disability, legal successes achieved by the Disability Rights Movement could afford intersex people more rights. Even though some intersex activists oppose appealing to legislations and policies that pertain to people with disabilities (e.g. the Americans with Disabilities Act [ADA], the United Nations Convention on the Rights of Persons with Disabilities [CRPD]) to make
rights claims (Greenberg 2012b: 118), doing so is nonetheless a potential option which could allow intersex people to gain legal protections or recognition in certain circumstances (2012b: 113-125).^9^

In a rather contentious piece about endorsing DSD nomenclature (see G. Davis 2015a; Feder and Karkazis 2008; Holmes ed. 2009; Feder 2009, 2014), founder of Intersex Initiative, social justice activist, and writer, Emi Koyama contends:

Critical disability theories point out that our flesh and bones are consistently given meanings and interpretations through social structures. While most people understand the word “disability” to refer to a list of physical characteristics that cause difficulties or inconveniences to people who possess them or those around them, and from that point of view one could argue that intersex has nothing to do with disability because it does not cause any difficulties or inconveniences on its own. But to a disability theorist, disability is not simply a characteristic of one’s body, but the product of social institutions that divide human bodies into normal and abnormal, privileging certain bodies over others. In this view, the physical condition that necessitates the use of a wheelchair in order to move about is not itself a disability; social and architectural structures that deprives a wheelchair user of full participation in the society is what disables her. Similarly, intersex activist Esther Morris’s observation that “not having a vagina was not my problem; having to get one was,” can be paraphrased to say: not having a vagina was not a disability; the social expectation that she needed to get one in order to live a happy and productive life marked her body disabled. (Koyama 2006: n.p.).

Koyama draws readers’ attention to the social model of disability, disability theorists’ conception that disability is (often or mostly) a social phenomenon (see Clare [1999] 2009,

[^9]: Using the language of disability, particularly the language of impairment, bolstered the landmark case concerning intersex genital mutilation, Crawford v. Medical University Of South Carolina (2017). The case concerned the outcomes and ethics of an unnecessary genital surgery performed on M.C. (a pseudonym), a black socio-medically assigned female intersex child who was adopted by Pamela and John Mark Crawford. M.C. experiences numerous adverse consequences from surgery and has never identified with his assigned female gender or sex. The Order Approving Settlement signed by the Presiding Judge, The Honorable DeAndrea Gist Benjamin, reads: “Plaintiffs in this case allege that Petitioner M.C. has incurred medical bills, pain and suffering, psychological damages, and permanent impairment [emphasis added]” (Crawford v. Medical University 2017: 2). While the word “disability” is not used, disability is central. The medical malpractice claim hinges on the fact that the surgical intervention created various gratuitous body-mind disabilities or, as the document reads, “impairments” (Crawford v. Medical University 2017: 2). The lawsuit settled in M.C.’s favour. Over the next sixteen years, M.C. will be compensated $440,000USD. Many intersex studies scholars, intersex activists and advocates, and legal professionals have been following this case for a number of years because it was – is – groundbreaking. This case is the first of its kind and, subsequently, garnered quite a bit of media and scholastic attention (see Albrighton 2015; Baumgartner 2017; Tamar-Mattis 2015; Carpenter 2013b; Ghorayshi 2015, 2017; Marusic 2017; Readhead 2015; Koman 2015; Bennett-Smith 2015; Lambert 2017; “Intersex in the Courts” n.d.; Lambert 2017).

This disability studies’ anti-essentialist, social approach to embodiments coincides with and supports intersex studies scholars and activists’ claim that intersex (or DSD) is a social phenomenon.¹⁰ Both fields work to undermine the essentializing, medicalizing ideology of ab/normal (see L. Davis 1995; L. Davis ed. 2013a; Dreger 2004; Feder 2009; Hacking 1990; Fausto-Sterling 2000b; Kessler 1990, 1998; G. Davis 2013; Stone 2008) and the notion that “[living] with and through difference” (Holmes 2008b: 175) is always and already tragic and ought to be avoided.

Koyama also explicates that some individuals maintain that intersex is not really a disability issue but rather a sex or sexuality issue: “[s]ome have said that intersex is different from other disabilities because it evokes people’s deeply held anxieties about gender and sexuality. But the same can be said for many other disabilities as well [e.g. conjoined twins, see Dreger 2005]. [...] I’d like to remind ourselves that our gender and sexual frontlines are not distinct from the battleground of disability politics” (2006: n.p. also see Baril 2015a, 2015b).

Koyama rightly highlights the pitfalls of reductive reasoning. Intersectional – or “intersextional” (see Preciado 2005: 155; “Intersex-ionality” 2016; #intersexionality n.d.; Lahood dir. 2012) – analyses demonstrate that any part of one’s (perceived) embodiment or subjectivity does not exist in isolation. Similar to McRuer’s (2006) observations that compulsory heterosexuality and compulsory able-bodiedness depend upon one another,

¹⁰ To illustrate further, intersex studies scholar and activist Suzanne J. Kessler explains, “[h]ow hard one ‘looks’ at genitals and what one ‘sees,’” or does not see, “is not constrained by the optic nerve but by ideology” (1998: 44-45). Traits perceived to be sexually “ambiguous” or “variant” (Kessler 1998) are often deemed innately abnormal, freaky, and disabled. That assessment is an ideological allegation. Feminist disability studies scholar Garland-Thomson similarly notes in Staring (2009) and Freakery (1996), how one stares, looks, or gawks at people with (perceived) disabilities is typically informed by ableist, essentializing beliefs.
Koyama gestures towards the fact that, compulsory heterosexuality, compulsory able-bodiedness, and compulsory dyadism (or compulsory non-intersex embodiment) – an expression I elaborate on in the next chapter – depend on and constitute each other. Interphobia and ableism are intertwined systems of oppression that work to violently define, “cure,” and eradicate people’s characteristics deemed disabled, wrong, freakish, and abnormal.

Intersex Variations, Paradigmatic Disabilities, and Comments on Identification

Wilkerson notes that intersex studies scholars may consider analyzing intersex issues through disability frameworks “a perverse and wayward impulse” given that intersex cannot “be readily assimilated into conventional notions of disability” (2012: 185). Intersex variations, according to this logic, are not readily legible as “paradigmatic” disabilities (Mollow and McRuer 2012: 12). The dominant (mis)representations of people with disabilities in mainstream culture have resulted in the proliferation of the image of a “paradigmatic disabled person” (Mollow and McRuer 2012: 12; also see Garland-Thomson ed. 1996; Couser 2009; Clare [1999] 2009; Razack 1998; Clark and Myser 1996; Ostman 1996). People with paradigmatic disabilities are understood as having “real” or “legitimate” disabilities. They have disabilities that are immediately visible and widely known (e.g. Down syndrome, paraplegia). This image effectively erases and contributes to the stigmatization, objectification, and/or delegitimization of other people with disabilities, including individuals with invisible disabilities (e.g. Multiple Chemical Sensitivity, chronic pain), mental health disabilities (e.g. depression, disordered eating, bipolar

11 Disability studies scholars have also produced a problematic paradigmatic disabled person as well (see McRuer and Mollow 2012). Ensuring that both mainstream media and disability studies scholars do not reproduce a reductive or singular image of disability opens up space for more voices to be heard, for more conversations about impairment, cure, and restoration (see Clare 2017).
disability),

disabling illnesses (e.g. complications from HIV, cancer, Rheumatoid Arthritis),

or not widely known disabilities (such as, perhaps, intersex variations) (see Samuels 2012; Matthews and Harrington 2000; Banks and Kaschak eds. 2003; Murphy et al. 1988; Cahill and Eggleston 1995; Wendell 1996, 2013). Intersex traits perhaps do not fall under conventional or paradigmatic understandings of disabilities, even though medical professionals deem intersex traits disordered, disabled, or diseased. Consequently, writing about intersex through a disability lens may seem out of place, misrepresentative, or offensive, especially if one maintains that intersex traits are not disabilities (Wilkerson 2012).

That being said, intersex characteristics can be, and are being, integrated into conventional notions of disability. As Carpenter identifies, WHO’s definition of disability “applies to intersex” (2012: n.p.). Furthermore, intersex variations are often conflated with or narrated explicitly as paradigmatic disabilities and diseases to justify unnecessary medical interventions on intersex people and to rationalize employing reproductive technologies to select against intersex (see Chapter 4). Bioethicist Robert Sparrow, for instance, claims intersex traits are analogous to “leglessness” and “deafness” and insists these morphologies deviate from

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12 Disability and mad studies scholars and activists debate about whether or not mental health issues (e.g. anxiety, panic disorders, disordered eating, post-traumatic stress disorder, depression, addiction, and suicidal ideation) are disabilities. Including mental health issues into the scope of disability is contested for a number of reasons: “real” disabilities are typically assumed to be legible physical issues; mental health disabilities are seen as something one can or should control; and many individuals who identify as “mad” (i.e. people with mental health issues) do not identify as disabled (see Gorman 2013; LeFrançois, Menzies, and Reaume eds. 2013; Beresford 2000; Corrigan et al. 2000; Price 2013; Beresford et al. 1996). Nevertheless, many disability and mad studies scholars argue mental/psychiatric issues are disability issues or are disabilities because, for example, the body and the mind are not separate entities and because disability is an ever-shifting (discursive) construction (see Beresford 2000; Beresford et al. 1996; Price 2013; Puar 2011, 2013b; Minkowitz 2014; Garland-Thomson 2002; LeFrançois, Menzies, and Reaume eds. 2013).

13 Disability studies scholars have debated over the possible distinction between illness and disability (see Murphy et al. 1988; Cahill and Eggleston 1995; Wendell 1996, 2013). Those who insist on a distinction do so to highlight the fact that people with disabilities are perfectly “healthy.” This argument echoes the “they are just like us/we are just like you” narrative. This argument may be a valiant attempt to normalize differences and make disability legible or palatable to enabled folks, but it relies on the problematic un/healthy binary and can reinforce stigma associated with certain illnesses (e.g. HIV/AIDS) (Wendell 1996; Adam-Smith and Goss 2005). Moreover, claiming that there ought to be a distinction erases so many disabled people’s pain and suffering and reinforces what Mollow and McRuer refer to as the “paradigmatic disabled person” (2012: 12).
“species-typical functioning” (2013: 32). Thus, according to Sparrow, using reproductive technologies to select against intersex, like leglessness and deafness, is “morally permissible” and “perhaps even morally required” (2013: 29, 34). This conflation highlights the fact that intersex is being integrated into conventional, ableist notions of disability. Disability and intersex are, as always, in the process of being discursively “made and remade [...] by historical agents” (Mollow and McRuer 2012: 7), typically privileged, able-bodied, non-intersex agents with sociopolitical and medical power (see Peers 2009, 2012, 2015; G. Davis 2015a; Holmes 2011; Magubane 2014; Dreger 1999, 1998a, 1998b; Reis 2009; Feder and Karkazis 2008).14

Similar to the debates around whether mental health issues or chronic illnesses are (or are not) disabilities or fall under the broad category “disability” (see Burstow, LeFrançois, and Diamond eds. 2014; LeFrançois, Menzies, and Reaume eds. 2013; Beresford et al. 1996; Beresford 2000; Aubrecht 2012; Lewiecki-Wilson 2003; Price 2013), one could debate whether or not intersex variations are “really” or “really like” (paradigmatic) disabilities. This debate could lead down problematically essentializing paths in that intersex could be understood as innate disability rather than a cultural process with material consequences. Avoiding such an essentializing path, Lena Eckert describes the process of “intersexualization” and explains, “there would be no such thing as intersexuality were it not for the process of pathologization that goes hand in hand with the construction of intersexuality” (2009: 41). In understanding intersex (and disability) as a process, I do not think the debate about whether intersex traits are “really” or

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14 To elaborate, “making” people with disabilities is an ongoing project invested in re/solidifying what is deemed “normal” and results in denying those deemed disabled of agency and self-determination to define themselves and decide what happens to their bodies (Clare [1999] 2009, 2017; Wendell 1996; Berger 2013; Linton 1998; Koch 2004; Peers 2009, 2012; Kleege 1999; Omansky Gordon and Rosenblum 2001; McRuer 2006). Contesting and reappropriating terms (e.g. crip, hermaphrodite, intersex, special, DSD), twisting rhetoric, and making new discourses is essential to intersex and disability activism and scholarship. Doing so challenges the epistemic privilege of medical “experts;” doing so is also a practice of power reclamation (see Wendell 1996; G. Davis 2015a; McRuer 2006). Reappropriated terms and twisted discourses are further testaments to the fact that bodily categories are constantly in the process of being un/made and testaments to the power and creativity of defiant, marginalized people.
“really like” disabilities ought to be a (main) concern. The most pressing issue is addressing and combating the ableism and interphobia used to justify violence and the eradication of bodily diversity. Actively resisting association with disability – or attempting to demonstrate that intersex is not “really like that” – reproduces ableist sentiments and is counterproductive given that ableist ideologies are exploited to justify interphobic violence (see Sparrow 2013; Chapter 4). Hence, taking an anti-essentialist approach and remaining open to the permeability and flexibility of disability and intersex, I am concerned with how the creation, stigmatization, pathologization, and eradication of disability, intersex, and intersex-as-disability occurs and is maintained. Understanding the “how” is vital in the ongoing battle against intersecting oppressive systems.

Furthermore, just as I do not maintain that intersex people ought to claim or identify as queer, even though I recognize the connection between intersex and queerness as well as interphobia and queerphobia (see Morland 2009; Pagonis 2016b; Behrmann and Ravitsky 2013; G Davis 2015a; Karkazis 2008; Feder 2014), in drawing connections between intersex and disability, I do not necessitate or argue that intersex people ought to claim disability or crip as identities. Even though throughout this dissertation one can quite easily find evidence that supports intersex people identifying as disabled or crip, my project is not particularly concerned with identity politics. That is not to deny the political importance of intersex, disability, crip, and queer identification or the importance of addressing the difficult questions concerning identification even, perhaps especially, when there are no easy answers: “[t]here are no easy answers to these incessant questions of identity and belonging; no easy way of drawing boundaries between who should be in and who should be out” (Erevelles 2014: n.p.). Claiming an identity is an ethically complicated decision that requires a critical examination of the social,
material, historical, and political power relations that mold the identity (see Samuels 2012; Mollow and McRuer 2012; Linton 1998; Viloria 2017; Attakora-Gyan 2015; A. Jones 2015; Thomsen 2016a).

Answering questions surrounding identity politics – who is in and who is out (see Wiegman 2012) – is not merely beyond this scope of this project. For this project, identity is not a pressing concern for a few reasons. First, whilst I acknowledge the political benefits of identification, I am not particularly comfortable policing how people identify (see Viloria 2017). Second, encouraging intersex people to identify with disability or crip – or claiming intersex identity and disability identity are fundamentally linked in some way – is unnecessary to demonstrating that intersex and disability are intertwined discursive and social justice issues. And, third, given the anti-essentialist and post-identity theories I root my analyses in (see Chapter 1), attempting to draw definitive “in” and “out” boundaries run contrary to my project. Or, to quote McRuer and Mollow, “what is interpretable as disability” – or a disability issue – “need not be tethered to a disability identity” (2012: 13; also see L. Davis 2013c). I can analyze intersex and “intersexualization” (Eckert 2009: 41) without being tethered to an intersex, queer, disability, or crip identity.

of intersex need not be bound to identity is a rather commonplace idea in intersex studies literature and activist work. Intersex as an identity (not merely anatomical traits or diagnoses) is becoming increasingly common, particularly in intersex activist circles (see G. Davis 2014, 2015a, 2016; Viloria 2017; Preves 2003; Odasso in Villarreal 2017; Sean Wall 2015a, 2015b, 2016; Pagonis 2015a, 2015b). However, physical characteristics deemed intersex, sexually “ambiguous,” “variant,” or disordered (i.e. DSD) are typically not tied to intersex identity. Some people with intersex traits do not claim or outright reject intersex as an identity, idea, or diagnosis. Other folks welcome DSD nomenclature or identify with disorder (G. Davis 2015a). Whereas other individuals reject intersex and DSD labels as colonial impositions and celebrate their own culturally specific identities, social categories, languages, and traditions (see Mitra 2014a; Reddy 2005; Atluri 2012; Vigneault 2011; Orr and Watson forthcoming; Chapter 3). Intersex is often not tethered to an intersex identity. Challenging interphobia and fighting for people’s autonomy is not dependent on identification. Hence, rather than debate about whether intersex variations are or are not disabilities and whether intersex people can or ought to identify with disability, my project takes an anti-essentialist, post-identity politics approach to remain open to the porous, shifting nature of categorizing bodies and subjectivities (see Somerville 2008; Daston and Galison 2007; Laqueur 1992; Reis 2005, 2009; V. Smith [1998] 2013; Rupp and Thomsen 2016). This positioning enables me to detect intersex and disability as well as interphobia and ableism “in multiple, often unexpected, locations” (McRuer and Mollow 2012: 13).

In remaining open to unexpected locations and the complexity of categorization and embodiment, I strive to remain attuned to how “[g]ender reaches into disability; disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of
race” (Clare [1999] 2009: 143); race envelops intersex (see Chapter 3; Reis 2005, 2009; Sean Wall 2015b; Somerville 2000; Magubane 2014; Willis ed. 2010); intersex extends out to disability (see Holmes 2008b, 2011; Koyama 2006) “... everything finally piling into a single human body” (Clare [1999] 2009: 143). Given this complexity, analyzing any aspect of embodiment “means writing about this entire maze” (Clare [1999] 2009: 143; also see Crenshaw 1989, 1991; Nash 2008; Cho, Crenshaw, and McCall 2013; Crenshaw et al. eds. 1995; Carbado et al. 2013; Puar 2007; Stienstra and Nyerere 2016). I aim to write about this entire maze. Yet, I am aware there are sections of the maze, despite my best efforts, that will be left untrodden. As I write, passageways shift, footpaths become harder to perceive as foliage grows, new walkways are assembled, and my situatedness (see Haraway 1988; Potter 2006) will advance and/or impede how I navigate the various landscapes. That said, I begin my venture in (and will continue to venture back to) the thoroughfares where intersex and disability (and interphobia and ableism) intersect, a section of the labyrinth that has been largely overlooked, undertheorized. I hope that my exploration is a contribution to the reimagining of an intersex politic intertwined with disability so more fruitful alliances between intersex and disability groups and scholars can form, so more equitable futures for intersex people, individuals with disabilities, crips, intersex folks with disabilities, and disabled people with intersex traits are constructed. And, in more general terms, I hope to contribute to the ongoing intersex, feminist, queer, disability, and crip projects that explore and rebuild this complex maze, projects that reimagine human categorization, celebrate diverse modes of being, and are invested in creating just futures.
Chapter Summaries

In Chapter 1, I present a review of the theoretical literatures – queer, feminist, disability, crip, and hauntology – focusing particularly on how these schools of thought theorize sex, gender, dis/ability, and trauma. After I elaborate on intersex studies’ intimate relationship with queer and feminist theories, I then unpack how feminist disability and crip theories specifically benefit intersex studies projects. Here I suggest that intersex studies conceptions of intersex and disorder requires a feminist disability, crip approach in order to recognize that interphobia is justified via ableism. Inspired by the popularization of dyad nomenclature by various intersex groups to describe the sex binary and non-intersex people as well as scholars who analyze how ideologies become compulsory, I advance the expression “compulsory dyadism” to theorize the institutionalized nature of interphobia. To emphasize the intersection of compulsory dyadism and disability, I illustrate that certain manifestations of interphobia result in disabilities by mobilizing Eunjung Kim’s expression, “curative violence” (2017: 10). Recognizing that intersex and disability scholarship often employ haunting and ghostly rhetoric, I close the chapter by elaborating on the theoretical benefits of hauntology and why spectral metaphors are peppered throughout – or haunt – this dissertation.

The following substantive chapters are organized into cases studies of interphobic violence. These case studies form an archive of the interconnectedness of intersex and disability, compulsory dyadism and able-bodiedness. In Chapter 2, I turn my attention to the medical management of people with intersex characteristics. I focus specifically on nonconsensual and medically unnecessary interventions, including intersex genital mutilation (IGM), hormone replacement therapy (HRT), and medical surveillance (e.g. routine genital examinations). Attending to scholarly literature about the apparent successes/failures of medical management
and bearing witness to intersex people’s testimonies to medical trauma, I note that the various short and long-term injurious consequences of medical management are not explicitly narrated as disabilities. I suggest that narrating the consequences as disabilities can be beneficial to intersex human rights projects. Moreover, acknowledging the trauma incurred as disabilities points to a locus for intersex and disability studies and activism to align.

Continuing my investigation, in Chapter 3 I turn to the seemingly unending mainstream, medical, and academic fascination and concern with the un/fairness of sport (inter)sex testing policies and procedures (see Cooky and Dworkin 2013; Wackwitz 1996, 2003; Maccartney and Garlick 2008; Pieper 2014, 2016; Tucker 2016; Karkazis 2016a, 2016b; M. Adam 2016; Critchley 2016; Magubane 2014; Munro 2010; Hoad 2010; Orr and Watson forthcoming; Ginnane dir. 2011; Kelner and Rudd 2017; Bermon and Garnier 2017; Beswick 2017). In tracing the history of sport sex testing – what groups of people were and currently are rendered (suspect) intersex, hermaphrodites, or men – I note that nationality, sexism, racism, and colonialism converge and fuel this interphobic practice. Currently, women of colour from colonization nations in the Global South are targeted for sex testing. Black South African runner Caster Semenya is, arguably, the most well-known athlete to be caught in the cross fires of a sex testing controversy. Analyzing sex testing and Semenya’s case through a disability lens may seem like an unusual inclination because world-class athletes are not typically construed as disabled (see K. Hall 2011). Nevertheless, approaching sport sex testing and analyzing mainstream discourses surrounding the practice through a disability lens enables me to identify a discrepancy: intersex is pathologized and defined as a disorder/disability/disease by medical professionals in and outside of sport contexts, but in the context of sport, intersex traits are represented as unfair advantages whereas outside of sport they are represented as inherent, disordered lack. Identifying
this contradiction and discursive shift opens up a conversation about how, when, and why the supposed effects of intersex-/as-disability change given the context. In opening up this conversation, I contest the supposed need to segregate sport by (perceived) sex and dis/ability.

In Chapter 4, I synthesize bioethical, governmental, and reproductive clinic literature pertaining to reproductive technologies, specifically preimplantation genetic diagnosis (PGD). PGD can accompany in vitro fertilization (IVF) and was originally developed to circumvent life-threatening genetic diseases (Behrmann and Ravitsky 2013). That said, PGD can be, and currently is, used to test for hundreds of characteristics, including non-fatal but culturally devalued morphologies like Down syndrome, deafness, blindness, and a variety of intersex variations (Carpenter qtd. by Amato 2016: 17; Carpenter 2014b). In synthesizing the relevant literatures through a feminist disability framework reveals that selecting against intersex variations via PGD is a contemporary or “new” eugenic practice (see Magnet 2013; G. Allen 1989; Garton 2000; Baker 2002; Campbell 2000; S. Long 2015; Sparkes 1999; Farrall 1985; Shakespeare 1998; Thomsen 2013; Hansen and King 2001; McLaren [1990] 2014; Grekul, Krahn, and Odynak 2004; Beaud and Prevost 1996; L. Davis 2013b; Chesterton and Perry eds. 2000; Kevles 1985; Kerr and Shakespeare 2002; Gould 1981). Disability studies’ theories and analyses of eugenics provide invaluable insights to combating the systems and discourses that normalize and cultivate the best conditions for eugenic practices and choices. Moreover, I underscore that ableist logics are mobilized as justifications for selecting against intersex. Intersex traits are conflated with or narrated explicitly as (paradigmatic) disabilities and, therefore, framed as insufferable, sometimes even fatal, characteristics.

In conclusion, I return to the central concern of this dissertation – the intersection of intersex and disability, interphobia and ableism – to assess its implications for thinking about
combating the institutionalized eradication of intersex and/as disability and thinking about intersex futures. Intersex activist Pidgeon Pagonis declares through their art: “The future is Intersex” (n.d.: n.p.). And I suggest, intersex futures will be enriched by disability; disabled futures will be enriched by intersex. An alignment between intersex and disability – integrating disability knowledges, theories and perspectives into intersex rights claims and analyses – will benefit scholars and activists in the ongoing battle against compulsory dyadism as well as able-bodiedness. As this battle continues, and as the link between disability and intersex is further explored, futures will be reimagined and retheorized.
Chapter 1
Theoretical Framework and Methodology

Introduction

When I conceptualize (the benefits of) weaving disability theories into intersex studies, I am thinking specifically of feminist disability and crip theories. Feminist disability and crip theories, however, are not the only scaffolds this dissertation rests upon. My project is inevitably interdisciplinary. Not only has my scholastic instruction been interdisciplinary, the intersex (and disability) studies projects I am inspired by and engage with are also often interdisciplinary, approached by and integrate a variety of fields and theoretical lens: bioethics (G. Davis 2013; Behrmann and Ravitsky 2013; Holmes 2008b); feminist science studies (Fausto-Sterling 1993, 2000a, 2000b; Jordan-Young 2010); theories of law (Greenberg 2012a, 2012b; Kolbe 2009); sociology (G. Davis 2015a); history (Reis 2005, 2009); anthropology (Karkazis 2008); queer and gender studies (Butler 2004; Morland 2009); sports studies (Cooper 2010; Cooky and Dworkin 2013); critical race theory (Magubane 2014; Munro 2010; Hoad 2010); disability studies (Spurgas 2009; Holmes 2009, 2011). Hence, while I prominently figure disability theories, my project is ultimately an interdisciplinary endeavor. Similar to Alison Kafer, I “move back and forth between naming this project one of ‘feminist and queer disability studies’ and one of ‘crip theory,’ raising the possibility that the two can be, and often are, intertwined in practice” (2013: 16). I move back and forth between conceptualizing my project as one of “intersex studies” and “disability studies” aware that these frameworks can be, although not often are, threaded together.

That said, to approach the quandary that certain iterations of intersex identitarianism and intersex human rights claims are sometimes distanced from disability, I put intersex studies
theorizations of intersex, disorder, disability, and de/pathologization in conversation with feminist disability and crip theorizations of precisely the same subjects. Together these theories allow me to perceive and analyze multiple locations of intersex/-as-disability, to identify and pull apart discursive threads operating through various representations of and literature pertaining to intersex/-as-disability. Ultimately, I can analyze interphobia and approach the systemic eradication of intersex in new ways.

In this chapter, I begin by situating intersex studies’ intimate association with feminist and queer theories so that I can develop my proposal that such theories, as they pertain to intersex, are strengthened by disability theories. I signal to a few ways that feminist, queer, intersex projects would benefit from disability analyses. I then provide ample explanation for advancing the theoretical concept “compulsory dyadism.” Such a justification is necessary given some intersex people’s contentious relationship with dyad nomenclature. After explaining the theoretical edge of compulsory dyadism, I suggest that compulsory dyadism and compulsory able-bodiedness are interconnected by working with Kim’s conception of “curative violence” (2017: 10) and highlighting the consequences acquired via curative violence as disabilities. I then situate the various short and long-term disabilities intersex individuals live with in theories of hauntology. Doing so advances intersex and disability literature that employs ghostly rhetoric.

All of these theories are presented as groundwork so that I can develop my arguments in subsequent chapters. I close this chapter by detailing my methodology, textual and critical discourse analysis, and why and how I approach the diverse set of texts that I chose to engage with throughout this dissertation.
Feminist and Queer Theories and Disability

To contextualize my interventions and properly explain how intersex studies projects would benefit from feminist disability and crip theories, I begin by outlining the dominant theoretical tenets of intersex studies. In stark contrast to essentialist, medical approaches taken by many medical, science, and bioethics scholars/professionals (see Sparrow 2013; Trafimow 2013; I. Hughes et al. 2006; Houk and Lee 2008), intersex studies scholars from across disciplines often root their studies in feminist and queer theories.

The history of and relationship between feminist theory and queer theory are debated and messy (Warhol and Lanser eds. 2015; Jagose 2009; Halperin 1995; Butler [1990] 2006, 1994a, 1994b). Queer and feminist theoretical traditions have, at times, been positioned as oppositional (see Jagose 2009: 164), the former understood as anti-essentialist and post-structural and the latter often deemed essentialist. Even though queer and feminist theories have and continue to occupy “riffted grounds” (Butler 1994a: 21), they are not inherently oppositional. On the contrary, queer and feminist theories are complementary, “braided together in ongoing relations” (Jagose 2009: 164). This braid is not tidy; there has never been definitive perspectives within or between queer theory or feminist theory (e.g. the sex wars, identity politics, anti-/essentialism).

There is no universal or “monolithic” (Rupp and Thomsen 2016: 895) queer or feminist theory. Like feminist theory, queer theory “is not any one thing” (Jagose 2009: 159). As critical projects, they are flexible and often elusive. Attempting to define “queer theory,” for example, is often construed as “a paradoxical ambition” (Jagose 2009: 158) given that it “prominently insists on the radical unknowability of its future formations” (2009: 158; also see Halberstam 1997; Sedgwick 1993). Nevertheless, feminist and queer theoretical traditions and projects are tangled together. They have in/formed and continue to in/form each other.
Drawing from and building upon feminist scholars’ radical *anti*-essentialist critiques of the category “woman” (see Rich 1980; Rubin 1984; Bersani 1987; Sedgwick 1985, 1990), queer theorists contend that, like gender, “one’s biological sex is also a performative and technical transmitter for the cultural demands” (Holmes 2000: 88; also see de Lauretis 1991; S. Ahmed 2010; Butler [1990] 2006, 1993, 1994a, 1994b, 2004; Berlant 2011; Berlant and Edelman 2013; Muñoz 1999; Halberstam 2005, 2011; Hennessey 2000; N. Sullivan 2003; C. Cohen 1997; Floyd 2009; Preciado 2013). “Male” or “female” sex is not an essential characteristic or essence. And there are no stable or objective positions to make assertions about biology, sex, desire, gender, or sexuality. Rather than innate attributes (Jordan-Young 2010), these aspect of one’s embodiment are culturally, discursively, and literally constructed and performed (Foucault [1978] 1990; Preciado 2013; Butler [1990] 2006). “There is nothing to discover in sex or in sexual identity; there is no *inside* [emphasis in the original],” Paul B. Preciado explains; “[t]he truth about sex is not a disclosure; it is *sexdesign* [emphasis in the original]” (2013: 35). Bodies, sex, anatomical characteristics, subjectivities, and desires do not reveal truths when one “looks” (Kessler 1998; Garland-Thomson 2009) or investigates – “There is nothing to discover in nature; there is no hidden secret” (Preciado 2013: 35). Bodies are literally re/unmade – redesigned – by consuming and being shaped by, for example, Prozac, testosterone, estrogen, progesterone, the Pill, Ritalin, blood, living human eggs, Viagra, silicone, and surgeries (Preciado 2013). There is, therefore, no innately un/natural state of being or becoming. Various things we agree to, are coerced to agree to, or are forced to ingest, consume, become, or excrete design us and help us deviate from, acquire, embody, or perform hegemonic or culturally de/valued anatomies, bodies, genders, subjectivities, and sexualities.
This feminist, queer theoretical understanding of sex, biology, and gender has been integral to intersex studies projects. That is, rather than reinforce the sex and gender binaries, intersex studies scholars draw from feminist and queer theories to illustrate how and why dominant discourses, practices, and institutions “administer” (Ezie 2011: 141) legible (Butler [1990] 2006) sex (i.e. sexdesign [Preciado 2013: 35) to uphold the epistemological fiction – or the “shattered epistemology” (Preciado 2013: 103) – of sex and gender dimorphism. As explained by intersex studies and feminist science studies scholar Anne Fausto-Sterling, “[the idea that there are only two sexes is an incorrigible proposition” (2000b: 19). Fausto-Sterling demonstrates in her pivotal book Sexing the Body, “[t]here is no either/or. Rather, there are shades of difference” (2000b: 3; also see Fausto-Sterling 2000a, 1993; Laqueur 1992: 19; Kessler and McKenna 1978; Chase 1998b, 2006; Dreger 1998a, 1998b, 1999; Preves 2003; Herdt 1994; Warnke 2011; Karkazis 2008; Roen 2005; Jordan-Young 2010; Holmes 2008a, 2008b; Klöppel 2009; Holmes ed. 2009; Oudshoorn 1994). Given that there is no either/or, intersex studies scholars demonstrate that medical interventions to ensure intersex people’s bodies “fit” an epistemological fiction are acts of violence, not medical care or cure.

In addition to undermining the sex binary, feminist and queer theoretical approaches to nonnormative sexual acts, desires, pleasures, sensations, and shame have also been important to

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15 Despite the seemingly apparent nature of biological sex dimorphism or “dyadism,” this belief was not always maintained. Like Alice Dreger (1998b), Georgia Warnke (2011), and Nelly Oudshoorn (1994), Thomas Laqueur outlines that before the late eighteenth century when sex dimorphism came to dominate Western popular consciousness and medical theory, men and women were not understood to be “different in every conceivable aspect of body and soul, in every physical and moral aspect” (1992: 5). Rather, sex difference and observable differences in morphologies were thought of as variations of one type of possible body. Women and men were not wholly different; women were understood to be underdeveloped, inside out men. Claiming that the one-sex-two-gender model gave way to the “correct” two-sex-two-gender model because of scientific advancements and “discoveries” may seem reasonable (see Klöppel 2009; Jordan-Young 2010; Dreger 1999a; Fausto-Sterling 2000b). Yet, this claim is misguided; there is no scientific evidence that proves bodies are (or ought to be) dimorphous. In Laqueur’s terms “sexual difference was created despite, not because of, new discoveries” (1992: 169). The Western sex binary has been imposed onto “a world of continuous shades of difference and similarity” (1992: 19). Science does not reveal objective truths (Daston and Galison 2007) about the body; science and scientific discourses constitute the body as sexed as well as gendered.
intersex studies analyses of systemic shaming, unnecessary, and nonconsensual medical practices. And, integrating queer analyses into intersex projects also nuances and benefits queer theory. For example, some queer analyses of sexual pleasures and desires, Iain Morland notes, fall short when intersex and interphobia are not considered: “queer theory’s assumption of a sensorial basis to cultural critique flounders when confronted with the desensitized intersex body” (2009: 287). The fact that many intersex people’s genitals and ability to feel genital sensations are altered or removed complicates queer analyses that focus on pleasure and sensation. Or, in other words, the fact that intersex people’s ability to fully participate in the pleasure economy (see Jennaway 2002; Foucault [1978] 1990; Shildrick 2007; Hennessy 2000; Manderson and Jolly eds. 1997) is limited, and often compounded by shame, is not accounted for by most queer analyses of sexual pleasure, sensation, shame, and desire (see Koomah 2017). Nevertheless, “if queer theory can tell us why pleasure is valuable, then it follows a queer discourse of pleasure can pinpoint why the diminution of pleasure makes genital desensitizations wrong” (Morland 2009: 288). Queer theory is indispensable to intersex studies and combating interphobia, specifically intersex genital mutilation (IGM), because it “lets us argue that desensitization is not an acceptable side effect of normalizing surgery, because genitalia are for touching, not for looking at” (2009: 296; also see Chase 1998a; Kessler 1998; Chapter 4). Feminist and queer theories undeniably benefit from, and are intertwined with, intersex studies projects (see Morland 2009; Holmes 2000, 2009; Spurgas 2009; Roen 2009). These theories, however, gain a critical edge when they take disability into account, when they are transformed into feminist disability and crip theories (see Garland-Thomson 2002, 2005, 2011; McRuer and Mollow eds. 2012; Kafer 2013; K. Hall ed. 2011). Subsequently, approaching an intersex studies project with a feminist, crip disability lens will be particularly nuanced and revealing.
Feminist theorists, Garland-Thomson explains, often do not take disability into account and “many disability studies scholars simply do not know either feminist theory or the institutional history of women’s studies” (2011: 13). When disability is incorporated into feminist theory, the research produced is not simply about women with disabilities (Garland-Thomson 2002, 2005, 2011; K. Hall 2011), although such research is an important site of inquiry (see Donaldson 2002, 2011; Mintz 2011; Zitzelsberger 2005). Feminist disability studies is also not an additive endeavor, about adding disability to feminist projects or analyses of gender. Kim Q. Hall elucidates in her edited collection Feminist Disability Studies: “understanding feminist disability studies as simply a combination of feminism and disability studies dulls its critical edge and lessens its potential to intervene in theoretical and social transformation. […] Instead […] it transforms both fields” (2011: 1). Feminist disability studies denaturalizes and reimagines disability and gender (see K. Hall 2011: 1; Garland-Thomson 2005: 1557; Kafer 2013; McRuer and Mollow eds. 2012; Clare 2013, 2017). For example, while the fact that women have been conceptualized as disabled, defective, or inside out men is not new (see Laqueur 1992), K. Hall notes (2011: 3-4), some feminist scholars, such as Iris Marion Young, flip the narrative and argue that women are “physically handicapped” or disabled by heterocentrism and the patriarchy (I. Young 2005: 42). I. Young argues that women’s bodies are not disabled, society’s ideologies are disabled. Arguments like I. Young’s are met with “ambivalence” (K. Hall 2011: 4) when approached with a feminist disability lens because they suggest that disability is innately polluting, disability must be “fixed,” and social justice for women can only be achieved at the expense of people with disabilities.

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16 Many disability studies scholars do and have actively integrated feminist theories (see Clare [1999] 2009; Wendell 1996) before “feminist disability studies” proper was explicitly defined.
When integrated into an intersex studies project, feminist disability studies contribute to reimagining inter/sex and disability. In fact, Garland-Thomson (2005) and K. Hall (2011) imply that a feminist disability lens is necessary when analyzing intersex people’s bodies – bodies that “spectacularly violate sacred ideologies of Western culture” (Garland-Thomson 2011: 26) – and the medical imperative to “cure” said bodies. Likewise, I maintain that such an approach is required when analyzing the numerous ways people with intersex traits – characteristics deemed disordered, disabled, and diseased – are effected and affected by interphobia. A feminist disability lens prompts me to pause at the medicalizing conceptualization of intersex as disordered, disabled, or diseased. It helps me identify and, therefore, combat the ableism used to justify unnecessary and irreversible interventions. That is, a feminist disability lens pushes analyses about intersex characteristics, interphobia, and the pervasive desire to “fix” people with intersex traits further than feminist theory alone.17

Similar to many feminist theorists, queer theorists rarely take disability into account (McRuer 2006; P. Anderson and Kitchin 2000; Desjardins 2012; Siebers 2012; Wilkerson 2002; Shakespeare 2000; Zitzelsberger 2005). Crip theory was the remedy to – or perhaps the result of – the “overdue conversation between queer theory and disability studies” (Bérubé 2006: vii). Like feminist disability studies, crip theory is not an “additive” venture “in which identity categories are checked off one by one as they are ‘accounted’ for theoretically” (Bérubé 2006: vii). Disability transforms or “crips” theories and projects about queerness. Crip theorists are

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17 Recalling K. Hall’s (2011) sense of ambivalence towards I. Young’s (2005) claim after viewing it through a feminist disability studies lens, perhaps one also feels a tinge of ambivalence when looking at the following two quotes through a feminist disability studies lens: Adams recalls being told, “[i]t [intersex] is a disorder because it has caused so much disorder in my life,” by another intersex person at a conference (Adams qtd. by Caplan-Bricker 2017: n.p.); “Intersex embodiments are congenital variations that are disabling […] in that they are corporeal configurations that violate cultural standards” (Karkazis 2008: 10). A feminist disability studies lens can help deconstruct these quotes in a new way. One may consider intersex to be disabled because they violate norms. Yet, these quotes also imply that cultural standards are disabling (or disordering) and, if this is the case, feminist disability studies is imperative to ensuring ableism is not reproduced.
attuned to the ways compulsory heterosexuality and able-bodiedness are institutionalized in intersecting ways (see Guter and Killacky eds. 2004; McRuer 2006, 2011; Kafer 2013; McRuer and Mollow eds. 2011; O’Connell 2011; Clare [1999] 2009, 2001, 2013, 2017; Löfgren-Mårtenson 2013; Cosenza 2010; Sandahl 2003; C. Kelly and Orsini eds. 2016; Peers, Brittain, and McRuer 2012; Baril 2015a, 2015b). Crip theorists, therefore, attend to the ways that disability and queerness are re/unmade, interconnect, and are given meaning; they “[seek] to crip or destabilize categories of meaning” (Rinaldi and Halifax 2016: 245). In understanding the critical edge of crip theory, I am driven to consider how intersex figures in the political project of crippling and subverting hegemonic, heteronormative, homonormative, queerphobic, and ableist discourses and categories.

The analytical capacity of crip theory is demonstrated when one, for instance, crips discourses surrounding queer social justice movements (McRuer 2006, 2011). Doing so reveals that queer social justice movements often reproduce ableist discourses, collude with violent institutions, and come at the expense of people with disabilities. Consider the push for same-sex marriage. McRuer (2006), Lisa Duggan (2002), among others (G. Brown 2009; Van Eeden-Moorefield et al. 2011; Richardson 2005; Whitehead 2011) observed that same-sex marriage has been framed as fundamentally liberatory and liberal, but the project colluded with a historically violent institution (i.e. marriage) and neoliberalism. Moreover, some arguments for institutionalizing same-sex marriage reproduce homonormative, queerphobic, and ableist narratives. For example, same-sex marriage was sometimes justified on the grounds that doing so would be an adequate remedy to the spread of HIV/AIDS (McRuer 2006). In conflating queerness with the supposed horrific spread of disability, disease, and degeneracy, this reasoning unnecessarily restigmatizes queer folks and (queer) people with HIV/AIDS, a highly stigmatized
disabling illness (see McRuer 2006; Huebenthal 2017; Gonzalez 2010; Adam-Smith and Goss 2005). Justifying same-sex marriage need not include re/stigmatizing already marginalized groups. Pushing this crip analysis of same-sex marriage further to illustrate that both crip and intersex studies can benefit from each other, the mainstream media’s insistence that same-sex marriage was the “main” or “first step” to queer justice worth celebrating erases the fact that “disabled” intersex people’s bodies are literally mutilated or “enabled” to fit into the same-/different-sex marriage model (Orr 2015).

Queer and feminist theories are enriched by integrating disability and transforming into feminist disability and crip theories. Subsequently, an intersex studies project rooted in feminist and queer theories can only benefit from “folding” (McRuer 2006: 71) in said theories and exploring how intersex, queerness, disability, and crip “twist” (Kafer 2013: 16) into each other. In unpacking how they twist together, I am resolute that a feminist disability, crip lens is indispensable to intersex studies projects and activism.

*Compulsory Dyadism*

The word “dyad” – meaning two – is employed by a variety of academic fields to describe a pair. In sociology, for example, a dyad usually refers to a pair of two people; in music, it is a set of notes or pitches; in the field of biology, a dyad typically refers to a pair of chromatids; in pedagogy studies, it is often used to describe two students working together; in feminist, sexuality, and queer studies, like the term “binary,” dyad is typically employed in reference to the two (contested) sexes and genders (see Letendre 2009; N. Fraser 1989; Coogan 2011; Abbey et al. 1987). The word “dyad” is also used to theorize a variety of cultural phenomena. For instance, “dyadic power theory” is employed in communication studies to name and examine the
power dynamics between two people in a familial relationship (see Dunbar 2004; Rollins and Bahr 1976); in sexuality studies, the “dyadic imaginary” draws attention to ways heterosexuality, coupledom, and monogamy are naturalized (see Hidalgo, Barber, and Hunter 2008; Sheff 2011). Dyad, dyadic, and dyadism are also used by many intersex activists and organizations (see Costello 2009a, 2009b, 2009c, 2012, 2013; von Klan 2016; Plattner 2011; Ray n.d., 2017; Andry 2015; OII; InterACT Advocates for Intersex Youth; AIS-DSD Support Group; Actually Intersex). Like some scholars, these intersex activists and organizations use these monikers to describe the sex binary or, as intersex and trans activist and scholar Cary Gabriel Costello aptly puts it, the “myth of dyadic sex” (2009a: n.p.). “Intersex people using the word dyad,” intersex activist and writer Karin Plattner similarly explains, “seem to be using it in place of the word binary” (2011: n.p.).

Taking note of the popularization of dyad nomenclature within intersex communities and evidently drawing inspiration from the theoretical and pragmatic utility of phrases like “compulsory heterosexuality” (Rich 1980, 2003; Butler [1990] 2006; Kafer 2003, 2013), “compulsory able-bodiedness” (McRuer 2006, 2011, 2013; Snyder and Mitchell 2010; Kafer 2003, 2013; Puar 2009), and “compulsory reproduction/motherhood” (Maroney 1985; Edelman 2004; Deifelt 2005; Butler [1990] 2006) coined and employed by feminist, disability, and queer theorists, I advance the phrase “compulsory dyadism.” The expression is a useful tool to name, unpack, and undermine the institutionalized epistemological fiction of sex dimorphism or “dyadism,” the cultural mandate that people’s bodies and embodied performances must align with, reproduce, and reconfirm the male-female sex binary. Despite the fact that the ideology of dyadic sex is “shattered” (Preciado 2013: 103) – or, perhaps more accurately expressed, it was never whole, defensible, or representative of bodies to begin with (Dreger 1999; Foucault [1978]
– people with intersex traits who violate this sanctified, primarily Western, cultural belief (see Garland-Thomson 2011; Crouch 1999; Vigneault 2011; Warnke 2011; N. Menon 2011; Mitra 2014a; Reddy 2005; Atluri 2012; Lugones 2007) are regarded as innately disordered, disabled, or diseased (Holmes 2008; Mitra 2014a; Sparrow 2013; G. Davis 2015a). And, therefore, so the logic goes, they must be “fixed;” the traits must be eradicated.

The idea that there are two, mutually exclusive sexes is not merely a belief. The sex binary remains the dominant way people’s bodies are categorized, represented, and treated in and by various, but not distinct, cultural domains: medical, political, domestic, social, legal, governmental. Dyadism is an institutionalized cultural demand. If dyadism was not culturally mandated various forms of physical and symbolic violence would not have been (see Reis 2005, 2009; Dreger 1999; Magubane 2014; Munro 2010) and would not continue to be systemic: medically unnecessary and nonconsensual interventions would not be the dominant medical protocol (see Chapter 2; Méndez 2013, 2016; United Nations Human Rights 2017; Kessler 1998; Karkazis 2008; Klöppel 2016; Jordan-Young, Sönksen, and Katrina Karkazis 2014; Kirkland 2017); sport sex segregation as well as sex testing and requiring people who “fail” said tests undergo medically unnecessary interventions would not be institutionalized (see Chapter 3; Jordan-Young, Sönksen, and Katrina Karkazis 2014; Orr and Watson forthcoming; Dworkin and Cooky 2012; Pieper 2014, 2016); intersex people would not be systematically shamed, silenced, pathologized, abused, and objectified in and outside of medical contexts (Chapter 2; Dreger ed.

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18 Malta is the exception. In April 2015 Malta was the first and remains the only nation to ban intersex genital mutilation (see S. Fraser 2016; Carpenter in United Nations Human Rights 2017: n.p.; Ghattas 2013: 19). Malta also offers an “X” marker for passports and other governmental identification cards as well as work permits (Pace 2017). In December 2015, the Chilean Ministry of Health published “Instructions of health care to intersex children,” which unequivocally orders medical professionals to cease normalizing treatments on intersex children until they are old enough to decide if and when they want to undergo interventions (see Carpenter 2016a; Lavers 2016). These instructions, however, are not law. That said, it appears that Chile and Portugal may follow Malta’s lead in the near future (Marchiano 2017).
1999; Cooky, Dycus, and Dworkin 2013; L. Anderson 2009; Creighton et al. 2002; Clare 2017; Tosh 2013; T. Alexander 1997; Astorino 2010; Koyama 2003; Shelley Wall 2010; Koomah 2017); “male” and “female” would not be the only recognized sexes;\(^{19}\) laws concerning reproductive technologies would not encourage (potentially) pregnant people to select against intersex traits (see Chapter 4; Carpenter 2016b; Costello 2014c; O’Neill and Blackmer 2015). I put forth “compulsory dyadism” to interpret and theorize the myriad, systemic ways dyadism is demanded and institutionalized.

Instead of the expression compulsory dyadism, one could propose repurposing Danielle Antoinette Hidalgo, Kristen Barber, and Erica Hunter’s expression: the “dyadic imaginary” (2008: 171). As noted above, the “dyadic imaginary” is used to deconstruct the presumed naturalness of heterosexuality, compledom, and monogamy. The dyadic imaginary, Hidalgo, Barber, and Hunter write, is “an ideology or hegemonic concept that renders non-dyadic [i.e. lesbian, gay] intimate and sexual relationship forms invisible and unnatural” (2008: 173). One could propose expanding this idea to analyze interphobia and the sex dyad as well. Arguably, doing so would nuance the current iteration of the dyadic imaginary. However, I proceed with the phrase compulsory dyadism because the word “compulsory” emphasizes the systemic, cultural dictate of dyadism in a way that the word “imaginary” does not. “Imaginary” implies that dyadism is merely a belief; it does not immediately convey that dyadism is institutionalized. And highlighting the systemic nature of dyadism is imperative because, as noted on Transgender, Non-Binary, Intersex: Support and Activism Club’s website, dyadism is the “institutional [emphasis added] response which assumes that all people are one of 2 narrow sex classifications

\(^{19}\) Some countries and cultures do recognize, celebrate, and/or institutionalize “a third sex/gender” (e.g. India, Germany, Australia). This recognition, however, does not grant full citizenship status or prevent interphobic violence (e.g. one’s sex/gender will not be reflected on all legal documents; public spaces such as bathrooms are still sexed/gendered as male or female; intersex genital mutilation remains legal).
and therefore excludes the needs, concerns and life experiences of intersex people; [dyadism] awards power to non-intersex people and denies privileges/rights to intersex people” (“Kyriarchy and Discrimination” n.d.: n.p.).

The words dyad and dyadic are also used by some intersex people as synonyms for non-intersex individuals, people who do not have intersex traits. Plattner affirms: “‘Dyad’ is a noun used by some intersex people to refer to non-intersex people [...]. ‘Dyadic’ is the adjective used in reference to non-intersex people” (2011: n.p.). Similarly defined on InterACT’s webpage, “What Is Intersex? An Intersex Faq By Inter/Act.” “Some intersex people have started using dyadic to describe those who are not intersex (meaning, they fit the ‘male’ or ‘female’ [sex] binary” (2015: n.p.). Put simply, dyad is to intersex as cis is to trans, enabled is to disabled, or heterosexual is to homosexual.

There are theoretical and pragmatic benefits to having a word to designate non-intersex people. Intersex activist and writer, Claudia Astorino, elucidates:

I have heard the phrase “dyadic” a few times since talking to intersex activists and in reading about intersex in general. I didn’t really understand what this word meant at first, but in context, I came to realize that it was shorthand for “non-intersex.” This puzzled me a bit. I don’t think it would be a bad idea to have an adjective meaning “non-intersex.” Having a term like “intersex” without an opposite serves to identify an individual as intersex, but doesn’t really help you understand what a not-intersex person is. The implication is that non-intersex people are just “normal,” and because they’re “normal,” they don’t need to have an extra word applied to them. The extra-word burden is on those people that are different. But having an opposite-word can be really important, because instead of having the “normal” state of being and the weirdo one with the funny name, having two words means that for this state of being, there’s more than one way to be. There’s no value judgment implicit in having multiple terms for a different states of being [sic] like there is in having a term only for the less-typical one. (Astorino 2012: n.p.).

For Astorino, “dyad” and “dyadic” help abate the “extra-word burden” that renders intersex people abnormal biological deviants (2012: n.p.). These words are instruments intersex activists
and intersex studies scholars can use to identify, make visible, and deconstruct compulsory
dyadism and dyad privilege.

The advantages Astorino describe are similar to the benefits accrued from the academic
and mainstream proliferation of “cisgender” or “cis” nomenclature (see Stryker 2006, 2008;
Stryker and Whittle eds. 2006; Aultman 2014; Enke 2013; Johnson 2013; Lennon and Mistler
2014; Spencer 2015; L. Miller 2015; Yep, Russo, and Allen 2015; Serano 2009). Emerging from
trans activism in the 1990s, “cis” makes visible the seeming invisibility of cisness, cis privilege,
cisnormativity, and cissexism. Cis terminology helps scholars and activists undermine and
criticiz[e] many commonplace ways of describing sex and gender. The terms man
and woman [emphases in the original], left unmarked, tend to normalize cisness –
reinforcing the unstated “naturalness” of being cisgender. Thus using the
identifications of “cis man” or “cis woman,” alongside the usage of “transman”
and “transwoman,” resists that norm reproduction and the marginalization of
trans* people that such norms effect. (Aultman 2014: 61-62).

Or in Leland G. Spencer’s terms, “by actively naming cisgender privilege and social structures of
cisnormativity, we resist defining transgender persons as Other and everyone else as normal”
(2015: xix). Astorino and other intersex activists and organizations employ dyad and dyadic for
the same reasons: to resist defining intersex individuals as Other and dyadic people as normal, to
name, identify, and combat dyad privilege, compulsory dyadism, and interphobia.

Intersex-dyad discourse also combats the linguistic erasure that “cisgender rhetoric
facilitates” (Viloria 2014: n.p.). Without denying the benefits of cis nomenclature, intersex
activist, scholar, Chairperson of OII, and founder and Executive Director of OII-USA, Hida
Viloria explains,

if you are born intersex, this [cis-trans discourse] doesn’t actually apply to you
because there are [emphasis in the original] no gender norms attributed to your
biological sex as society doesn’t even acknowledge that it exists. Indeed, as “cis”
means “on this side of”, and “trans” means, “on the other side of”, those of us
who are not on either [emphasis in the original] side of this binary framework of
sex are inherently excluded from cisgender rhetoric. And note, we [intersex people] didn’t used to be, back when people simply said “trans*” or “non-trans*.” (Viloria 2014: n.p.).

In an effort to combat the intersex erasure that the promotion and adoption of cis rhetoric unwitting produces, after conversing with Viloria about this concern, Costello proposed adding the expression “ipso gender” to trans and cis discourses (see Costello 2014a; 2014b, 2015; Viloria 2014; Viloria and Zzyym 2015).

“Ipso” simply means self (Paine et al. 2007); and, to clarify, “inter” means between. Currently, the word ipso is most frequently used in scientific discourses. Speaking of Costello’s proposed term in LGBT Weekly, Autumn Sandeen explains: “[i]n chemistry, which gives us the language of cis and trans isomers, there are chemicals based upon a ring structure, called arene rings. When a chemical substitution is made in the same place on the rings, this is referred to as ‘ipso’ substitution” (2014: n.p.). Hence, with linguistic inventiveness, Costello proposes:

[a] cis gender intersex person would be one with an intermediate gender identity, since that ‘matches’ their birth sex. An ipso gender intersex person would identify with the binary sex they were medically assigned [...]. And a trans gender intersex person would be one who identifies with the binary sex other than the one they were assigned by doctors. (Costello 2014b: n.p.).

According to Costello’s suggested terminology, ipso gender intersex people identify with the male or female sex they were socio-medically assigned; their identity remained “in the same place,” so to speak. While there are “drawbacks” to ipso gender (Costello 2014b: n.p.; also see Andry 2016), for example, it “does not resolve the challenges that intersex people pose to successfully discussing ‘cisgender privilege’” (Viloria 2014: n.p.), these linguistic devices and conversations are vital in combating intersex erasure and are integral to intersex people’s self-determination and narration.

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20 Isomer refers to one of two or more compounds, radicals, or ions that contain the same number of atoms of the same elements but differ in structure.
Returning focus to dyad terminology, while there are advantages to using said nomenclature, there are also concerns that must be addressed. Astorino voices some of these concerns:

I don’t think that dyadic is the greatest choice. The term dyadic means “two” – a dyad, a pair. By calling a non-intersex person a dyadic male or female, you’re basically saying that everyone who’s not intersex fits nicely into that binary of male, female. But the fact that intersex people exist at all means that there is, and never was, dyadic sex as long as intersex people were around. By using the term dyadic to refer to non-intersex people, it totally glosses over the implications of intersex people existing: that binary sex is [not] actually real. If biological sex isn’t binary, then using a term like “dyadic” to describe non-intersex makes about as much sense as saying we’ve got a binary color wheel that’s composed of red and blue, when we know full well that there’s purple and orange and magenta out there, being awesome. (Astorino 2012: n.p.).


The male-female and intersex-dyad dualisms are not merely theoretically complicated and contested. There are pragmatic and ongoing debates about who is (not) intersex and who, therefore, can be included in intersex spaces and speak to intersex experiences (see O’Rourke and Giffney 2009; Holmes 2002; Kessler 1998; Dreger 1999; “What is Intersex?” n.d.). Viloria
discusses this debate as it pertains to people claiming (or “masquerading” as) intersex. “[C]ertain [intersex] community members have a fear,” Viloria recounts, “that there are trans people pretending to be intersex and that it will be bad for the movement” (2017: 328). I quote Viloria at length:

I’ve been hearing about this fear since I came out as intersex twenty years ago, and I still hear it today. Recently, some intersex people I know have told me that people who weren’t born intersex but are identifying as such are not working against, or even talking about, the irreversible harms of IGM [intersex genital mutilation]. In fact, they say these people are jeopardizing efforts to address IGM by diverting the focus to other issues, and I agree that if that’s true, it isn’t great. However, in the long run [emphasis in the original], given that intersex babies are operated on precisely because people think it’s an undesirable way to be, it seems far from hurtful if adults who weren’t born intersex nevertheless want [emphasis in the original] to be identified as intersex. It demonstrates that it’s actually something desirable (which personally I believe). I also don’t think anyone has the right to tell another person that they have to be born with certain sex characteristics in order to identify as the gender associated with those sex characteristics. In fact, intersex people are living proof that gender doesn’t always match biological sex. [...] Therefore, at the risk of provoking the wrath of biological determinists, I feel compelled to point out that if both trans and intersex people demonstrate that neither sex nor gender is determined by one’s biological sex at birth, why does being intersex have to be determined this way? (Viloria 2017: 328-329).

Viloria is, understandably so, wary about apparently non-intersex people identifying as intersex, especially without condemning IGM and other manifestations of compulsory dyadism. Claiming an identity is an ethically complicated decision (Mollow and McRuer 2012; Linton 1998) that requires accountability and a critical examination of the social, material, historical, and political power relations that mold the identity in question. That being said, Viloria’s reasons for refusing to police how people identify are politically and theoretically compelling. If one is invested in anti-essentialism and recognizes how anti-essentialism figures in intersex, trans, and queer human rights and identity claims, policing who is (not) or who should (not) identify as intersex, man, woman, genderqueer, non-binary, &c. becomes quite tricky; indeed, I believe, indefensible.
As these conversations continue, the theoretical and pragmatic limits of the dyad-intersex or non-/intersex binaries will be further questioned.

Despite the issues taken with naming non-intersex people dyadic, currently this term appears to be the most adopted by intersex activists and organizations. Other terms, however, such as sex typical, intrasex (“intra” meaning inside), perisex (“peri” meaning about or around), juxtasex (“juxta” meaning nearby), and endosex (“endo” meaning within), have been proposed, debated, and used to refer to people who do not have intersex traits (see Schulter 2017; Actually Intersex n.d; Fuck Yeah Sex Education n.d.). To describe and outline a couple of these terms and debates, “sex typical” is employed by various enterprises such as Sex Development Genetics and Biology, an initiative of the Research Program in Disorders of Sex Development funded by National Health and Medical Research Council (NHMRC) Australia (see Koopman 2014). “Sex typical” has the danger of reproducing the notion that its counterpart, intersex, is inherently abnormal, freakish, and pathological. The word typical, Astorino argues, “doesn’t have the same connotation as ‘normal’ [...], but I think that people would still say, ‘Oh, you’re sex-atypical.....’ and not think of the distinction between a/typical as more/less frequent but less/more weird” (2013: n.p). In other words, this language renders intersex atypical and atypicality is often conflated with abnormality and, in turn, pathology.

On the discussion forum Fuck Yeah Sex Education, perisex is defined and endorsed by one of the forum’s moderator, Mod H. In contrast to “inter,” which, as noted above, means between, “peri” means about, near, or around. Perisex, according to Mod H, “does not imply a sex binary nor does it imply non intersex people strictly fit a binary system, rather it suggests that there are people who are closer to what has been constructed (in western culture) to be ‘male’ and ‘female’ and those people do not fall into the intersex umbrella” (2014: n.p.). This term,
perhaps, could avoid some of Astorino’s concerns, namely it may not repathologize intersex and it seemingly does not reproduce the idea that sex is dichotomous.

On the discussion forum Actually Intersex, perisex is rejected and dyad is endorsed because, according to moderator Mod C, dyadic people coined perisex. “I don’t remember who exactly coined it [perisex],” Mod C explains,

but it happened after a certain intersex blogger made a post (intended for the intersex community only!) criticizing the word “dyadic” and while I didn’t necessarily agree with their opinions, I understood their point of view. However, dyadics took the opportunity to coin their own phrase that was less othering of them (as if they haven’t been othering us since forever). It’s kinda like Mod D said a while back; if dyadics really had their way, they’d just be called “normal.” (Mod C in “metasoma” 2016: n.p.).

In a similar vein, an anonymous individual on the forum asked: “What is perisex and why do dyadics keep telling me to call them that instead? Honestly, until they all stop calling me the H-slur [hermaphrodite] I literally DGAF [don’t give a fuck] about what they’d like to be called…” (Anonymous in “Anonymous Asked” 2016: n.p.). Mod C responds: “My feelings exactly. It’s the same as when cis people flip out over being called ‘cis’ and demand a label of their own invention. We won’t do it. Perisex is a silly word and was invented by dyadics to restore their power imbalance, and I’m not having it” (Mod C in “Anonymous Asked” 2016: n.p.). Intersex people have historically and systematically been denied the power the name and define bodies and experiences of oppression (G. Davis 2014; Feder and Karkazis 2008). Hence, rejecting language that was not created by (and for) intersex people in the attempt to name and combat interphobia and compulsory dyadism is a meaningful repudiation. Doing so is a means to re/claim power over intersex as well as a means to re/define ab/normality.

“Endo” means within, inside, or internal. According to Mod C on Actually Intersex, endosex is problematic because it, too, was invented by a non-intersex, dyadic person (Mod C in
“Anonymous Asked” (2015). Mod D claims that endosex sounds too much like intersex and therefore minimizes dyadic privilege (Mod D in “Anonymous Asked” 2015). Nevertheless, Heike Susanne Bödeker, a German intersex activist and writer, employed the term endosex several years ago (see Bödeker 2000). The word also appears in Margo Schulter’s essay, “Owning Endosex Privilege and Supporting the Intersex Community: WPATH, Intersex Genital Mutilation (IGM), and Sex Variant Bodies,” featured in The TransAdvocate (2017). Schulter’s piece is thoughtful and insightful, but there is no discussion about why endosex, as opposed to another term, is used to name non-intersex people. Nevertheless, as the acknowledgement section notes, Cary Gabriel Costello – a prominent intersex and trans activist and scholar who appears to typically employ dyad terminology (see 2009a, 2009b, 2009c) – provided feedback, suggestions, and support to Schulter during the writing process. Schulter’s essay is also promoted on OII USA’s website (see “The TransAdvocate” 2017).

Conversations about nomenclature pertaining to non/inter/sex as well as DSD embodiments will continue within and between activists, transnational communities, cultures, and languages (see Viloria 2017; G. Davis 2015a; Holmes 2009; Karkazis 2008; Koyama 2006; Reis 2005, 2009; Feder and Karkazis 2008; Houk and Lee 2008; Davies et al. 2011; Dreger and Herndon 2009; Feder 2009; Barthold 2011; Astorino 2012). Terminology will inevitably shift through time and space. While using dyad to name non-intersex people is common among

21 Unfortunately, I cannot find any sources that explain why Bödeker prefers (or preferred) this term.
22 I was fortunate enough to witness and engage in such conversations at the After the Recognition of Intersex Human Rights conference sponsored by the Institute of Advanced Studies at the University of Surrey, Guildford, Surrey, UK (2016). Numerous intersex activists and intersex studies scholars from several countries attended the conference. Conversations about terminology were frequently revisited and hotly debated. To me, the most compelling aspect of these debates came from scholars and activists whose first language is not English. They drew attention to the Anglocentrism of adopted and endorsed intersex terminology. They pointed out that the terms deemed offensive or in/appropriate to some English-speaking intersex people was the most apt translation, not offensive in their language, or was lost in translation. Ensuring that there is ample and respectful space for discussing terminology across languages and cultures, and combating Anglocentrism within the Intersex Rights Movement, is vital as these conversations continue. For an example of this sort of discussion, see Small Luk (2015).
various intersex people, activists, and organizations, doing so is also rightly questioned and disputed. Yet, employing dyad nomenclature to describe an ideology – the male-female sex binary – is not contested. Dyad is befitting. Like the way that Costello (2009a, 2009b, 2009c) employs dyad terminology, I use the expression “compulsory dyadism” to highlight, describe, and resist the instituted, interphobic cultural demand that people must not have intersex traits or identify as intersex. People’s bodies and identities are not dyadic. They are more various, beautiful, and defiant than instituted ideologies expect and allow them to be. To quote Astorino again, “there’s purple and orange and magenta out there, being awesome” (2012: n.p.). Yet, compulsory dyadism is real and has profound material consequences.

To reiterate, I employ dyad nomenclature and the expression “compulsory dyadism” to describe an instituted ideological mandate, not to describe a definitive biological state or identity. I do not use this terminology to reaffirm male-female or intersex-dyad dichotomies. I remain open to conversations about language and the practice of naming and categorizing (see Butler [1990] 2006), to future rhetorical shifts that better capture and challenge institutionalized oppression and support and reflect intersex communities and intersex people’s self-determination.

Body-Mind Disabilities

Approaching compulsory dyadism through a feminist disability studies lens demonstrates that compulsory dyadism is intertwined with or is an iteration of compulsory able-bodiedness. In recognizing this interconnection, theorizing intersex and disability together is not merely beneficial, doing so is necessary. A site in which intersex and disability are evidently on the same continuum is the fact that intersex people who “fail” to comply with compulsory dyadism
are deemed disordered, disabled, or diseased by medical professionals. Or, as Morgan Holmes explains, a disability lens is crucial because “the medical presupposition that intersex characteristics are inherently disabling to social viability remains the take-for-granted truth from which clinical practice proceeds” (2008b: 169; also see Holmes 2011). Intersex traits that breach compulsory dyadism are simultaneously construed as violating compulsory able-bodiedness.

The relationship between compulsory dyadism and compulsory able-bodiedness, and the necessity of crippling analyses of intersex issues, is further illustrated by the reasoning for and consequences of nonconsensual, unnecessary medical interventions. As I discuss at length in Chapter 2, ironically, in the attempt to “fix” or “enable” apparently disordered intersex people, medical professionals often subject these people to various procedures that typically result in various short and long-term physical and psychological disabilities. Or, in more accurate terms, these interventions result in various “body-mind” disabilities (Clare 2017: xvi). Clare writes of the phrase “body-mind:”

I followed the lead of many communities and spiritual traditions that recognize body and mind not as two entities but as one, resisting the dualism built into white Western culture. Some use the word bodymind [emphasis in the original] or mindbody [emphasis in the original]; others choose body/maid [emphasis in the original] or body-and-mind [emphasis in the original]. I settled on body-mind [emphasis in the original] in order to recognize both the inextricable relationships between our bodies and our minds and the ways in which the ideology of cure operates as if the two are distinct -- the mind superior to the body, the mind defining personhood, the mind separating humans from nonhumans. (Clare 2017: xvi).

The white, Western, Cartesian tradition of conceptualizing the mind and the body as distinct entities does not theoretically or pragmatically reflect people’s embodied, subjective experiences (B. Turner 2001). Thus, rather than using terms like “physical disability,” “psychological disability,” and “mental health issues” that reproduce the body-mind dyad and misrepresent dis/abilities, many disability scholars employ terms like “body-mind.” These terms work to
acknowledge the fact the body and the mind are not discrete aspects of a person. I follow suit and employ the phrase body-mind disabilities.

I use the language of disability to describe the embodied harm acquired by intersex people at the hands of medical professionals. Intersex studies scholars and activists employ other terms and discourses to outline and resist the medical model that seeks to eliminate intersex variations. For instance, the language of mutilation and the expression “intersex genital mutilation” (IGM) are used to emphasize the damaging consequences of various medical procedures (see Pagonis 2016b; Chase 1998b, 2002, 2006; Ehrenreich and Barr 2005). This discourse is also used to draw attention to the fact that these “corrective” procedures are similar to, the same thing as, or sometimes “more” “physical[ly] and psychological[ly]” harmful (Ehrenreich and Barr 2005: 74) than female genital mutilation/cutting (FGM/C). That is to say, like FGM/C, IGM is a cultural practice. IGM is not and could never be “objective” medicine (see Pagonis 2016b; Chase 1998a 1998b, 2002, 2006; Ehrenreich and Barr 2005; Paget [1988] 2004; Treichler 1999; Reagan, Tomes, and Treichler eds. 2007; van Dijck 2005; Daston and Galison 2007). Drawing from renowned intersex activist and scholar Cheryl Chase (also known as Bo Laurent) (1998a, 1998b, 2002, 2006), Nancy Ehrenreich and Mark Barr write, “Western feminism has represented African genital cutting as primitive, irrational, harmful, and deserving of condemnation. The Western medical community has represented its genital cutting [performed on intersex people] as modern, scientific, healing, and above reproach” (2005: 71). This discursive “double standard,” to borrow from Chase, functions to “other” African girls and women and protect medical professionals who harm intersex people, primarily infants and children (2002: 145). “Normalizing” medical projects and their consequences have also been referred to as torturous (“Committee against Torture” 2016; Méndez 2013, 2016; Guillot, Bauer,
and Truffer 2016) or queering (Morland 2009; Roen 2005). I have yet to come across intersex studies scholars or activists who explicitly frame the effects as disabling.\(^{23}\)

Thinking about the consequences of the violent, “curative,” medical model as disabling is not a rejection of the other narratives used to understand and combat nonconsensual interventions. I hope that conceptualizing the effects as disabling is a productive discursive tool that can be used to hold medical professional accountable and help alter policies and laws about “normalizing” interventions. Additionally, referring to the effects as disabling may also better reflect some intersex people’s realities of living with body-mind disabilities caused by medical protocols and procedures.

I realize that there is a potential danger in referring to the consequences of “curative” medical intervention as body-mind disabilities. Doing so could be misinterpreted as or twisted into what Clare refers to as “cautionary tales” (2017: 129). In such tales, the “tragedy” of disability (see Goodley 2011, 2014; Campbell 2009; Peers 2009) is used as justification for advocating against unjust, violent practices and oppressive circumstances. In describing cautionary tales, Clare asks readers to consider “a series of advertisements in the Sierra Club’s campaign Beyond Coal” (2017: 55):

In one [advertisement], the tagline reads, “Asthma. Birth defects. Cancer. Enough.,” superimposed over a looming smoke-belching power plant. In another, we see the big belly of a pregnant woman dressed in pink, one hand cupping her stomach. Her skin is light brown. Her face isn’t visible. Her belly is captioned, “This little bundle of joy is now a reservoir of mercury.” The fine print tells us: “Mercury pollution from our nation’s coal-burning power plants is harming pregnant women and their unborn children. Mercury is a powerful neurotoxin that can damage the brain and nervous system – causing developmental problems and learning disabilities.” To persuade viewers that these plants need to be shut down,

\(^{23}\) Although such a claim would coincide with Koyama’s analysis, Koyama does not explicitly frame the consequences of medical interventions as disabling. Rather, the fact that intersex traits are marked as disabled is stressed: “intersex activist Esther Morris’s observation that ‘not having a vagina was not my problem; having to get one was,’ can be paraphrased to say: not having a vagina was not a disability; the social expectation that she needed to get one in order to live happy and productive life marked her body disabled” (2006: n.p.).
both ads use disability to make an argument about the consequences of environmental destruction. There is so much to pull apart here about gender and race. The second ad relies on stereotypes about femininity and the supposed vulnerability of women and children. It objectifies a woman of color, reducing her to a body part, which is then further reduced to a reservoir. But at the center of this argument lies disability. (Clare 2017: 55).

These stories propose that a form of violence ought to cease because it produces body-mind disabilities and body-mind disabilities ought to be avoided at all costs (Clare 2017). Similar to the advertisements Clare (2017) writes of, the narration that nonconsensual, unnecessary medical interventions enacted on people with intersex variations produce body-mind disabilities could be misread or repurposed as a disability cautionary tale. Such a tale would read something like this: interventions need to stop because they produce disabilities; disabilities are inherently inferior; therefore, they ought to be avoided at all costs. Rather than focusing on the fact that these “curative” (Kim 2017) medical practices are violent, violate the Hippocratic Oath (see Pagonis 2017b; Ford 2001; Grabham 2007), and are rooted in the unsubstantiated and indefensible ideology that sex is dyadic, a cautionary re-telling of this narrative relies on ableist ideologies to oppose violent practices.

In addition to the fact that my suggestion – medical interventions produce body-mind disabilities – could be repurposed into an ableist cautionary tale, Morland’s observation that “desensitization is not an acceptable side effect of normalizing surgery” (2009: 296) could be similarly distorted. The “desensitization” Morland speaks of – the injured nerves, removed genital tissue/structures, dulled sensation, inability to experience genital pleasure or orgasm, and/or painful genitals – are acquired body-mind disabilities. An observer could repurpose this argument into an ableist declaration: surgeries need to stop because they produce disabilities and disabilities are inherently undesirable and inferior.
That being said, we also must ask, as Clare does, how might we account for and “bear witness to body-mind loss” (2017: 60). We cannot simply ignore it. While we need to critique and avoid reproducing ableist cautionary tales, we also need to acknowledge and discuss the sometimes unwanted reality of living with certain disabilities, for example, chronic pain, the inability to orgasm, depression, and anxiety. As readers’ will observe in Chapter 2, many intersex people who experience these sorts of acquired body-mind disabilities, or “body-mind loss” (Clare 2017: 60), foreground them in their testimonies. Many intersex people describe in detail these painful disabled aspects of their body-minds, note that they dislike living with these consequences, and use them as reasons for why unnecessary interventions need to be outlawed. One could argue that these testimonies are, therefore, cautionary tales. Yet, I maintain that these personal accounts made by intersex people are different from Clare’s (2017) cautionary tale example of the Sierra Club’s campaign Beyond Coal in that the former are personal narratives, not massive campaigns that implicitly claim to speak for or of the subjects in question. Hence, not only do I believe that these intersex testimonies need to be respected and centralized in analyses of gratuitous medical intervention in order to properly “bear witness to body-mind loss” (Clare 2017: 60), I also maintain that centralizing intersex people’s acquired body-mind disabilities and rejecting oppressive systems and ideologies are not mutually exclusive. The way in which I plan to hold both of these threads is to integrate the language of “curative violence” (Kim 2017: 10).

many intersex people experience. To avoid the dangers of the cautionary tale whilst centralizing intersex individuals’ testimonies to acquired disabilities, I make use of Eunjung Kim’s expression “curative violence” (2017: 10). Drawing from Judith Butler’s notion of “normative violence” (1990] 2006: xx) and Alison Kafer’s concept, “curative time” (2013: 27), Kim employs the expression,

“curative violence” in order to describe the exercise of force to erase differences for the putative betterment of the Other. Curative violence occurs when cure is what actually frames the presence of disability as a problem and ends up destroying the subject in the curative process. In this sense, curative violence recalls the notion of the _pharmakon_ [emphasis in the original],24 at once remedy and poison—a remedy that harms. Various kinds of remedy—symbolic, religious, mystical, and medical—and their meanings in culture and public policy make cure a politically charged practice that profoundly influences how we think about bodies and disabilities. The violence associated with cure exists at two levels: first, the violence of denying a place for disability and illness as different ways of living and, second, the physical and material violence against people with disabilities that are justified in the name of cure. (Kim 2017: 14).

Violence and the supposed demand to cure, or quest to remedy, “abnormality” are intertwined. The mission to cure intersex folks of their supposed disability, disorder, or disease, often results in a variety of disabilities. In Kim’s terms, the “curative process” an intersex person is subjected to involves “physical and material violence” and can “[destroy] the subject” (2017: 14); hence, “cure and disability coexist as a process” (2017: 9).

In other words, curative violence, as it pertains to “disabled” people with intersex traits, typically produces disabilities, disabilities “created by other people as a result of the laws of public life” (Moltmann 1998: 107) and the oppressive ideologies that underpin said laws (see Orsini 2007). That is to say, drawing from disability studies scholars Nirmala Erevelles and Andrea Minear, intersex individuals are “constituted as non-citizens and (no)bodies by the very social institutions [...] that are designed to protect, nurture, and empower them” (2010: 127; also

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24 Kim writes, “In Dissemination (95–116), Jacques Derrida discusses the word pharmakon as used in Plato’s Phaedrus, in order to describe the effect of writing on forgetfulness and speech” (2017: 236).
see Grabham 2007). The very institutions (medicine, law, government) that claim to serve, heal, and/or safeguard all people have, in direct and indirect ways, contributed to gratuitously creating disabled intersex body-minds and experiences.

The expression “curative violence” allows me to acknowledge the embodied disabling consequences of medical interventions as processes of compulsory dyadism and able-bodiedness without reproducing a cautionary tale. In other words, the phrase enables me to highlight, rather than deemphasize (Clare 2017), the incorrigible institutionalized interphobic practices that actively, irreversibly, and often knowingly (see Chapter 2), create body-mind disabilities whilst still acknowledging and accounting for intersex people’s personal reports of body-mind disabilities and loss. The phrase is also a useful tool because it does not foreclose on the fact that intersex people can and do take pride in their body-mind disabilities, even though they were created in violent circumstances. Clare explains:

I remember my conversation with the woman whose body-mind has been shaped by military pollution, remember her slogan, “I hate the military and love my body.” I sit with the question: how do we witness, name, and resist the injustices that reshape and damage all kinds of body-minds [...]. I think about how we might bear witness to body-mind loss while also loving ourselves just as we are right now. I begin to understand restoration – both of ecosystems and of health – as one particular relationship between the past, present, and future. (Clare 2017: 60).

Many body-mind disabilities people have acquired were acquired in violent, curative circumstances, but the disabilities themselves are not innately wrong. Similar to the woman disabled by military pollution Clare speaks of, intersex people with body-mind disabilities acquired via curative violence experience loss, pain, and suffering. However, intersex pride and self-love is palpable (see Viloria 2015c, 2017; Carpenter 2013a; Weeks 2017; G. Davis 2016; Pagonis n.d.). “Bodily and/or psychic [...] scars,” to quote Karen Hammer, “become not only evidence of wounding but also a new surface on which to form community,” self-love, and

Ultimately, keeping Kim’s phrase “curative violence” in mind whilst discussing intersex folks’ acquired body-mind disabilities helps me theorize and oppose unnecessary medical interventions without reproducing a cautionary tale. It also calls for the need for restoration (Clare 2017). In recognizing the violent circumstances and their disabling consequences, restoration (Clare 2017) (or restorative justice [Daly 2000; Strang and Braithwaite eds. 2002; Daly and Stubbs 2006; van Wormer 2009]) becomes vital. Restoration includes instituting an *Age of Ethics*, as Alice Domurat Dreger’s edited collection is aptly titled (Dreger ed. 1999). Such an age would involve, for instance: ensuring that intersex people who underwent curative violence receive the body-mind care they need; attending to the wounds and scars that “haunt” many intersex people; listening to intersex individuals and bearing witness to their stories; outlawing violent, coercive medical practices; granting intersex people body-mind autonomy; holding medical professionals and institutions legally accountable; creating positive and destigmatizing representations of intersex people in medical and popular cultural contexts (see Dreger ed. 1999; Pagonis 2017b; Albritton 2015; Tamar-Mattis 2015; Ford 2001; Baumgartner 2017; Chase 1999; Gurney 2007; Akre 2016). It involves all of this and more because “[a] scar is more than a wound;” a scar is “more than just the body’s method of remembering a wound” (Hammer 2013: 159). Body-mind scars and disabilities created by violent curative practices are ghosts of abusive systems.

*Ghost*

As the haunting metaphors suggest, I weave in ghostly rhetoric. Or, in other words, such rhetoric
haunts this dissertation. Haunting imagery is peppered through both intersex and disability scholarship. “[T]he spectre of disability” (Belser and Betcher 2013: 344; also see McRuer 2006: 5), “the disability to come” (McRuer 2006: 5), “haunt[s] us all” (Garland-Thomson 1997: 9). That is to say, people are only ever “temporarily [emphasis in the original] able-bodied” or temporarily “enabled [emphasis in the original]” (Clare [1999] 2009: 82). Comparably, the shifting “phantasm” (Holmes 2002: 175) or “spectre of intersex” (Sparrow 2013: 29) haunts intersex people even if they were surgically or hormonally “fixed” (Spurgas 2009; Gurney 2007). The disabling outcomes of curative violence “[exist] in between the past and the future,” in “in-between spaces” (Kim 2017: 9). “The intersex body,” in other words, “is not ontological, but rather hauntological” (O’Rourke and Giffney 2009: x).

The notion of being haunted is not meant to frighten any seemingly “normate” (Garland-Thomson 1997: 8) readers or (further) stigmatize apparently “aberrant corporealit[ies]” (Shildrick 2002: 9). Being haunted is not unique. It is an everyday experience (Gordon 2008), “the state proper to being as such” (Fisher 2013: 44). “[E]veryone,” Trevor L. Hoag writes, “is haunted by someone or something; everyone senses the peculiar ‘presence/absence’ of that which they have lost, whether it is a loved one, a material object, a shattered ideal” (2014: 10). Considering intersex people in particular, many are haunted by, for instance, traumatic memories, acquired body-mind disabilities, an ability that was “taken” (Devore in Harrison dir. 2011: n.p.), or a “paradoxical nostalgia [...] for all the futures that were lost” (Fisher 2013: 45; also see Chapter 2; O’Rourke and Giffney 2009; Cameron 1999, 2007; Chase 1998a, 1998b, 2006; Lahood dir. 2012; Karkazis 2008; Koyama 2003; Harrison dir. 2011; Devore 1999, 2011,

25 “The term normate [emphasis in the original],” coined and described by Rosemarie Garland-Thomson, examines “the disabled figure,” “names the veiled subject position of cultural self, the figure outlined by the array of deviant others whose marked bodies shore up the normate’s boundaries. [...] the normate subject position emerges [...] only when we scrutinize the social processes and discourses that constitute physical and cultural otherness” (1997: 8). Normate subject positions are both deemed default and superior.
They are haunted by denied body-mind autonomy and self-determination (Koyama 2003; Magubane 2014; Preves 1999, 2003; G. Davis 2014, 2015a, 2015b). Compulsory dyadism haunts them.

The language of haunting is also not a fanciful, stylistic flare intended to sensationalize the violent circumstances in question or people’s experiences; haunting is a site of theoretical inquiry. Originally developed by Jacques Derrida ([1993] 1994), hauntology provides a critical lens to explore history, memory, trauma, and temporality. Hauntology provides a framework to investigate and give language to liminal things: things that cannot be classified as either being or non-being; traumatic consequences that are not constrained by linear time; and the relationship between absence and presence (C. Davis 2005, 2007; Gordon 2008, 2011; Fisher 2013; Hoag 2014; Buse and Stott eds. 1999). In taking stock of the in-between, not-quite-there, non-/being, and things that haunt and linger, one gains a unique perspective on the continuing, deferred, or denied outcomes of systemic, inequitable power relations. Reflecting on her pivotal book *Ghostly Matters* (2008), Avery Gordon explains, “haunting is one way in which abusive systems of power make themselves known and their impacts felt in everyday life, especially when they are supposedly over and done with” (2011: 2). Put differently, attending to that which haunts reveals the “complex rhetorical relationship between memory, ghosts, and justice” (Hoag 2014: 3), between body-mind dis/abilities, becoming, and in/equity.

In relation to compulsory dyadism, the traumatic body-mind consequences haunt intersex people even when medical management, surveillance, surgery, and hormone therapy are “supposedly over and done with” (Gordon 2011: 2). Even when the intersex marker has been apparently thoroughly removed or temporarily hidden/deferred, traumatic memories, a sense of shame, the knowledge of possible future curative violence, and/or acquired body-mind
disabilities are never “over and done with” (see Roen 2009; Spurgas 2009; Holmes 2002; O’Rourke and Giffney 2009). They haunt. And, these phantasms are ways the “unresolved social violence” (Gordon 2011: 2) of compulsory dyadism and the need for restoration (Clare 2017) make themselves known.

As I discuss further in Chapter 2, I conceptualize these haunting consequences of the socio-medical treatment of intersex as evidence of medical malpractice – “unresolved social violence” (Gordon 2011: 2) and “curative violence” (Kim 2017: 14) – not, as some medical professionals claim, medical mistakes (Carmack 2014; G. Davis 2015a; Truffer 2015: 111). In making this distinction, I must address the inevitability of medical mistakes and demonstrate that the current treatment of intersex variations does not constitute mistakes. Marianne A. Paget demonstrates in her book The Unity of Mistakes ([1988] 2004) that errors and mistakes are endemic to the practice of medicine. In Paget’s terms, medicine and medical care are “process[es] of discovery and response, of risked action and error” ([1988] 2004: 17). As a result, mistakes are “an existential reality” (Paget [1988] 2004: 17; also see Porter 1998; Claridge and Fabian 2005). And many people acquire (and are haunted by) body-mind disabilities because of such mistakes.

Paget’s analysis of medical mistakes is theoretically compelling because it challenges the dominant, misrepresentative notion that medical professionals are infallible “gods” (Cameron 2007: 164), unerring experts who always know best and, therefore, do not or cannot make mistakes. Intersex and disabled people, activists, and advocates as well as intersex and disability studies scholars also battle against the image of doctors as all-knowing, faultless experts in order to underline the need to question medical protocol concerning supposed abnormal and deviant embodiments. In countering the dominant perception of medical professionals as infallible, Paget
humanizes them. However, such humanization is often, and understandably so, absent from many intersex people’s testimonies to trauma, people who learned first-hand that doctors are not benevolent gods. Katrina Karkazis explains, numerous accounts “paint a disturbing image of half-crazed doctors running down hospital corridors wielding knives” (2008: 2). Neither the all-knowing authority nor the, arguably ableist, “half-crazed” (2008: 2) representations are accurate.

An accurate portrayal of medical and clinical work, as Paget’s investigation into the inescapability of mistakes demonstrates, emphasizes that medicine and medical care are not, and never could be, objective (Paget [1988] 2004; Ehrenreich and Barr 2005; Treichler 1999; Reagan, Tomes, and Treichler eds. 2007; van Dijck 2005; Daston and Galison 2007). An accurate portrayal emphasizes that medical labour is an ongoing practice of trial and error, “a practice of responding to the experience of illness” (Paget [1988] 2004: 21). And “the experience of illness,” or in the case of intersex, what is deemed an illness or diagnosed as disabled, diseased, or disordered, are products of and reflect cultural ideologies. That is, “medical experts are called to intervene” (Karkazis 2008: 96) when intersex is “observed” (see Kessler 1998) because intersex traits are culturally construed as innately abnormal, not because they are innately abnormal (Karkazis 2008; G. Davis 2015a; Preves 1999, 2003; Viloria 2017). Since medical professionals are taught to view intersex in this medicalizing manner, invasive interventions are rarely construed as malpractices or mistakes; such interventions are deemed proper medical protocol, protocol that is in the best interest of the patient.

Highlighting that medicine is a cultural “process” (Paget [1988] 2004: 17) and, consequently, always under revision is important in that doing so challenges dominant beliefs about medical professionals and objectivity. Nevertheless, most medical professionals seem to either fight against this revisionist “process” (Paget [1988] 2004: 17) or they remain largely
apathetic to this process when it comes to intersex variations (as well as, for example, disabled, fat, trans, queer, genderqueer, and non-binary embodiments/identities) (G. Davis 2013, 2014, 2015a, 2017; Chase 1998a, 1998b, 2002; Holmes ed. 2009; Pagonis 2017a, 2017b; Karkazis 2008). Many doctors are not especially invested in, or they are ambivalent towards, questioning the process of, and their commitment to, compulsory ways of being. This lack of investment is particularly evident given that the overwhelming testimonial and methodologically sound scholarly evidence that has been collected over decades suggests that the current (and historical) violent curative treatment of people with intersex variations is not beneficial to intersex people themselves and results in various body-mind disabilities. With this claim I am certainly not trying to fall back into dehumanizing medical professionals or framing them as “half-crazed” (Karkazis 2008: 2) monsters purposefully trying to harm intersex infants, children, adolescents, and adults. I am aware that doctors’ “intentions are more benevolent” (Karkazis 2008: 2; also see G. Davis 2017). Nevertheless, good intentions do not always result in good, ethical care. Good intentions can, and do, result in violently produced body-mind disabilities and re/institutionalize oppressive practices and protocols. In short, the current medical response to intersex is not evidence-based. Hence, narrating medical professionals’ actions as mistakes is misrepresentative and works to silence intersex people’s testimonies to trauma and acquired disabilities (see Chase 1999). In essence, I argue that the phantasms that haunt intersex people are remnants, reminders, or “remainders” (see Bailly 2009; Lacan 1992) of discriminatory medical protocol – medical malpractice – not mistakes. The haunting effects are not the consequences of medical mistakes but of institutionalized oppressive systems and gross negligence of evidence.

Integrating hauntology into my project may appear troubling because this language could be interpreted as problematically binary-oriented, about focusing on presence and absence. On
the contrary, hauntology is concerned with spectres that cannot be classified as either being or non-being, entities that do not conform to this binary. Rather than reify binaries, hauntology is intended to destabilize and deconstruct dichotomies maintained and enforced by dominant ontological and epistemological frameworks (Derrida [1993] 1994: 51). As explained by Jaco Gericke, “[a]s provocative metaphors, spectres are seen as challenging basic binary oppositions like ‘alive/dead’, ‘present/absent’ and ‘past/present’” (2012: 168). Similarly expressed by Nchamah Miller, “[h]auntology and spectrality work deconstructively as radical critique to question critical limits of dichotomies,” to “[expand] the binary or dialectical logic of actuality” (2003: 4, 11). Consequently, in addition to helping one identify unresolved violence, the language of hauntology provides an alternative to binary logic, however incomplete. The metaphors of ghosts, phantoms, and spectres are employed because alternative non-binary models are not quite articulable. Indeed, intersex, meaning between sexes, functions in this same way. Or, for another example, in queer theories and activism, the terms “genderqueer” and “non-binary” are currently used to express the inarticulable or un/imaginable nature of not (quite) being or identifying as cis or trans, man or woman. The language of hauntology is a liminal framework or in-process discourse. It is a model in transition from binary thinking to something new, not quite expressible yet. “The mystery the spectral hides is not unspeakable because it is taboo,” although it certain may be, “it simply cannot (yet) be articulated in the languages available to us” (C. Davis 2007: 13; also see Ely-Harper 2014; Renn 2012; C. Davis 2005), or, more precisely, the English language and Western discourses I am bound to and which I critique.

Hauntology also contributes to the project of subverting the problematic intersex-dyadic binary because it calls me to attend to the fact that intersex has never been a static, definitive idea or characteristic (Fausto-Sterling 1993, 2000a, 2000b; Dreger 1999; Astorino 2012; “What is
Intersex?” n.d.). Who is labelled intersex (or sexually “ambiguous” or disordered) and who is not, as I explore in Chapter 3, has always been and continues to be contested. Intersex, as an idea, is constantly under revision. Intersex, Holmes confirms, is “a perpetually shifting phantasm in the collective psyche of medicine and culture” (2002: 175; also see Fausto-Sterling 1993, 2000a, 2000b; Dreger 1999; Laqueur 1992; van Dijck 2005; Bowker and Star 1999; Reis 2005, 2009; Kincheloe 1999). Depending on the time and (global) cultural context, intersex is imagined to haunt certain body-minds more than others. Who is labeled intersex serves a political purpose and depends on the ideological context, not the “optic nerve” (Kessler 1998: 44-45).

Attending to this shifting phantasm is not simply a theoretical endeavor to draw attention to the fact that categories are socially constructed and binary thinking is insufficient. Analyzing who has been and who currently is suspected of hiding the spectre is about tracing and combating interphobic violence. Determining who has been and who is subjected to such violence is vital in order to understand and combat the insidious, morphic, and complex nature of compulsory dyadism and able-bodiedness.

Methodology

In a sense, the theorists I elaborated on above have determined my theoretical framework and my methodology, as I follow the methods often used by McRuer (2006), Clare ([1999] 2009, 2017), Fausto-Sterling (2000b), Kessler (1998), Holmes (2008b, 2011), and many others who examine cultural texts for their ideological transmissions and socio-political meanings. That is, I conduct textual and critical discourse analysis (see Creeber 2006; Machin and Mayr 2012; Hall [1973] 1999; Hall, Evans, and Nixon eds. 2013; Wodak and Meyer 2001; Fairclough 1989, 2013; Gregg
and Seigworth eds. 2010; Bazerman and Prior eds. 2008; Gershon and Malitsky 2011; Couser 2009; Wagner 2004; Rosenthal and Corner eds. 2005) on a wide range of representations of intersex and interphobic violence, including media, biomedical, legal, historical, scholarly, filmic, and intersex people’s self-representations.

“Language,” Charles Bazerman and Paul Prior contend, “is emergent, multiform, negotiated in the process, meaningful in the uptake, accomplishing social acts” (2008: 1). As feminist media studies scholars (see du Gay 1997; Hall, Evans, and Nixon eds. 2013; hooks 1996; Dyer 1984 2012, 2002; Collins 2004, 2006; Walters 2000) as well as intersex and disability scholars and activists have repeatedly demonstrated, “[t]here are no innocent texts” (Durham and Kellner 2012: 4). Language, images, and discourses are political. They de/pathologize, enact violence, re/define, are reappropriated, control, morph, de/stigmatize, and/or liberate. Or, in more Foucauldian terms, discourses are vectors of ideologies and power (Foucault 1979, 1991, [1978] 1990). Textual and critical discourse analysis provides the tools to detect and critique the socio-political power relations that are re/produced, re/presented, or resisted through semiotic vehicles.

This methodology has been critiqued because one can “read” or interpret a given text in countless ways (see Creeber 2006: 82; Fairclough 2013: 509; Fiske 1987 [1990]). Can one really gauge the validity of an argument or “reading” if there are innumerable ways to interpret a text? Scholars who use this methodology, including myself, do not claim that there is one definitive or objectively correct interpretation of a text. As Stuart Hall explains, texts usually impart “dominant or preferred meaning[s] [emphasis in the original]” ([1973] 1999: 513; also see Hall, Evans, and Nixon eds. 2013), meanings that are typically taken-for-granted hegemonic knowledges. Conducting a textual and critical discourse analyses of a given text allows one to
identify the preferred meanings and “look” in alternative ways (hooks 1992) or read “against” (Walters 2000: 238, 239; Nixon 2013; Namaste 2000, 2012) or “across” (Clare [1999] 2009: 120) the hegemonic grain.

To expand, this methodology provides me with the tools to accurately ascertain the dominant meanings and ideologies of a given text and, if need be, resist inequitable and oppressive narratives and ideologies. This methodology is an appropriate way to approach my research interest because unpacking the ideologies and meanings created through texts and discourses is a way to explore the relationship between intersex and disability, how inter/sexed and dis/abled body-minds are re/defined and literally, discursively, and ideologically managed. In a way, I am echoing Melissa Gregg: in many instances, “identity is performed and made meaningful through textual displays rather than encounters shared through physical proximity” (2010: 258). In addition, textual and critical discourse analysis permits me to cast a wide net and examine myriad representations of intersex which in turn keeps me open to multiple and unexpected sitings of and discourses about intersex/-as-disability. Ultimately, this methodology, coupled with a feminist, disability, queer, crip theoretical lens, provides me with the resources to read with and against the grain to determine the literal, political, and potential alignments between intersex and disability.

For specificity’s sake, in Chapter 2, I turn my attention to intersex people’s stories from documentary films (*Intersexion* [Lahood dir. 2012]; *I in 2000* [Clearway dir. 2007]; *Me, My Sex and I* [Harrison dir. 2011]), interviews (Pagonis 2016d; Sean Wall in Compton 2016; “What It’s Like To Be Intersex” 2015), personal accounts/analyses/memoirs (Cameron 1999, 2007; K. Walsh 2015; G. Davis 2016; Pagonis 2016a; Coventry n.d., 2017; Koyama 2006; Viloria 2017), public consultations (UN Human Rights 2017), as well as published studies, reports, and
centering intersex people’s testimonies is important. Too few analyses concerning individuals with intersex traits actually draw from intersex people’s stories. Analyses that exclude intersex individuals’ testimonies contribute to the “structural invisibility” (Crouch 1999: 36) of intersex people’s narratives and, too often, reproduce interphobic ideologies. In Chapter 3, I apply my methodology to scholarly, media, and various athletes’ responses to concerns about the un/fairness of sport sex testing policies and procedures (see Cooky and Dworkin 2013; Wackwitz 1996, 2003; Maccartney and Garlick 2008; Pieper 2014, 2016; Tucker 2016, 2017; Karkazis 2016a, 2016b; M. Adam 2016; Critchley 2016; S. Green 2016; Cooper 2010; Donnellan 2008; Magubane 2014; Cooky, Dycus, and Dworkin 2013; Munro 2010; Ginnane dir. 2011; J. Parker 2016; Blatchford 2016). These representations of sport sex testing allow me to compare and contrast how interphobia, ableism, sexism, nationality, racism, and colonialism figure in these conversations. In Chapter 4, I apply textual and critical discourse analysis to the academic texts from various fields (medicine, intersex and disability studies, bioethics, and philosophy) concerning the ethics of employing reproductive technologies, namely PGD, to select against or eliminate (potential) disabled and/or intersex traits. I also examine the discourses present in resources provided by fertility clinics and in governmental documents concerning the legal uses of and access to reproductive technologies. In reading these documents alongside each other, I uncover how intersex and disability are discursively created and intertwined and how compulsory dyadism and able-bodiedness are institutionalized.

In conducting my analyses on these various and diverse texts, I observe a cultural preoccupation with controlling and eliminating intersex variations, typically justified via
intersecting interphobic and ableist logics. I notice that powerful institutions (e.g. medical, governmental, sport) make it their concern to eliminate intersex/as-disability and also, when possible, responsibilize (possible) parents of intersex children to eliminate their children’s “disabling” intersex characteristics. Intersex, disability, interphobia, and ableism are discursively intertwined and institutionalized. It is clear that intersex people relentlessly combat compulsory dyadism but do not explicitly combat compulsory able-bodiedness. In approaching these texts with a feminist disability and crip lens, I identify and challenge the ableism that underpins interphobia.
Chapter 2

Intersex Mutilation: Medical Malpractice and Acquired Body-Mind Disabilities

If I went around and said, “open heart surgery is a sham and nobody should do it anymore, we should just stop,” a whole bunch of people would come out and say, “well actually open heart surgery saved me and I think we should not stop.” But, that hasn’t been happening around genital surgery [performed on intersex people]. (Cheryl Chase [Bo Laurent] in Lahood dir. 2012: n.p.)

Introduction

With some notable exceptions (Cornwall 2013; Greenberg 2012a, 2012b; Koyama 2006; Holmes 2008b, 2011; Spurgas 2009), intersex studies literature concerned with intersex mutilation frequently does not explicitly address disability theories, glosses over disability, and/or does not conceive of intersex as a disability or a disability issue. Indeed, in the attempt to distance from pathologization, there appears to be some inadvertent distancing from disability (see Wilkerson 2012; Cornwall 2009, 2013, 2015; Y. Menon 2011): “nobody wants to be a disorder ... who wants to be a fucking disorder? ... I don’t” (Millarca qtd. by G. Davis 2014: 19; also see G. Davis 2015a; Viloria 2017). This distancing may be underpinned by ableism. This lack of engagement with or distancing from disability is particularly surprising given the fact that the majority of medical professionals understand and treat intersex traits as disabilities, disorders, and/or diseases (see Holmes 2008b, 2011; G. Davis 2015a; Spurgas 2009; Mitra 2014a). In other words, this lack of engagement with disability studies is, I contend, at odds with the medicalization of intersex. Moreover, neglecting to integrate disability analyses into intersex studies projects is at odds with the fact that the “curative” (Kim 2017) medical treatment, or more accurately put, violent maltreatment, of people with intersex characteristics create body-mind disabilities.

As previously noted in Chapter 1, Kim describes “curative violence” as “the exercise of force to erase differences for the putative betterment of the Other. Curative violence occurs when
cure is what actually frames the presence of disability as a problem and ends up destroying the subject in the curative process” (2017: 14; also see Erevelles and Minear 2010; Grabham 2007). The medical management of individuals with intersex variations and the insistence to “cure” them exemplifies how dominant cultural ideologies – namely, compulsory dyadism, able-bodiedness, and heterosexuality – are violently institutionalized (e.g. medical, legal, governmental) and, in turn, literally disable intersex people’s body-minds. That is to say, the very institutions that claim to serve, heal, and/or safeguard all people have, in direct and indirect ways, contributed to gratuitously creating disabled intersex subjects all in the name of medical care and cure.

Some people with intersex anatomies have not endured invasive medical interventions and describe how “happy” (Viloria 2017: 194) and “blessed” (2017: 196) they are for escaping such mutilation (Quinn in “What It’s Like To Be Intersex?” 2015; also see Bougnères et al. 2017; Lahood dir. 2012). Many intersex people, however, testify to the harmful short- and long-term body-mind disabilities they acquired due to irreversible, dehumanizing, and humiliating interventions (e.g. intersex genital mutilation [IGM]/genital surgeries, hormone replacement therapy [HRT], repeated unnecessary genital examinations/displays, vaginal dilation, being photographed naked as children) (see Preves 1999, 2003; Chase 1998a, 1998b, 2006; Dreger ed. 1999; G. Davis 2015a, 2015b; Creighton et al. 2002; Kessler 1998; Sean Wall 2015b; Shelley Wall 2010; Pagonis 2015a, 2015b; Cameron 1999; Karkazis 2008; Grabham 2007; Holmes 2008a; Holmes ed. 2009; Koomah 2017; Lahood dir. 2012; Clearway dir. 2007; Viloria 2017; “What It’s Like To Be Intersex” 2015; Morland 2009; InterACT and Human Rights Watch 2017). Such disabling consequences include, but are not limited to, genital pain, (painful) scarring, loss of sexual sensation or ability to orgasm, anesthetic neurotoxicity, incontinence,
inability to urinate without assistive devices or discomfort, infection, fear of intimacy, depression, anxiety, post-traumatic stress disorder, and suicidal ideation.

In the language of haunting, these various disabling outcomes that many intersex people “live with and through” (Holmes 2008b: 175) can be understood as “way[s] in which abusive systems of power make themselves known and their impacts felt in everyday life, especially when they are supposedly over and done with” (Gordon 2011: 2). Similar to J. David Hester’s observation that sexual/biological “[l]iminality [intersex] is not erased by this intervention [e.g. IGM, HRT], but is reinforced through a pathology of medical practices that renders the body of the intersexed unnatural and suspicious, even after intervention” (2006: 48), Alyson K. Spurgas (2009) as well as Michael O’Rourke and Noreen Giffney (2009) argue that the “phantasm” (Holmes 2002: 175) or “spectre of intersex” (Sparrow 2013: 29) haunts the intersex child even if that child was surgically “fixed” or hormonally altered – even if interventions are “supposedly over and done with” (Gordon 2011: 2). To quote O’Rourke and Giffney, the discursive work of declaring – constituting – the intersex child “a boy” or “a girl” “necessarily fails since the intersex body, both pre- and post-surgical inscription, is still, always already, a site of contested being, a locus of ‘embodied becoming’ (Roen [2009]). The intersex body is not ontological, but rather hauntological” (O’Rourke and Giffney 2009: x). Pre-surgical and/or hormonal inscription, the intersex child is a site of contested being because it is “sexless” (Preves 1999: 52); the child is understood to be and is often made to feel like, as Martha Coventry testifies, “a sexual failure” (1999: 73). Echoing Judith Butler (1988), Coventry writes, the child’s “entrance into the social world may be halted until the child is sexed” (1999: 52). Until the child is sexed, or rendered “sexable” (Preves 1999: 52) via “sexdesign” (Preciado 2013: 35), the child is treated as a medical emergency. In other words, given that the child is
supposedly disabled, disordered, or diseased, until the child is “enabled” by medical interventions, the child is regarded as a medical emergency. However, the child’s body-mind is not an innate medical emergency, but rather a “social emergency” (Karkazis 2008: 96; also see G. Davis 2015a; Preves 1999, 2003; Viloria 2017). Even if medical intervention is completely medically unnecessary and is purely cosmetic, the “spectre of intersex” (Sparrow 2013: 29) must be cast out, exorcized (see B. Hughes 2000: 564), via various procedures because “the intersex body haunts, spectralises, conjures up unimaginable futures” (O’Rourke and Giffney 2009: x). The assumption is that the child, if left unaltered, could never lead a “normal” life or be loved as they are (see Viloria 2017); if left unaltered, the child has no clear future or “no good future” (Kafer 2013: 3). Nevertheless, to borrow Joshua Gunn’s phrase, “[e]xorcism is futile” (2004: 109).

The intersex phantasm cannot entirely be cast out of one’s body-mind. It lingers in the form of, for example, memories, scars, pain, depression, stigma, dissociation, shame, the loss of genital sensation, and “futures that were lost” (Fisher 2013: 45). And, given that the spectre always threatens to resurface and reveal itself again – for instance, as one goes through puberty – one must be constantly surveilled (Spurgas 2009) and endure repeated medical visits and examinations, more operations, vaginal dilation routines, and/or HRT routines. The spectre must be constantly deferred because it can never be completely cast out. Scars may fade, but they may never disappear; routines may cease, but the memory and embodied consequences will not (see Caruth 1996; Caruth ed. 1995; Felman and Laub 1992; Magnet 2017).^26

^26 The spectre haunts many parents of intersex children too; “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” (Holmes 2009: 6). While intersex is celebrated in some families, the “phantasm” (Holmes 2002: 175) can negatively impact how parent and other family members treat and impose gender on the child. Strict gender policing can ruin child-parent relationships and some parents are riddled with guilt for agreeing to unnecessary procedures (Preves 1999, 2003; Chase 1998b, 2006; Greenberg 2012b; G. Davis 2015a; Kessler 1998; Devore qtd. in DiProperzio 2013; Chase in Arana 2005: 38).
Intersex studies scholars, intersex activists and advocates, non-governmental organizations (NGOs) (e.g. Stop Intersex Genital Mutilation), and intergovernmental organizations (e.g. United Nations [UN]) use the language of mutilation (i.e. IGM), torture, inhumane, sexual assault or rape, invasion, and human rights violations to explain the myriad disabling consequences of “curative” medical models and violent erasure of intersex (Chase 1998a, 1998b, 2006; Wilson 2012a, 2012b, 2012c; Méndez 2013, 2016; Khan qtd. in Karkazis 2008: 1; May et al. qtd. by Jordan-Young 2010: 242; “Committee against Torture” 2016; Méndez 2013, 2016; Guillot, Bauer, and Truffer 2016; Truffer and Bauer 2017; InterACT and Human Rights Watch 2017; Lahood dir. 2012). Intersex and queer studies scholars have also employed the language of queering to describe and theorize the outcomes of medically managing intersex. Katrina Roen, for example, argues that medical interventions intended to “straighten out” intersex people’s anatomy and, in turn, gender and sexuality, “inevitably create newly queer beings” (2005: 270; also see Holmes 2000; Spurgas 2009; Morland 2009). All of these discourses have been and continue to be vital in the battle against interphobia and compulsory dyadism. That being said, I have not come across accounts or analyses that explicitly frame the effects of medical management as disabling.

In this chapter, therefore, I argue that these consequences should be understood as body-mind disabilities. In doing so, I highlight a troubling paradox: in an effort to fix/cure apparently disabled, diseased, or disordered intersex individuals, medical professionals violently create newly disabled subjects. Hence, some of the ways intersex haunts people who have been subjected to curative violence is through living with short- and long-term body-mind disabilities.

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27 Referring to “normalizing” surgical practices enacted on intersex infants, children, and adolescents as Intersex Genital Mutilation (IGM), many scholars and activists note that IGM and Female Genital Mutilation are “similar procedures” and comparable cultural traditions (see Chapter 1; Pagonis 2016d: n.p.; Chase 1998a, 1998b, 2002, 2006; Ehrenreich and Barr 2005).
“[T]he spectre of disability” (Belser and Betcher 2013: 344) therefore haunts many intersex people. In some circumstances, the intersex spectre and the disability spectre are indistinguishable, or are one in the same. For example, given that so many intersex individuals are subjected to invasive procedures and experience various body-mind disabilities, some people with intersex traits who have not undergone such interventions have questioned whether they rightly belong in intersex groups/spaces or if they are “truly” intersex. Hida Viloria (see “Hida Viloria” n.d.) illustrates this anxiety by recounting attending one of her first intersex retreats: “I’m worried I’ll be seen as too normal to be here. My genitals aren’t scarred like the others” (2017: 92); “maybe it’s [Viloria’s clitoris] not big enough to make me intersex” (2017: 93; also see Viloria in Lahood dir. 2012). Viloria also has “received reports from intersex people who have tried to join other intersex organizations but were dismissed because, having escaped IGM, they don’t have a medical diagnosis to ‘verify’ that they’re intersex” (2017: 328). According to Viloria’s account, some intersex people maintain that medical verification, mutilation, and/or disability are prerequisites to claiming intersex and entering intersex spaces/groups. In other words, even though the intersex folks in these organizations combat pathologization and the medical interventionist model, some paradoxically rely on medical diagnoses and trauma to assess whether (possible) members “truly” belong. Body-mind disabilities, mutilation, trauma, scar tissue, intersex, and intersex identification are often understood as being intertwined, linked. Despite this evident connection, intersex studies projects do not typically integrate disability theories.

In thinking through the ways many people with intersex traits live with body-mind disabilities due to medical intervention enables me to consider how disability and intersex are literally and discursively created (Peers 2012; Holmes 2002; Kim 2017; Kafer 2013) and how
they intersect or “[fold] into each other” (McRuer 2006: 71). The fact that body-mind disabilities are created because of interphobic and pathologizing responses to sexual variation and morphological diversity proves good reason for intersex and disability activism and scholarship to appeal to and ally with each other. Moreover, analyzing the embodied consequences of intersex mutilation as disabilities and, therefore, as a disability issue nuances the ongoing conversation about systemic intersex mutilation and compulsory dyadism. Such an analysis provides intersex activists, advocates, and scholars with a new discursive tool to confront the medical industrial complex as well as the legal realms that protect it. This tool, for example, bolsters Pidgeon Pagonis’ observation of a troubling contradiction: aspects of the Hippocratic Oath that doctors must vow, “doesn’t seem to apply” to people with intersex variations (2017b: 41; also see Grabham 2007; Ford 2001). Specifically, doctors must vow to do no harm to their patients. However, many doctors actively and repeatedly break this oath and disable intersex patients’ body-minds. Thinking through the ways intersex people are constituted as disabled in order to justify (disabling) interventions also highlights the importance of resisting disassociation with or “stigmaphobic distancing” from disability (McRuer 2006: 85; also see Y. Menon 2011; Cornwall 2011, 2013; Wilkerson 2012; Greenberg 2012b). Ultimately, in this chapter, I am thinking through and exploring the medical management of intersex variations through a disability and crip studies lens to see what benefits such an analysis accrues.

In the first section of this chapter, I outline the apparent health risks associated with intersex variations that may warrant irreversible medical intervention. As I explain in detail below, there are few confirmed, if any, health risks that stem from intersex traits themselves. Hence, the sheer number of intersex infants and children subjected to medical interventions signals that the procedures are for cosmetic and ideological, not medical, reasons. Further, there
is no substantial evidence to suggest nonconsensual, cosmetic procedures benefit intersex people. Nevertheless, irreversible and violently disabling procedures continue. In the four sections that follow, I focus on four main institutionalized medical procedures intended to manage, cure, surveil, and erase intersex markers: (1) hormone replacement therapy (HRT); (2) surgery; (3) genital examinations; and (4) withholding information and lying to intersex patients and their parents. In each respective section, after historicizing why and when these medical procedures became common practice, I center intersex people’s testimonies to medical harm and mutilation from various mediums. I bear witness to and analyze intersex people’s stories from documentary films (1 in 2000 [Clearway dir. 2007]; Intersexion [Lahood dir. 2012]; Me, My Sex and I [Harrison dir. 2011]), interviews (Pagonis 2016d; Sean Wall in Compton 2016; “What It’s Like To Be Intersex” 2015), personal accounts/analyses/memoirs (Cameron 1999, 2007; K. Walsh 2015; G. Davis 2016; Pagonis 2016a; Coventry 1998, 1999; Koyama 2006; Viloria 2017), public consultations (UN Human Rights 2017), as well as published studies, reports, and scholarly literature (G. Davis 2015a, 2015b; Dreger ed. 1999; Chase 1998b, 2006; Holmes ed. 2009; Migeon et al. 2002; Hester 2006; Arana 2005). By drawing attention to the fact that the consequences of curative medical interventions constitute disabilities, I highlight the productive political potential of conceptualizing intersex as a disability issue and identify a locus for intersex and disability studies and activism to align. Indeed, given that these medical practices disable intersex people’s body-minds, many intersex folks could claim disability and/or crip as identity, way of being, or politic.

I hope that the variety of avenues I draw from enables me to, to quote intersex scholar and activist Georgiann Davis, understand, communicate, and “[reflect] the diversity of

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28 Given that intersex people have often been subjected to a variety of these violently curative medical practices and protocols, some of the content in each section overlap. I section them off into these four categories for organizational purposes.
experiences within the intersex community” (2015b: 88). Given that this chapter focuses on people who were subjected to nonconsensual, “curative,” cosmetic medical procedures, however, I cannot capture the diversity of all intersex people’s experiences, namely intersex people who were subjected to such treatment but have not spoken publicly about their experiences and people who, remarkably, were not subjected to such treatment (see Viloria 2017). Moreover, I recognize that this chapter does not and cannot cover every medical practice that has, through time and space, gratuitously disabled intersex individuals’ body-minds (e.g. photographing naked, unconsenting intersex children’s “anomalies” [see Shelley Wall 2010; Creighton et al. 2002], medical professionals or their spokespeople revealing or “outing” people’s medical diagnoses [see Chapter 3], changing people’s legal gender statuses without their consent [see Foucault 1980; Velasco 2000; Velasco in Viloria 2017: 98]). I also cannot capture and describe every experience of disability created by the medical industrial complex. Each intersex person has had and will continue to have unique experiences and relationships with the institution and their body-mind dis/abilities (see G. Davis 2015a, 2015b). With that being said, I believe I provide an accurate picture of the disabling nature of the medical management of intersex which demonstrates the desperate need to dismantle violent institutional policies that reinforce compulsory dyadism, able-bodiedness, and heterosexuality.

Given that the medical practices wrongfully disable the body-minds of intersex people, in the following section, I ask: do medical professionals realize or recognize this fact? Many doctors typically do not explicitly acknowledge – indeed they often deny – the harm caused and body-mind disabilities created by various procedures. Yet, the clinical term “hypospadias cripple” signals otherwise. Doctors reserve the expression “hypospadias cripple” for intersex people with hypospadias who have undergone failed “corrective” surgeries and experience
myriad forms of short- and long-term body-mind disabilities. Hence, even though medical professionals often refuse to explicitly and publicly recognize the disabilities created, this descriptor is an unequivocal admission. Underscoring this recognition can be another approach to combating the current medical management of intersex and aligning with disability activism and scholarship.

To conclude this chapter, I elaborate further on whether or not the disabling, “curative” medical treatment of people with intersex traits can be construed as a mistake (see Chapter 1). The term, “mistake,” has been used by some clinicians who have conceded that the current medical management of intersex is harmful. For example, according to Adrienne Carmack, a urological surgeon, many of the medical interventions have been “mistakes” (2014: 67-68). Considering the differences between medical mistakes and malpractice (Paget [1998] 2004), whilst stressing doctors’ recognition of the body-mind disabilities created and the decades of transnational intersex rights activism, I highlight that these interventions are not mistakes. They are systemic, discriminatory malpractices.

Health Risks (or Lack Thereof) Associated with Intersex Variations

G. Davis (2013) notes that there is no unanimity about the health issues, risks, or impairments that stem directly from intersex traits. Synthesizing literature regarding these supposed issues associated with intersex traits themselves (not medical responses to said traits [e.g. nonconsensual surgery, HRT]), G. Davis observes that “the risks [...] vary substantially from study to study, leaving us to act on (what might be misguided) predictions about health factors” (2013: 52; also see Fausto-Sterling 2000b). While evidence varies substantially, I believe it is important to acknowledge that some people with intersex traits do (or may) experience health
problems or impairments because of their anatomy. Rather than minimize or ignore people with intersex traits who do (or may) experience body-mind health issues, such as discomfort, chronic urinary tract infection (UTI), dissociation, or dysphoria, due to their anatomical morphologies, we ought to be fighting to ensure these people can readily practice their autonomy and access the care (e.g. surgery, HRT, and/or counselling) they require. That is, combatting nonconsensual or coercive interventions and fighting for the right for people to consent to interventions are not mutually exclusive.

That being said, feminist intersex studies scholars and intersex activists claim that intersex variations themselves do not typically pose health risks – “[p]hysical health is usually not an issue” (Fausto-Sterling 2000b: 58; also see Kessler 1998; G. Davis 2013, 2015a; Kolbe 2009) – rather, the socio-medical responses are what cause harm. While “[s]ome intersex babies [with variant genitalia] might have problems with urinary tract infection [UTI], which, if very severe, can lead to kidney damage,” this possible problem that may affect some intersex people is routinely treatable via noninvasive means; and it definitely does not warrant nonconsensual cosmetic genital surgeries or HRT (Fausto-Sterling 2000b: 58). In fact, cosmetic genital operations can cause chronic UTIs and, as I detail below, a whole host of other complications (Kampantais et al. 2012; Cinman et al. 2012). Ultimately, the few intersex variations that may affect one’s health can be actively managed without nonconsensual cosmetic surgeries or HRT.

Congenital Adrenal Hyperplasia (CAH), an intersex variation attributed to and often conflated with intersex, is one such variation (Carpenter 2013c, 2013d; “Congenital Adrenal Hyperplasia” n.d.). CAH is a chronic adrenal condition in which one’s adrenal glands do not make enough vital hormones. Individuals with CAH have problems making enough cortisone, a hormone that aids the body in responding to stress or trauma (e.g. a cold, broken bones).
Mineralocorticoids, hormones that maintain one’s salt balance, and androgens, steroid hormones, may also be affected. Cosmetic, genital surgery is not needed to manage CAH, but when intersex traits are identifiable, such surgery often occurs.

To clarify, CAH is attributed to and often conflated with intersex because some people with CAH have traits that are deemed intersex. Not all individuals with CAH have said traits. CAH rarely causes intersex characteristics in people with XY chromosomes (assigned male) (Wilson 2012a; “Congenital Adrenal Hyperplasia” n.d.). Alternatively, CAH can occasionally cause intersex variations in XX individuals (assigned female) (Wilson 2012a; “Congenital Adrenal Hyperplasia” n.d.). Hence, intersex traits are a sort of symptom of or signal that there is an underlying medical issue. The difference between XY and XX individuals is due to the fact that CAH is associated with higher levels of prenatal testosterone and, therefore, may “virilize” or “masculinize” an assigned female fetus. That is, an assigned male’s “masculine” traits are not deemed intersex because such traits are expected and deemed normal. Assigned females are deemed incongruous, intersex, disordered. This is precisely what Eckert means by “the process of intersexualization” (2009: 64).

The supposed disordered masculinization (or intersexualization) of assigned females with CAH is, apparently, both physical and psychological. The pathologization of assigned females that apparently will physically and psychologically masculinize highlights the fact that compulsory heterosexuality as well as compulsory dyadism underpin “normalization” practices. Physical masculinization is identified as genital “ambiguity” or variance (e.g. an “enlarged” clitoris, a “shallow” vagina). Psychological virilization is looking or behaving in an “unfeminine” manner and “developing” lesbianism or bisexuality (see G. Davis 2015a; Dreger, Feder, and Tamar-Mattis 2012; Reis and Kessler 2010; James 2012; Sytsma 2006b). The idea of
psychological masculinization was proposed by John Money and colleagues (Money et al. 1956; Money 1968; Money and Ehrhardt 1972). Eckert summarizes:

John Money’s assertion that CAH females show increased intelligence and a propensity toward lesbianism as a consequence of virilization is proving of his patriarchal implication in the process of intersexualization. Money reports that ‘it is possible that the genetic factor responsible for CAH is linked to another genetic factor responsible for intellectual superiority’ (Money 1968: 40). Virilization as biological process based on hormones and genetic dispositions is thought to be responsible for intellectual achievement – a rather commonsense assertion that reveals deeply patriarchal reasoning. (Eckert 2009: 64-65).

The evidently reductionist (Jordan-Young 2012), sexist, and queerphobic proposal that assigned females with CAH pathologically physically and psychologically masculinize has been and continues to be used to justify nonconsensual and unnecessary genital surgeries, such as clitorectomies/clitoroplasty (Carpenter 2013d). This idea has also fueled the development and prescription of Dexamethasone (DEX), an experimental drug prescribed to a person who is pregnant with an assigned female fetus with CAH. Even at the risk of the pregnant person and fetus’ safety and health, DEX is prescribed to prevent the development of supposed physical and psychological masculinization (see Chapter 4; Dreger, Feder, and Tamar-Mattis 2012; “Dreger, Feder and Tamar-Mattis on Dex” 2012; Reis and Kessler 2010; James 2012; Bastien Charlebois 2014; “On the use of Dex” 2010; Sytsma 2006b).

Even though there are limited (and contested) health risks associated with intersex variations themselves, unnecessary cosmetic interventions intended to erase intersex markers occur all over the world (Ghattas 2013: 19; Ghattas at UN Human Rights 2017). Furthermore, despite the fact that intersex people have been testifying to the traumatizing and disabling effects

29 I use clitoroplasty and clitorectomy interchangeably here because the distinction between the two words “is more political than technical” (Chase 1998b: 151; also see Pagonis 2016d). The latter is usually applied to African girls and women who have experienced female genital mutilation/cutting (FGM/C) and the former is applied to intersex infants who have undergone medical intervention to reduce the size of their supposedly unacceptably large clitorises. The linguistic distinction functions to mask the similarities of the procedures and draw a sharp line between the “barbaric” Global South and the “developed,” “scientific” Global North.
of “curative” interventions for decades and there are a “frightening lack of follow up studies that would prove the actual benefits of non-lifesaving cosmetic genital surgeries and other medical interventions,” these procedures continue (Ghattas at UN Human Rights 2017: n.p.). In fact, finding an intersex person who has undergone irreversible and unnecessary procedures and is grateful such interventions occurred appears to be an impossible task, as the quote by Cheryl Chase at the beginning of this chapter illustrates (Chase in Lahood dir. 2012). Alice Domurat Dreger similarly affirms: “Journalists have gone [looking] for over a decade seeking one [intersex] person to go on camera, even behind a potted plant, and say, ‘yes, this [medical intervention] happen to me and I’m glad my parents made this decision.’ So, where are all of these people?” (in Lahood dir. 2012: n.p.). No such people appear to exist.

Given that there no justifiable circumstances to perform cosmetic interventions and given that intersex people themselves rightly claim they did not need to undergo such procedures, concerns about intersex anatomy are “more social than medical” (Fausto-Sterling 2000b: 58; also see G. Davis 2013, 2015a; Kessler 1998; van der Have at UN Human Rights 2017; Karkazis 2008; Viloria 2017). People with intersex variations are socially and politically distressing since they “[fly] in the face of taken-for-granted definitions of sexuality because an intersexed body cannot be contained under strict anatomical, functional or chromosomal categories” (Holmes 2000: 102). Intersex variations undermine dominant Western, dichotomous iterations of sex, gender, and sexuality (Crouch 1999; Vigneault 2011; Warnke 2011; N. Menon 2011; Mitra 2014a; Reddy 2005; Atluri 2012; Lugones 2007; Chapter 3). Or, to employ Rosemarie Garland-Thomson’s expression, people with intersex traits “spectacularly violate sacred ideologies of Western culture” (2011: 26). Intersex people embody heresy. In a way, the mutilating and disabling practices performed by medical professionals is an exorcism, a punishment, an
atonement, for defying consecrated Western principles, for undermining culturally mandated modes of being.

The medical professionals who endorse and perform such interventions, however, do not conceptualize these procedures as a means to restabilize Western ideologies and compulsory embodiments. They are taught and believe these procedures reorder the innately disabled, diseased, or disordered intersex body-mind (Holmes 2008). They may also believe they are being kind, preventing a child from enduring stigmatization, teasing, or bullying for “[living] with and through difference” (Holmes 2008: 175; also see F. Ahmed et al. 2016; Sparrow 2013; Trafimow 2013; Devore 1999, 2011, 2017; Coventry 1998; Roen 2009; Lee et al. 2016). Katrina Karkazis explains, doctors’ “intentions are more benevolent” (2008: 2; also see G. Davis 2017).

Nevertheless, good intentions do not necessarily result in good, ethical care. Intersex activist, Karen A. Walsh, reminds: “The Road to Hell is Paved with Good Intentions” (2015: 120). Benevolent intentions and disabling mutilation are not mutually exclusive. Yet, many medical professionals assume that the violence of surgery and other interventions will be forgotten because the procedures take place (or supposedly ought to take place) when children are too young to remember. These procedures, however, are not and cannot be forgotten.

Medical professionals, according to Katrina Roen (2009), are misguided when they presume that procedures, if performed early enough, will be forgotten. This presumption regards infant flesh as,

malleable enough that such delicate surgery might be “successful” and might be forgotten such that no loss might be experienced. This is the body as an object. Here, the act of surgery is understood to exist in the unremembered past of the self: the infant has not yet become [emphasis in the original] a subject to whom the body is an important marker of selfhood. (Roen 2009: 21).
The body-mind is not an object. The body-mind is an ongoing “event” (Roen 2009: 21), “a continual, life-long becoming” [emphasis in the original] in which any early surgery will be ever-present. The scarring, the aesthetic difference, the changes to sensation, are lived continuously. They are not discrete events [...] they are necessarily imbricated in the process of the emerging self” (2009: 21). In other words, nonconsensual surgical procedures are not isolated incidents; the “body-mind loss” (Clare 2017: 60) or acquired body-mind disabilities are inevitably enveloped into one’s becoming (Kim 2017). Intersex activist, writer, clinical psychologist, and sex therapist, Tiger Devore, illustrates this fact: “I’m very angry at the genitals that were taken away from me, very angry at how much good sensation was taken away from me. I would have liked to have a whole lot more say over the body I would have had, the life I would have had, and the identity I would have had” (in Lahood dir. 2012: n.p.).

Not only do many intersex people experience numerous interventions throughout their lives, such interventions literally de/reconstruct these people’s body-minds, lives, and identity formation. They continue to shape and comprise one’s cultivation of (medicalized) self. As Viloria writes: “[g]enitals that were removed can’t be brought back. It’s a wound that can’t be healed” (2017: 82). Medical interventions, accrued disabilities, wounds that “can’t be healed” (Viloria 2017: 83), and hospital visits shape and continue to shape one’s memories, embodiment, experiences, possibilities, life, and identities. Even if one is lied to about why or when surgery occurred, the body-mind remembers.

As noted above, this ever-presentness – that which cannot be forgotten or healed – is a sort of haunting (Spurgas 2009; O’Rourke and Giffney 2009). Like a phantom limb (see Howe 2006: 123), the removed and altered biological structures haunt. The attempt to cut out or render invisible the intersex marker and avoid the apparent trauma (see Lee et al. 2016; Sparrow 2013).

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30 Devore was one of the first publically known intersex people in America (Devore 2015).
of living with intersex anatomy “necessarily fails since the intersex body, both pre- and post-surgical inscription, is still, always already, a site of contested being” (O’Rourke and Giffney 2009: x). The “spectre of intersex” (Sparrow 2013: 29) cannot be completely cast out, exorcized (see B. Hughes 2000: 564); “the intersex body haunts” (O’Rourke and Giffney 2009: x). And pervasive and lifelong issues like “lack of sensation, repeat surgeries, infertility, scarring, painful intercourse, depression and trauma” (Carpenter 2013d: n.p.) are constant reminders of and continuations of disabling, curative violence.

The consequences of surgery are not the only ways that intersex continually haunts. If surgery is deemed unnecessary, “a variety of other medical treatments are mandated,” such as HRT, surveilling tests and examinations, and vaginal dilation (Spurgas 2009: 113; also see Kessler 1998). This “form of medical management paradoxically produces biomedical subjects who are inherently ambiguous or, at the very least, understood as being always at-risk [emphasis in the original] for problematic ambiguity” (Spurgas 2009: 113). Removed or managed intersex markers linger, threaten to reemerge, never really go away, or do reemerge. In other words, the intersex body-mind is a “haunted [emphasis in the original] body that must be constantly surveilled and preemptively managed so that the individual’s at-risk status is never realized” (Spurgas 2009: 114).

Body-Mind Disabilities Created by “Curative,” Cosmetic, Nonconsensual, and/or Coercive Interventions:

Hormone Replacement Therapy

Many people with intersex variations are forced or coerced to take medically unnecessary “female” or “male” hormones so their embodiment “coincides” with or emphasizes their
assigned gender (Cameron 1999, 2007; Sean Wall 2015b; Wall in “What It’s Like To Be Intersex” 2015; Arana 2005; Klöppel 2009; L. Long 2015). In intersex studies literature, the effects of HRT are not explored as frequently as IGM. Hence, I begin with HRT as a mutilating intervention with disabling consequences. In Paul B. Preciado’s terms, imposed HRT is a form of somato-power (2013: 68), an internalized “[technology] of gender” (2013: 387), “sexdesign” (2013: 35), or “biodrag” (2013: 191), that aims to reorder or “cure” the queerly disordered or crip intersex subject on the molecular level.

HRT became a common treatment method in the 1950s. Steroid hormones were discovered and subsequently sexed and gendered (i.e. labeled male or female) in the 1920s (Klöppel 2009; Jordan-Young 2010; Dreger 1999; Fausto-Sterling 2000b; Laqueur 1992). This discovery was, and continues to be quite destabilizing (see Chapter 3). “Sex hormones” complicated the already fragile, but nevertheless defended, sex dyad: “The development of identification tools for ‘sex hormones’ [...] further blurred the ideal of distinct sex criteria, because the new technologies revealed previously unapprehended discrepancies between sex determinants” (Klöppel 2009: 173). For example, this discovery revealed that sex hormone levels varied widely within and between assigned sexes/genders. “Male” hormones do not necessarily counter or prevent “female” characteristics, and “female” hormones do not necessarily counter “male” characteristics.31 That said, the belief in the sex binary persisted and the idea that hormones “contribute substantially to the formation of [female- or] male-gender identity” was established, primarily by Money and colleagues, within the medical community and in mainstream culture (Imperato-McGinley et al. qtd. by Eckert 2009: 64).

31 The discovery of “sex chromosomes” in the 1950s also undermined the idea of sex dimorphism (Klöppel 2009: 173). People learned that there are more than two chromosome formations. In addition to XX and XY, Myra J. Hird explains, “[t]here are many variations of ‘sex’ [chromosomes]: XXY, XXXY, XXXXY, XXXY, XXXYY to name only a few [emphasis added]. [...] The only thing that does not exist is a pure (Y or YY) male” (2000: 354).
It is important to acknowledge that sex hormones were not really discovered. They were invented: “[p]reexisting ideas about masculinity and femininity caused scientists to look for, create tests for, classify, and perceive steroid hormones in a way that fit them into a dualistic system of sex” (Jordan-Young 2010: 16). Socio-political ideologies about gender led scientists and doctors to label testosterone as male and estrogen as female (Oudshoorn 1994). This labeling re/stabilized “presupposed essential differences in male and female bodies” (Eckert 2009: 64).

With this in mind, “sex is in some important sense, an effect of gender” (Jordan-Young 2010: 17); gender precedes sex (Butler [1990] 2006; [1993] 2011; Laqueur 1992; Adkins and Leonard 2005; Delphy 2005). The idea that sex is a social construction does not deny the materiality of the people’s morphologies; it does not deny that we all have hormones, chromosomes, and anatomical formations that interact, shape, and affect us and our relationships with our mind-bodies, identities, and the world. Rather, Fausto-Sterling explains (quoting Butler), the idea that gender precedes sex reminds us that “every time we return to the body as something that exists prior to socialization, prior to discourse about male and female, Butler writes, ‘we discover that matter is fully sedimented with discourses on sex and sexuality that prefigure and constrain the uses to which that term can be put’” (Fausto-Sterling 2000b: 22). One’s anatomical and biological attributes are material entities that continually re/produce and are re/produced by discourses. And, if one’s characteristics are pathologized – as is the case with intersex variations – one will (most likely) be literally re/produced, de/reconstructed, by a variety of medical interventions. If this discursive relation goes unacknowledged, our descriptions about anatomical variations are misrepresentative and fall short, often resulting in the pathologization or “intersexualization” (Eckert 2009: 64) of people with (perceived [Kessler 1998: 44]) sex differences or disabilities.
“Normal” sex hormone levels were assumed to be essential for “normal” (i.e. heteronormative) gender and sexuality identity formation. Since intersex people are perceived as developing abnormally – or to use Kathryn Bond Stockton’s (2009) term, “sideways” – HRT emerged alongside surgical treatments in the 1950s. In the 1950s the pediatric Endocrine Clinic of John Hopkins Hospital in Baltimore, America, outlined a “novel treatment plan [...] that scheduled ‘corrections’ of intersexual genitals and hormone therapy in early infancy in order to assure an unambiguous rearing as boy or girl and thereby a ‘normal’ psychosexual development” (Klöppel 2009: 173; also see Wilkins 1950). HRT was deemed necessary for intersex children to grow up to be “properly” gendered and sexual subjects. Almost a century since the invention of hormones, many medical professionals still “[believe] that gendered behaviors [result], at least in part, from hormonal exposure during gestation” (G. Davis 2015b: 71). This belief is called brain organizational theory. Brain organizational theorists (see Swaab 2009; Dörner 1975, 2010; Valla and Ceci 2011; O’Keefe 2016; O’Keefe in Villarreal 2016; O’Keefe in Rudolph 2016; Brizendine 2006) maintain that hormones make people have male or female and gay or straight brains (Jordan-Young 2010, 2012; Young and Balaban 2006; G. Kelly 2012). That is, according to brain organizational theory, certain hormones literally form the brain to have female or male and gay or straight structures. Hence, tinkering with hormone levels prenatally or postnatally will apparently shape one’s brain structures and, therefore, one’s gender expression and identity as well as sexuality.

Nevertheless, evidence does not substantiate this theory about hormones, gender, sexuality, and brain development and structuring (Jordan-Young 2010, 2012; Young and Balaban 2006; G. Kelly 2012). A comprehensive meta-analysis of brain organization studies demonstrates that there is no solid evidence to support this theory. Rebecca Jordan-Young
explains: “evidence that human brains are hormonally organized to be either masculine or
feminine turns out to be surprisingly disjointed, and even contradictory” (2010: 3). Elaborating
further, Jordan-Young notes that brain organization researchers fail to “include social variables
in their models” and do not “explore potential interactions between these [variables] and the
hormones that they see as main actors” (2010: 8). Brain organization researchers do not entertain
the idea that gender precedes sex or that, in addition to hormones, people’s socio-cultural
experiences also literally shape people’s brains and influence their sexed, sexual, and gendered
behaviour. Even though there are evident methodological and theoretical failings and a lack of
evidence, many medical professionals and scientists imply this theory is a settled scientific fact.
This is deeply worrisome: “the stakes involved in prematurely promoting this theory to a ‘fact’
of human development are high, both for the advancement of science and for social debates that
draw on science” (Jordan-Young 2010: 3). The stakes are particularly high for intersex people
who are subjected to nonconsensual or coercive hormonal treatments precisely because of this
unsubstantiated theory. And, the stakes are also high for broader LGBTQI communities.

In certain circumstances, HRT is medically necessary, not cosmetic. For example, people
with CAH (who have intersex traits) typically need to take a variety of hormone replacements
(e.g. hydrocortisone, prednisone, fludrocortisone) throughout their lives to ensure metabolic
balance. In other circumstances, hormones are not medically necessary but are prescribed to
reinforce one’s assigned sex and gender. These circumstances illustrate the stakes and the
violent, disabling consequences of nonconsensual or coercive HRT management. Consider
David Cameron’s story. Medical professionals assured Cameron and his family that he was a
“normal” boy child even though he appeared different, more “feminine,” than other boys his age
(Cameron 1999, 2007; Cameron in Lahood dir. 2012). Yet, when he was 20, Cameron learned of
his intersex variation, XXY-47, also known as Klinefelter syndrome. Cameron explains: “I was informed that I was genetically sterile and that my ‘sex glands’ produced only 10 percent of what was considered normal testosterone levels for a male” (1999: 91). Cameron’s doctor advised he “immediately start testosterone replacement therapy” (1999: 91; also see 2007: 163-164). This advice was given without psychological or emotional counselling and without discussing Cameron’s gender identity. Cameron “always felt caught between the sexes” (1999: 91), “more feminine” (1999: 93). His doctor also advised HRT without fully informing him of the various side-effects testosterone would have on his body-mind (1999: 93). To quote Cameron, “I was told that my ‘sex drive would increase,’ I would ‘gain weight and my shoulders would broaden,’ and that I would have to do this [take testosterone] every two weeks for the rest of my life” (1999: 91). His doctor did not tell him he “was about to go through puberty again with a vengeance [emphasis in the original] … in my thirties” (2007: 164). Wanting to increase his sex drive, he “faithfully got [his] 300 mg. injections of testosterone every two weeks” (1999: 93).

Cameron enjoyed his (temporarily) increased sex drive and his budding beard (2007: 164); but, to Cameron’s consternation, his body was soon blanketed with hair and his head started to bald (1999: 93). His prostate also enlarged considerably. It grew so large that he “had to take medication to urinate” (2007: 164). All of these changes were, in Cameron’s words, “[altering] my sense of self” (2007: 164) and, in turned, caused long-term “emotional issues” (1999: 93). As his prostate continued to enlarge, he was finally informed of some of the long-term effects of HRT. Continuing with the injections could lead to Cameron developing prostate, breast, or testicular cancer. Cameron began to “think of the testosterone as a poison” (1999: 93) and he started to question whether the doctor’s (coercive) advice and his subsequent decision to take HRT was correct (1999: 94).
Even with the current and prospective disabling effects, his doctor urged Cameron to continue with the injections and encouraged him to “improve the [masculinizing] effect” by undergoing testicular implant and breast removal cosmetic surgeries. He decided against the seemingly more invasive implant and removal interventions. Heeding the medical advice to continue with testosterone injections, however, his prostate and urinary problems persisted and Cameron was “put on another drug to try and compensate for the side-effects of the testosterone” (1999: 94). After nineteen years of injections, he decided to stop. Coming off HRT, he experienced “fatigues, mood swings, depression, [and] more difficulty urinating” (1999: 94). In an effort to combat these disabling side-effects, he later began using daily androgen patches. The patches, however, did not alleviate his depression or mood swings. The visibility of the patches made Cameron self-conscious and they also produced “constant skin rashes and itchiness” (1999: 95). The epidermal problems prompted another medical treatment: hydrocortisone cream. These patches were a haunting daily reminder to Cameron that he “was different” (1999: 95). His depression intensified and two large fat deposits formed: “one on the back of my neck, [...] and the other in the form of a spare tire under my navel” (1999: 95).

The ongoing and compounding body-mind effects, and the constant medical management and surveillance aimed to keep the intersex spectre at bay, robbed Cameron of his self-control (also see van der Have in United Nations Human Rights 2017). Cameron’s doctor worked to continually defer and cast out the intersex phantasm, at the expense of Cameron’s body-mind health, self-determination, and sense of gendered self/identity. Understandably, he wanted “more control over [his] destiny,” but he was acutely aware that he could never return to what his body-mind was before these coercive, irreversible medical interventions (1999: 95). Despite medical professionals’ efforts to make Cameron into a “proper” man, he is still “a unique blend of [...]
female and male essences” (1999: 96). Finding the (now closed) Intersex Society of North American helped Cameron trust his own embodied experiences and challenge the idea that doctors are infallible gods (2007: 164). “My endocrinologist was not a God,” Cameron writes, although I trusted that he knew what was best for me at the time. [...] I feel that I was rushed into an experience that I wasn’t ready for and that my doctor deceived me. Doctors do not have all the correct information on sex, gender, and sexuality diversity. Not everything needs to be pathologized just because it is different [emphasis in the original]. I’ve learned to trust my own life experience, not fitting into our “two sex/two genders: Western binary system.” [...] After that first intersex support group, I learned that, for me, my sense of gender as a “blend” is okay. (Cameron 2007: 164).

As Cameron’s story illustrates, medical professionals do not always have one’s best interest in mind, even when they believe they do. Rather than support one’s well-being and provide all the relevant information for proper consent, a doctor’s advice may primarily work to uphold valued cultural mandates and result in body-mind disabilities.

In many situations, HRT is medically unnecessary but intersex patients and/or their parents are coerced to agree, often without all the information. Patients and/or parents of intersex children understandably trust (god-like) doctors. In other circumstances, the medical need for hormones is created. Karen Walsh had to begin a life-long HRT regimen because of unnecessary surgical intervention:

I know now that it was not necessary to remove my gonads – my only source of endogenous hormones. [Since the unnecessary gonadal removal] I am at extraordinary risk for osteoporosis, as well as problems with libido. Additionally, I had problems feminizing during my “puberty”, since the Premarin was not well absorbed. It is a myth in the treatment of intersex that exogenous hormones work as well as endogenous ones. This is a lifelong problem for me. [...] I wish I had been given the choice to keep my testes with regular monitoring instead of rushing to surgery. Hormone replacement therapy is a poor substitute for the real thing – especially at age 15 with a long life ahead. (K. Walsh 2015: 122).32

32 K. Walsh’s assertion that HRT is a poor substitute for the real thing is not commentary about or commentary that can be applied to trans, intersex, genderqueer, and non-binary individuals who need, consent to, and are fully informed of the possible risks and benefits of HRT. On this topic, Cameron claims, the fact that trans people who
Due to needlessly rushing to remove Walsh’s testes, Walsh must remain on HRT and confront/anticipate various disabilities (also see Zieselman 2017).

Sean Saifa M. Wall, diagnosed with Androgen Insensitivity Syndrome (AIS), was similarly forced to undergo HRT. Medical professionals maintained that Wall was and ought to be female, even though he had always identified as male. He was subjected to “feminizing” surgery at the age of thirteen. His undescended testes were removed and he was “put on hormonal treatment which consisted of estrogen and progesterone” to reinforce his assigned female gender and sex (Wall in “What It’s Like To Be Intersex” 2015: n.p.). Sean Wall elaborates on his experiences as an “intersexualized” (Eckert 2009) subject:

The pain that I felt following the surgery was perhaps the worst pain that I have experienced in my entire life. After surgery, my pediatrician prescribed estrogen and Provera as a hormonal replacement regimen. Fatty deposits changed the shape and contours of my face. Once robust and chiseled thighs now harbored cellulite. The beginnings of facial hair and prominent body hair became wispy and nonexistent. What was hard and defined became soft. At no point did anyone ask me what I wanted to do with my body [emphasis in the original]. I actually missed the effects of my natural testosterone such as a deepening voice, increased hair and muscle mass; when I asked if I could take both testosterone and estrogen after surgery, my mother remarked, “You would look too weird.” The hormone therapy was coupled with intense social conditioning. I feel as if the social conditioning for young women raised with AIS is suffocating. When doctors prescribed hormones for me to take, my mother constantly reminded me how “beautiful” the little yellow pills would make me. (Sean Wall 2015b: 118).

At the age of 25, he decided to no longer conform to his socio-biologically assigned and imposed female sex and gender. The effects of the intense social conditioning and imposed “biodrag” (Preciado 2013: 191) – surgery and HRT – were evidently profoundly painful and unbearable for Wall. His embodied becoming was nonconsensually being literally de/reconstructed in ways that did not reflect his gender identity.

can give legal consent struggle to access HRT (as well as other procedures and forms of care) whereas HRT is often forced into intersex youths even though they cannot give legal consent is terribly ironic (2007: 164).
These sorts of testimonies necessitate fundamental changes to intersex HRT prescription practices and philosophies about brain organization theory. Rather than impose or create a need for HRT, medical professionals must listen to individuals’ needs and “put people in the hormonal environment where they feel comfortable” (Tamar-Mattis qtd. by Sean Wall 2015b: 119; also see Sean Wall 2015a; Tamar-Mattis in Arana 2005). Depending on the person, HRT intervention may or may not be required. When people are not (put) in the hormonal environment that enables them to live the life they are comfortable living, they do not simply feel uncomfortable. Forcing people to embody an ideology, a sex, and a gender that is not their own can cause people to experience profound body-mind disabilities, such as anxiety, depression, dysphoria, and dissociation, as well as unnecessary (prospective) disabling illnesses like cancer and osteoporosis (Arana 2005; K. Walsh 2015; Cameron 1999, 2007).

Body-Mind Disabilities Created by “Curative,” Cosmetic, Nonconsensual, and/or Coercive Interventions:

Surgeries

Surgically altering people with intersex characteristics to “cure” them of their perceived malady began in the mid-twentieth century alongside HRT. Dreger refers to the era in which surgery became common medical practice as the “Age of Surgery” (1999). Surgery became the conventional medical response to intersex not only because new technological and surgical tools were developed that could readily detect and (attempt to) cut out the intersex spectre. Surgery became routine primarily because of the popularization of John Money and his colleagues’ views about sex, gender, and, as one of Money’s books is titled, Sex Errors of the Body (Money 1968; also see Money et al. 1956; Money and Ehrhardt 1972; Fausto-Sterling 2000b). According to

33 Ulrike Klöppel (2009) supplements Dreger’s account of the “Ages.”
Money and his associates, surgery is paramount because a child must have “normal” looking genitals (also see Sparrow 2013) to develop a “healthy,” “normal” gender identity and sexuality. Surgeries can include, but are not limited to, building up of phallic tissue (i.e. phalloplasty), the creation of a vagina (i.e. vaginoplasty), amputating clitoral tissue (i.e. clitoroplasty/clitorectomy), relocating the urethral meatus (or “pee-hole”) (i.e. hypospadias repair), and removing gonads (i.e. gonadectomy or orchidectomy) (Grabham 2007: 30-31). While Money’s epistemological reign is over because his theories about (surgically constructing) sex and gender proved to be both incorrect and actively violent (Fausto-Sterling 2000b), surgical practices are still common today. The idea that children must have “normal” looking genitals to, for instance, avoid teasing and develop “properly,” persists (see Sparrow 2013; Trafimow 2013; Lahood dir. 2012; Chapter 4), despite the fact that intersex people have been, for decades, attesting to the gratuitously disabling and violating nature of nonconsensual surgery.

34 Historically, in Western contexts, vaginoplasties and clitoroplasties/clitorectomies have been considerably more widespread than phalloplasties (Gurney 2007; Chase 1998b; Bastien Charlebois 2014; Kessler 1998). In 1998, Chase estimated that “90 percent” of infants with variant genitals were assigned female “by excising genital tissue” (1998a: 192). Quoting Melissa Hendricks (1993), Chase continues: “[m]embers of the John Hopkins intersex team have justified female assignment by saying, ‘You can make a hole, but you can’t build a pole’” (1998b: 192). Or, put in slightly different terms by John Gearhart, a paediatric urologist who worked with John Money at John Hopkins, “it is easier to dig a hole than build a pole” (Gearhart qtd. by Holmes 2008a: 148; qtd. by Bastien Charlebois 2014: 5; qtd. by Gurney 2007: 633). Holmes reports that Gearhart “deeply regrets” making such a statement (Holmes 2008a: 148). Typically, without much consideration for the intersex assigned girl child’s genital sensitivity, Janik Bastien Charlebois explains, “[t]oday, it is still commonplace to hear doctors maintain that a vagina eventually must be created or deepened in order to allow sexual activity, thus testifying to the deep heterocentrist,” sexist, interphobic, queerphobic, ableist, and “androcentrist, perspectives that orient their practice” (2014: 5; also see Chapter 4). Outside of Western contexts, surgical trends can vary due to differing manifestations of these discriminatory ideologies. Consider, for example, China. Chinese intersex activist, Small Luk, writes: “[t]he traditional Chinese way is patriarchal. Amongst the majority of families and parents, sons are more welcome, to continue the family line. Parents, family systems, communities, doctors and even the government tend to force intersex children, even intersex teens, to have genital ‘normalising’ surgery or medical intervention, to be men” (2015: n.p.). That is, even though it may be “easier to dig a hole” and neglect assigned females’ genital pleasure, in China more intersex people are assigned male and surgically (i.e. phalloplasty) and/or hormonally altered. While there is a difference between Western nations and China, both phenomena are different manifestations of intersecting discriminatory ideologies and systems. Compounding the issue in China, “the ‘one child policy’ has resulted in the abandonment and killing of baby girls, but also infants with intersex traits. Families in China have to pay the majority of medical expenses themselves, resulting in extreme poverty, or in rural areas, no treatment or surgery but a stronger likelihood of being killed or abandoned” (2015: n.p.). Due to the instituted, but now phased out, one-child policy, many culturally devalued children have been killed or abandoned in China.
But how common are these surgical practices? Obtaining information regarding how often IGM occurs is difficult; such information “is privileged, it’s private” (Carpenter at UN Human Rights 2017: n.p.). Patient confidentiality could figure in keeping this information privileged and private. Yet, for government budgetary and funding purposes and public health, hospitals are required to routinely release information without disclosing patient information. For example, the Canadian Institute for Health Information publically releases provincial statistical reports concerning, for instance, workforce, access and wait times, how often particular procedures take place (e.g. cardiac implants, dental surgeries, mastectomies), and how often people are diagnosed with various pathologies (e.g. types of cancer) (“Quick Stats”; also see Government of Canada’s Canada Health Act 2017). Information regarding intersex diagnoses (i.e. DSD) and “treatment” remains absent and private from these sorts of reports “because disclosure of such information discloses human rights violations” (Carpenter at UN Human Rights 2017: n.p.); such information reveals that the medical institution is capable of harming and disabling infants and children for cosmetic purposes. Keeping this information private is a means to protect hospitals and doctors from criticism and is also a means to deny abuses. That being said, there are estimates. Anne Fausto-Sterling (2000b) estimates that 30-80 percent of intersex children are forced to undergo more than one surgical procedure, some children are subjected to up to five surgeries (also see “Intersex Health” 2011).35

Recently – primarily since the 2006 publication of the “Consensus Statement on Management of Intersex Disorders” and the mainstream visibility of the Intersex Rights Movement (see I. Hughes et al. 2006; also see Houk and Lee 2008; Lee et al. 2016; G. Davis 2015a; Viloria 2017; Karkazis 2008) – many medical professionals claim that the number of

35 Some people with intersex traits have been subjected to well over a dozen surgeries (see Devore in Harrison 2011; Gregorio 2017b; Viloria 2017; Kessler 1998; Hillman in Clearway dir. 2007; McDonald 2016).
surgeries performed on unconsenting intersex infants and children are declining. Nevertheless, “rhetoric of changes to medical practices remain unsubstantiated” (Carpenter at UN Human Rights 2017: n.p.; also see Ghattas at UN Human Rights 2017; Bauer et al. 2016; Klöppel 2016). In fact, “Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care” (Lee et al. 2016), the follow-up report to “Consensus Statement on Management of Intersex Disorders” (I. Hughes et al. 2006), notes that there is a “high prevalence of normalizing surgery” (Lee et al. 2016: 167). Like the 2006 report, the 2016 report does not do enough curtail early cosmetic surgical intervention. While the report notes that “[i]n some cohorts, adults’ dissatisfaction with their early surgery is high” (Lee et al. 2016: 167), it does not wholly condemn such procedures. The report merely suggests delaying procedures and combining them with psychological evaluations: “HRT and surgery should [emphasis added] commence only after a full psychological evaluation at the appropriate age for each fully informed patient” (2017: 172-173). However, being informed does not equal informed consent.

Besides medical professionals’ public proclamations and seemingly productive conversations about due process and policy (see Weber 2017; Lee et al. 2016; I. Hughes et al. 2006), no evidence can substantiate the claim that medical practices have changed in any significant way in the last decade.

Given that information is privileged and difficult to obtain, there is only one comprehensive, methodologically sound quantitative study concerning IGM. The study, “Zur

36 In October 2005, fifty experts from various fields (e.g. urology, genetics, endocrinology, and gender studies) as well as some intersex activists gathered to revise the medical treatment guidelines (see Karkazis 2008; Greenberg 2012a; G. Davis 2015a). This meeting was the first but not last of its kind. The results of the meeting and the contentious revised guidelines were published (I. Hughes et al. 2006). The statement claims that having intersex anatomy is not shameful. Paradoxically, surgery, particularly for girl children, is still endorsed to “control the ‘sex’ of the body” (Karkazis 2008: 5). The statement also claims that psychological care should be integral to treatment and, in (re)medicalizing fashion, “intersex” was replaced with the diagnostic phrase “Disorders of Sex Development” (DSD). According to G. Davis, the new DSD terminology worked enabled medical professionals “to reclaim their jurisdiction over intersex” (2015a: 54).
Aktualität kosmetischer Operationen „uneindeutiger” Genitalien im Kindesalter“ (‘On the current state of cosmetic surgery of ‘ambiguous’ genitalia in childhood’), was conducted in Germany by Ulrike Klöppel (2016). As described by intersex activist, lecturer, and co-founder of OII Europe, Dan Christian Ghattas, at the 2017 United Nations Human Rights’ public consultation on protection against violence and discrimination based on sexual orientation and gender identity, the study,

is a retrospective, statistical data assessment from hospital statistics based on case flat-rates on feminizing and masculinizing genital surgeries carried out in that respective country’s hospitals between 2005 and 2014. The study focuses on children under the age of 10. [...] One of the key findings is that the development of the relative frequency of so-called feminizing genital surgeries showed no significant decline. (Ghattas at UN Human Rights 2017: n.p.).

Between 2005 and 2014, the number of “feminizing” surgeries remained almost the exact same and the number of “masculinizing” surgeries rose (Ghattas at UN Human Rights 2017). “This is really worrying,” Ghattas concludes, “especially in light of medical practitioners declaring that surgeries on intersex children have significantly decreased in the past years” (at United Nations Human Rights 2017: n.p.; also see Ghattas 2013).

These statistics are also troubling given that certain nations and jurisdictions claim to protect intersex people from discrimination. For instance, “X” or “U” sex/gender identification options instituted by various countries (e.g. Australia, Canada, Germany), states (e.g. California), and provinces (e.g. Ontario, British Columbia), or, more specifically, Ontario, Canada’s Bill

37 “X” stands for indeterminate, unspecified, or intersex. “U” stands for unspecified or unknown. Having a letter for intersex that is clear, representative, and destigmatizing is important. Hence, the letter “X” – the most popular unknown variable in algebra one solves for – seems peculiar to me. Having the “U” stand for unspecified seems like a good option given that it implies one (reasonably) did not choose to disclose their anatomical characteristics or gender identity. While not all people want to be intelligible (Butler [1990] 2006), “indeterminate” and “unknown” are dehumanizing terms in this context given that they indicate one is illegible, indecipherable, not properly human. Rather than adding more options, removing sex/gender as a category on identification documents all together is, I maintain, the best recourse. Vancouver-based lawyer, Barbara Findlay, and Morgane Oger, the chair of the Trans Alliance Society in Vancouver, also advocate for removing sex/gender from birth certificates cards and other identification cards and argue that, in Canada, one’s race or father’s occupation is no longer recorded on birth
33, Toby’s Act (Right to be Free from Discriminatory and Harassment Because of Gender Identity or Gender Expression) (Government of Ontario 2012) claim to both represent and protect intersex people (as well as other marginalized individuals) from discrimination and violence (see Carpenter 2014a; “High Court recognises ‘non-specific’ gender” 2014; T. Bennett 2014; Roxas 2017; Australia 2015; Australian Human Rights Commission 2009; de Silva 2017; Joseph 2017; Nandi 2013). These legislations benefit certain manifestations of discrimination and reflect certain intersex people’s identities. However, since intersex mutilation takes place in these locations, the apparent protections are not all-encompassing. These legislations are merely a gesture at diversity, acceptance, and inclusivity. They are guises of intersex protection; they do not protect intersex people from disabling curative violence at the hands of doctors.

Speaking at the 2007 Human Rights Commission in San Francisco, intersex activist, author, and artist, Thea Hillman, describes some of the disabling consequences of surgery:

I’ve heard of people being taken to the hospital with no idea why and waking up with bandages around their genitals. I’ve heard stories of friends being born with genitals that had sexual function and sensation and then been given surgery that took both away. I’ve heard of people who receive so-called “repair” surgeries and the next surgery failed and the next surgery failed and they were on their sixteenth surgery in twenty-three years. I’ve heard stories about loss of continence from surgery, chronic infections and illness due to surgery, and I have heard stories of surgically created vaginas that leak, that smell, and that come unattached from the body. (Hillman in Clearway dir. 2007: n.p.; also see Hillman 2008).

Intersex activists and scholars are still reporting these sorts of disabling consequences (Carpenter 2013d; UN Human Rights 2017; G. Davis 2015a; Interface Project n.d.; Intersex Day Project n.d.; Lahood dir. 2012): “[t]he impacts of surgery can be seen in a high prevalence of lack of sensation, repeat surgeries, infertility, scarring, painful intercourse, depression and trauma. These issues are pervasive, and lifelong” (Carpenter 2013c: n.p.).
For a more specific testimony, Tiger Devore, recounts their childhood experiences of various disabilities created by medical professionals:

I would go back to school [from summer holiday] and I would have a tube running into my body with a sack on my leg underneath my pants that would collect my urine. So, I didn’t use boy’s bathrooms. I didn’t use girl’s bathrooms. I had to go to the nurse’s office [...] to empty out this sack. So, I didn’t really have a sense of belonging to a sex on the basis of bathroom choice particularly. But also, instead of playing baseball or football and put my body at risk, I would play jacks with the girls or I would jump rope with the girls. So, there was this confusion about how masculine I’m supposed to be, how feminine I’m supposed to be, what rules do I play by, which games do I choose, because the messages were very confusing. Of course, I could never tell anybody what was happening [...] I always had to keep it a big secret [...]. I couldn’t tell anybody that I was having surgery “down there,” where I’m not supposed to talk about, where I’m not supposed to touch. Going back and forth to the doctors, which happened all the time, because there were infections and complications and breakdown of wounds [...]. I was enduring a lot of pain and very invasive procedures. [...] Unless there is a medical necessity to change the appearance of those genitals, I don’t think they should be cut on at all. I think they should be prevented from being cut on. It’s the kids’ genitals. It’s not the parents’ genitals. It’s not the doctors’ genitals. It’s the kids’ genitals. And when they’re young adults, they’re going to want their genitals to work. (Devore in Harrison dir. 2011; also see Devore 1999, 2011, 2015; Devore in Lahood dir. 2012).

Devore’s account illustrates, the genitals surgeons re/create without consent do not “normalize,” “enable,” or “cure” the apparently disordered patient, but rather cause confusion, shame, and a host body-mind disabilities that haunt people for their entire lives. As Devore states, “I lost a tremendous amount of feeling tissue that I would like to have still. And that was taken from me” (in Harrison dir. 2011). That which was taken from Devore, “the futures that were lost” (Fisher 2013: 45), haunts.

Since the advent of the Intersex Rights Movement in the 1990s, many medical professionals claim that surgical techniques have improved over the decades (Chase 1999). They claim surgery may not or will not cause a patient to, for example, lose sensation or orgasm capacity. I do not doubt that techniques have improved since surgery became common practice
in the 1950s (Dreger 1999: 11; Klöppel 2009: 173). However, surgery always carries risks. General anesthesia and sedation can have long term neurodevelopmental effects on children’s developing brains (Andropoulos and Greene 2017; Baratz 2017). Hence, the use of anesthesia should be limited to “serious or life-threatening congenital conditions for which there are no alternative treatments and for which treatment cannot be delayed” (Andropoulos and Greene 2017: 906). Furthermore, cutting into or cutting off intersex children’s delicate flesh always carries risks of infection, loss of sensation, scarring, and possibly infertility. And surgeries unequivocally communicate to children that they are wrong and freakish and cannot be loved the way they were born. Improved techniques also do not negate the fact that infants and children cannot consent to cosmetic surgery. Improved surgical techniques do not negate the fact that many people wish such interventions never took place. And improved techniques do not compensate, recognize, or help restore those who live with body-mind disabilities created by this violent, curative model. Ultimately, as Chase articulates, claiming “‘surgery is better now,’ is a strategy for silencing intersexed adults: it relieves surgeons indefinitely of the responsibility of listening to any former patient. If genital surgery is indeed ‘better now’ and getting better all the time, that is actually a strong argument for allowing intersex children to be free of nonconsensual early surgery” (1999: 151).

To be clear, I do not oppose improving surgical techniques. Consenting intersex, trans, genderqueer, and non-binary people who seek such interventions benefit tremendously from such improvements. However, unconsenting children do not benefit from unnecessary surgeries that typically result in a variety of disabilities. Rather than surgically alter intersex people’s bodies, emphasizing consent and reinforcing that their body-minds are beautiful and not shameful will be beneficial.
Body-Mind Disabilities Created by “Curative,” Cosmetic, Nonconsensual, and/or Coercive Interventions:

Genital Examinations and Displays

In addition to surgery and HRT, medical professionals have carried out other violent practices that result in body-mind disabilities, such as unnecessary genital examinations, also known as “medical display[s]” (Koyama 2003: 2; also see Hillman in Clearway dir. 2007) and “shaming examinations” (Lind and Brzuzy 2008: 272). Many intersex infants, children, and adolescents have been subjected to numerous medically unnecessary genital examinations and displays without being told why such procedures take place and, in many circumstances, why they take place so frequently. These procedures perpetuate the idea that intersex traits are shameful, pathological curiosities. They teach intersex people to be embarrassed of their anatomical characteristics, they effectively remove body-mind autonomy and integrity, and result in a plethora of body-mind disabilities. To borrow from Rosemarie Garland-Thomson, these examinations contribute to “the social processes of enfreakment” (1996: 10). 38

The social process of enfreakment includes voyeuristically objectifying and therefore dehumanizing people perceived to be monstrous, different, deviant, disabled, and/or pathological. This perception is explicitly reflected in Vincent Guillot’s story. When Guillot was born with intersex traits, his mother was told that “she had given birth to a monster” (Guillot in “Not a Girl” 2017: n.p.). People of colour, people with disabilities, non-citizens or foreigners, women, people with intersex traits, and LGBTQ individuals have historically been and currently are the people typically subjected to the process of enfreakment (see Clare [1999] 2009; Garland-

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38 Genital examinations are medically necessary sometimes. However, I am speaking of the frequent genital examinations, exposures, and manipulations that are medically unnecessary, but nevertheless, take place.
That is, people prone to enfreakment, show themselves in many different and culturally specific ways, but what is monstrous about them is most often the form of their embodiment. They are, in an important sense, what Donna Haraway calls “inappropriate/d others” in that they challenge and resist normative human being, in the first instance by their aberrant corporeality. (Shildrick 2002: 9).

Put differently, “monstrous” people and/or ways of being in the world are “located outside the boundaries of the proper” (Shildrick 2002: 5).

A person is often enfreaked during cultural rituals of observation and objectification. The perhaps most obvious example of enfreakment is the presumably antiquated freak show. Many scholars, however, demonstrate that freak shows continue to occur. Freak shows did not fall out of fashion but morphed alongside shifting cultural sensibilities and technologies into, for example, talk shows, reality shows, pornography, bodybuilding events, medical theatres, and documentaries (Clare [1999] 2009; Garland-Thomson ed. 1996; Garland-Thomson 1997; Bogdan 1988; Chemers 2008; Dennett 1996; Clark and Myser 1996). In addition to entertaining audiences, freak shows (contemporary or otherwise) primarily function to validate the spectator’s sense of normalcy. Spectators assume they observe “a freak of nature” as opposed to “a freak of culture” and are “[assured] that they are not freaks” (Garland-Thomson 1996: 10). The freak’s “monstrous” quality is presumed to be innately pathological, inferior, or degenerative rather than constructed by and evaluated against cultural ideologies of normality, or the dominant “schemes of recognition” (Butler [1990] 2006: 2). Intersex people are acutely aware of this process. Intersex activist Kimberly Zieselman, for example, in various circumstances was made to feel like “a real freak of nature, damaged and alone” (2015: 124; also see Zieselman 2017).
Suzanne Kessler’s draws attention to some of the specific ways intersex people are enfreaked in more contemporary venues:

Television talk shows parade the real people who are living in intersexed bodies for the entertainment of an audience that is motivated like any old-fashioned side show crowd to gawk at the bizarre. Unlike a real sideshow, though, the remarkable genitals are not on view, and the audience is titillated only by the idea of intersex. Producers and consumers of pornography are intrigued by intersex genitals [...] The viewer can think: Look at how many different sexual acts can take place at the same time! I can watch “homosexual acts” without my heterosexuality being called into question (or vice versa) because the gender of those people on the screen is (in some sense) both or neither. (Kessler 1998: 5).

Gawking at, even being titillated by, objectifying representations of intersex people reaffirms the viewer’s sense of normality. In contrast to the examples Kessler highlights, there are numerous noteworthy humanizing self-/representations of intersex people (see Interface Project n.d.; Clearway dir. 2007; Harrison dir. 2011; P. Hart dir. 2010; Lahood dir. 2012; Intersex Day Project n.d.; Avery 2016; “What It’s Like To Be Intersex 2015; Sean Wall 2015a; Yaeger 2017; Viloria 2017). Such examples are typically created and produced by intersex people or in collaboration with intersex people. Nevertheless, people with intersex traits are still often enfreaked (see S. Hart 2009; Hurst 2009; Cooky, Dycus, and Dworkin 2013; Magubane 2014). Even though the audience may be relatively small, I conceptualize clinical settings in which repeated unnecessary genital examinations take place as sites of re/enfreakment that disable intersex subjects.

39 One can also consider how intersex people have been objectified and enfreaked by medical photography (see Creighton et al. 2002; Shelley Wall 2010). Since these photographs are in medical texts and are displayed in medical settings, the “objective” medical guise and gaze partially mask or dispel viewers’ anxieties about objectifying and staring at the intersex “freak.” In fact, the medical photographs often explicitly block out the intersex person’s gaze so the viewer can comfortably stare without having to meet and therefore register a human gaze; one can stare and effectively not see a human. As Shelley Wall explains, “the image’s compositional structure itself positions the person under scrutiny as a powerless object laid open to the ‘clinical gaze’ and unable to stare back” (2010: 81). The photograph incites the viewer to interpret the intersex person as a freaky object to be observed.

40 Not all representations of intersex people will assure viewers that they are “normal.” For example, the National Post’s “‘Ordinary bloke’ prepares for hysterectomy after doctors discover womb during bladder cancer test” (Sawer 2015), explains that a presumably typical man discovered he had intersex traits at the age of 37. This sort of article may not reaffirm readers of their perceived normality. It may prompt them to question their own normality and wonder if the intersex spectre is haunting them too. Stories about supposedly normal people who discover they have intersex traits are, in part, so intriguing because they challenge assumptions about the presumed legibility or transparency of bodies (see van Dijck 2005).
Positioning people with intersex traits as freaks in clinical settings during shaming examinations and displays do not merely work to validate the viewer’s sense of normalcy, re/legitimize consecrated Western ideologies, or “educate” accompanying medical professionals, students, or residents. Enfreaking intersex people in these circumstances is also a means to frighten parents, to convince them that their child is a freaky anomaly and therefore needs ongoing medical intervention and/or surveillance. In these circumstances, medical professionals teach parents to view their child as a freak; they create an emergency, a “state of exception,” which “lays the groundwork for justifying medically unnecessary interventions” (G. Davis 2015a: 23; also see Roen 2009; Karkazis 2008: 96; Preves 1999, 2003; Danaon and Krämer 2017; Viloria 2017: 204; Steuli 2013). The body-mind disabilities unduly caused by being enfreaked during these examinations are profound.

Many intersex people attest to the body-mind disabilities caused by or during unnecessary genital examinations. For instance, Joan Whelan (2002), Lynnell Stephani Long (2015), Sean Wall (2015b), Konrad Blair (2015), among many others (see Clearway dir. 2007; Harrison dir. 2011; Koomah 2017; Larson 2017) recall doctors, medical residents, and students performing or observing mortifying genital examinations on them without being told why such exams were happening (also see Koyama 2003).41 In Blair’s words, no one explained “why I had to be humiliated and ashamed, again and again” (2015: 90). L. Long recounts: “The most horrible experience I remember is laying in bed with IV’s in both arms, having my doctor and at least fifteen student doctors stare at my genitals, and leaving without pulling down my hospital gown. I laid there exposed for over an hour until the nurse finally came in to change the IV bag.”

41 Sometimes, unnecessary surgery occurs in tandem with medical displays. As Viloria recounts hearing Robin’s story at a conference, “Robin is next to speak, and she also remembers growing up before her surgery. She was initially raised as a boy, but then her parents and doctors decided she wasn’t developing enough as a male. So they performed a surgery on her in what she calls a ‘teaching theatre,’ where hordes of doctors and med students shuffled through the OR [operating room] to study her unusual genitals” (2017: 82).
(qtd. by Arana 2005: 43). These medical displays inevitably cause intersex people to feel “different” (Sean Wall 2015b: 117), “freakish” (K. Walsh 2015: 120), like “freaks” (Driver at UN Human Rights 2017: n.p.; Zieselman 2015: 123; Garcia 2015: 93; Peterson 2015: 108; Quinn 2015: 109; Coventry 1998, 1999; G. Davis 2015a). These moments are undeniably “devastating and dehumanizing” (Koomah 2017: n.p.) and detrimental to one’s body-mind wellbeing. “Many intersex adults report that it was not necessarily the surgery that was most devastating for their self-esteem,” Emi Koyama explicates, for many, it is the repeated exposure to what we call “medical displays,” or the rampant practice where a child is stripped down to nude and placed on the bed while many doctors, nurses, medical students, and others come in and out of the room, touching and prodding and laughing to each other. Children who experience this get the distinct sense that there is something terribly wrong with who they are and are deeply traumatized. (Koyama 2003: 2).

These demeaning practices are one of the many reasons intersex people report experiencing depression, poor body image, dissociation, anxiety, shame, self-loathing, and post-traumatic stress disorder (Arana 2005: 19). It is, therefore, vital to frame these examinations as both enfreaking and disabling.

The examinations, considered alongside parental consent and some medical professionals’ poor bedside manners, further illustrate how destructive these experiences are. Laura Inter\(^43\) recounts:

\(^{42}\) Not all people want to feel or be seen as normal or not freaky. As Butler explicates, not all people desire to be recognized as legible, normal humans: “there are advantages to remaining less than intelligible [...]. Indeed, if my options are loathsome, if I have no desire to be recognized within a certain set of norms, then it follows that my sense of survival depends upon escaping the clutch of those norms by which recognition is conferred” ([1990] 2006: 3). Some people in the diverse intersex community seek to be recognized within a certain set of norms whereas others do not. Some individuals celebrate being outside the bounds of normal, others celebrate their normality, and others demand we must broaden what is deemed normal. Each person has a different narration of their body-mind and identities and each activist has their own unique approach to intersex activism, narrativization, and survival. Whatever one’s narrative may be, intersex activists are demanding body-mind autonomy and an end to violent medical practices.

\(^{43}\) The name Laura Inter is a pseudonym.
from the time I turned one, I was subjected to genital examinations twice a year, during which the endocrinologist would touch my genitals and look to see how they were developing. These unnecessary and intrusive examinations had a profound effect on me. As a young child, I did not understand why I had to lower my pants in front of a stranger – the endocrinologist – and let him touch me. The fact that my mother was present, and approved of this was something that made me feel completely helpless. All this seemed very strange to me; I found it confusing, and terribly uncomfortable, and I just felt it wasn’t right. I remember the doctor always spoke as if I wasn’t right there, and I did not always understand everything the doctor said when I was young, because of all the medical terms he used. I grew up with a feeling of being “inadequate,” of having a sense that something was wrong with me, though I didn’t know exactly what. These exams lasted until I was about 12 years old. Years later, as I began my adult, sexual life, I realized how much those displays had affected me emotionally. (Inter 2015: 95).

When a child witnesses their parent agree to and be present during these examinations they are not only bewildered and scared, they may, as Michel Reiter felt, feel betrayed by their parents: “I had about 200 examinations in my life. I didn’t want these examinations, but my mother took me to them. I didn’t trust her. I saw her collaborating with my enemies” (Reiter in Lahood dir. 2012: n.p.). Moreover, failing to meet the intersex patient as a person rather than an object to be viewed, manipulated, and fixed – speaking as if the patient is not even there – denies their subjectivity and humanity.44 In other words, there is an important distinction between the looked-at-ness and the not looked-at-ness of intersex people’s physical characteristics. They are simultaneously being looked at (as disordered, freaky objects) and examined whilst not being looked at (as humans).45 Ultimately, a trusting relationship is not cultivated between patient and doctor as well as child and parent in these circumstances (Preves 2003; Karkazis 2008; Danaon and Krämer 2017).

44 Janet Green’s subjectivity and humanity was effectively denied when, “nobody [in the hospital] was looking into my eyes [...]. Nobody actually looked at me other than up the sheets” (in Harrison dir. 2011). It is perhaps unsurprising that some medical professionals fail to meet an intersex person’s gaze because the photographs of intersex people with blocked out eyes in medical texts have taught them to resist meeting the intersex person’s gaze.

45 The various ways in which intersex people testify to the myriad disabling traumas – in film, at conferences and conventions, in print, in online forums, through art – teaches viewers, forces viewers, to meet the intersex gaze, to see and conceptualize intersex people as people.
Some medical examinations cause other sorts of body-mind disabilities. Truffer recounts an exam that caused lifelong urinary problems:

During my childhood, I spent a lot of time in doctor’s offices and hospitals, suffering countless examinations of my genitals and urethral opening. When I was two, our family doctor stuck his finger into my urethral opening; I was screaming very loud, my father says. My mother had to put me into warm water because every time I had to pee I screamed in pain. Later I was hurried to the hospital with a bad infection. Still today my urethra often hurts after going to the toilet. I knew early in my life that I was different. I learned fragments of the truth only after decades of ignorance and denial. (Truffer 2015: 111).

Manipulating children’s delicate genital tissue repeatedly, for no apparent medical reason, can result in lifelong issues, as Truffer’s testimony demonstrates.

Some medical examinations, after initial inspection, also include dilating assigned female children and adolescents whose vaginas are deemed too small or shallow. In more specific terms, I am referring to the ways in which dilators – hard dildo-like instruments – are used to non-surgically deepen vaginas that do not have a uterus or cervix and are deemed too short for a penis to fit inside. Medical professionals pejoratively refer to these vaginas as “blind pouch vaginas” (see Mendonca et al. 2009: 183). The words “blind” and “pouch” provide us with quite a bit of insight into the ideological underpinnings of dilation. According to medical professionals and the broader ableist culture, blindness is a disabling lack or loss that must, if possible, be avoided (Vidali 2010; Hesford and Brueggemann 2007; Dolmage 2014; Schor 1999; Titchkosky 2005).

Given this understanding, “the collective representation of blindness,” Rod Michalko and Tanya Titchkosky explain, is that “of a ‘need for help’” (2001: 215). Hence, similar to the ways many other blind metaphors function, labelling these people’s vaginas “blind” is an ableist tactic to reaffirm the supposed necessity of dilation.46 Dilation, or so the ableist metaphoric logic goes,

46 There are a variety of blind metaphors (e.g. one is blind to reality) as well as a number of stereotypes about and representations of blind people (e.g. blind people have super-human hearing abilities, are musically inclined, helpless, spiritual). See Naomi Schor (1999), Julia Miele Rodas (2009), Amy Vidali (2010), among others (Dolmage
will give “sight” to “blind” vaginas. The term “pouch” is also disconcerting, implying vaginas are merely a repository. Discussing intersex surgeries and blind pouch vaginas, intersex activist, Emily Quinn, demands, “please stop talking about my vagina like it’s some weird purse,” a pocket intended to hold something (i.e. a penis) (“Intersex Surgeries” 2016: n.p.).

These dildo-like tools are also used to maintain or “improve” vaginas surgically constructed by vaginoplasties, to make sure the vagina does not “go blind” again. Vaginoplasties “can cause infertility; [...] the constructed vagina can smell like a bowel; it can necessitate constant use of sanitary napkins; it frequently requires repeated surgical revisions; and it is usually created or deepened for the expressed goal of accommodating a penis, rather than for the satisfaction of the patients” (Arana 2005: 212; also see Hillman in Clearway dir. 2007). And, dilation during genital examinations “is often painful and humiliating” (Arana 2005: 21; also see Kessler 1998).

Claudia Astorino, further explains and documents her own experiences of repeated genital examinations and vaginal dilation:

Female-assigned intersex kids’ vaginal canal size is also assessed by doctors, to ensure that it’s long enough to fit a penis inside of it. Doctors might surgically construct or re-construct vaginas, which can result in a host of health problems and necessitate multiple, multiple surgeries. [...] Non-surgical methods are also used to increase or maintain vaginal length by regularly using medical dildos to stretch the vagina over months and years. [...] I had a dilation procedure performed for almost every exam I had with intersex doctors from the time I was 8 until I was 16, so that they could check how long my vagina was as I grew. I absolutely hated these procedures. I mean, imagine a man as old as your father or your grandfather, who you don’t know, inserting a medical dildo into you each time you saw him, knowing that you can’t question the doctor’s orders and just accept that you have to undergo these uncomfortable procedures for your health. Imagine a decade or so later, realizing that these procedures did nothing to track your health, and have everything to with grown men feeling good about the fact that you could fuck some dude someday like a “normal girl”. That all those traumatizing procedures weren’t actually medically relevant at all, and it was
actually within my right to refuse those examinations. (Astorino 2013: n.p.; also see Astorino 2010).

Astorino’s account of repeatedly enduring humiliation and pain at the hands of father-figure-like doctors for no health-related reason clearly draws attention to the compulsory heteronormativity and phallogocentrism that fuels the interphobic practice of dilation. The end goal of these de/reconstructing procedures is clearly to, in Kira Triea’s terms, “make the hermaphrodite fuckable” (1999: 143; also see Triea 1994).47

In addition to doctors dilating assigned girl children to make them “fuckable” for prospective adult men, parents have also been instructed by doctors to dilate their children: “usually the mother,” Koyama explains, “is required to ‘dilate’ the [child’s] vagina with hard instruments every day for months in order to ensure that the vagina won’t close off” or go blind (2003: 2). “The psychological effects” of “therapeutically” dilating or “penetrating” one’s child are extremely damaging (Wilson 2012c: n.p.). When a child becomes old enough to dilate themselves, they are often forced to do so (Wilson 2012b). When one does not comply, they may be “punished by parents and sent to psychologists for psychiatric ‘treatment’ because our [intersex people’s] unwillingness to subject ourselves to the pain of dilation and the indignity of it all is seen as a kind of madness, a type of insanity” (Wilson 2012b: n.p.). The fact that one would opt to have a supposed disabled, “blind” vagina is utterly inconceivable because disability is deemed innately inferior and, therefore, ought to be avoided as all costs. When one actively avoids pain and distress, and when one in/advertently refuses the discriminatory imperative that assigned females must have a vagina capable of accommodating a penis, one is pathologized in a new way. One is presumed insane or unstable. Rather than being “insane,” one is attempting to act autonomously and avoid body-mind trauma.

47 In Chapter 4, I explain in more detail the queerphobia and heteronormativity that motivates the phallogocentric notion that assigned females must have a vagina that can accommodate a penis.
In stark contrast to numerous intersex people’s testimonies, Berenice Bilharinho Mendonca and colleagues claim, referencing Maria Helena Palma Sircili et al. (2006) and Elaine Maria Frade Costa et al. (1997), vaginal dilation is “an effective treatment choice […], resulting in good outcomes […] good cosmetic and functional results” (Mendonca et al. 2009: 184). However, the studies referenced have small sample sizes, are unclear, and the conclusions appear to contradict other elements of the studies. This is typically the trend: “research on intersex people is conducted by non-intersex clinicians, based on small samples and case studies of people who have been treated by the institution conducting the study. There is sample bias, and selection bias” (Carpenter 2013d: n.p.). In Costa et al.’s (1997) study, only 12 people who underwent dilation post-vaginoplasty were interviewed. The authors report that 87% of the participants have “satisfactory” sexual intercourse. However, “satisfactory” sex is not defined and the study does not include any quotations from the interviews. Interestingly, the authors note that patients dealt with “anxiety” and “anguish” in relation to dilator use (Costa et al. 1997: 231). Sircili et al.’s (2006) study includes only three people who underwent dilation. They claim that the participants had “good functional results” (2006: 209). Yet, the (phallogocentric) definition of good functional results appears to be that an object the size of a “normal” penis can fit inside the vagina (Sircili et al. 2006). Good functional results (for prospective penises) are not the same as sexual satisfaction (for patients); the two should not be conflated. Moreover, participant details appear to contradict the claim that dilation had good results. Two of the three participants report not engaging in sexual activity. Two of the three patients deal with vaginal stenosis, symptoms of which include pain, dryness, burning, friable tissue, bleeding and discomfort during penetrative sex, UTIs, and urinary incontinence. And, one of the three participants experience
“intercourse with pain” (Sircili et al. 2006: 210). These studies are misrepresentative, contradictory, and methodologically problematic.

More recently studies contest the claim that dilation is successful. Heng Zhang et al. conducted a 14-year follow-up study on patients and explain, using evidently problematic language, “[f]or patients without vagina [sic] or with poorly developed vagina [sic], vaginal dilation usually has unfavorable therapeutic efficacy” (2013: 3). Likewise, Jatinder Kumar et al. warn against dilating children: “vaginal dilatation should not be undertaken before puberty. Emphasis should be on functional outcome [“importance of clitoris for orgasm”] rather than at strictly cosmetic appearance” (2012: 291). These more methodologically sound studies more accurately reflect many intersex people’s experiences of trauma and body-mind disability and rightly emphasize the importance of the intersex person’s (not a prospective man’s) sensation and orgasm. They also echo Arana’s report on intersex human rights: “there is no medical need for a preadolescent girl to have a vagina” (2005: 19). Pushing this idea further, I suggest that there is no need for anyone to have a vagina unless one voices such a need and can appropriately consent to the risks of surgery and/or dilation.

Other texts also emphasize consent and caution against vaginal dilation (see Clinical Guidelines 2006; Mendonca et al. 2009). However, some of these texts are problematic. For example, Bilharinho Mendonca et al. write: “[i]n patients who wish to initiate sexual activity, dilation of the blind vaginal pouch with acrylic moulds or surgical neovagina promote development of a vagina adequate for sexual intercourse” (2009: 183). While emphasizing the importance of patients’ wishes is vital and good medical practice, this iteration of consent reproduces heteronormativity, phallogocentrism, interphobia, and dyadism. Sexual activity or intercourse is conflated with penis-in-vagina sex. Any other kind of sex is not even recognized as sex. Employing this sort of discourse – when one is ready to have sex they can choose dilation and/or surgery – whilst in conversation with intersex patients erases and delegitimizes nonheterosexual, queer, and intersex life paths and sexual possibilities. This narrative, as many of the testimonies in this chapter illustrate, makes intersex people feel abnormal which, in turn, can work to coerce intersex patients to “choose” irreversible cosmetic interventions that restabilize discriminatory ideologies and disable body-minds.
Body-Mind Disabilities Created by “Curative,” Cosmetic, Nonconsensual, and/or Coercive Interventions:

Deceiving, Lying, Misinforming, and Withholding

Lying to intersex patients and their families about diagnoses, the effects of intersex traits, and procedures have also been integral to “curing,” surveilling, erasing, and disabling people with intersex characteristics. Since the age of surgery began, lying to or deceiving patients has been standard practice (Ashley 1962; Cornwall 2010; Money 1968; Money and Ehrhardt 1972; Preves 2003; Natarajan 1996; Dreger 1999, 1998b; Dreger ed. 1999; Fausto-Sterling 2000b; G. Davis 2015a). While lying to intersex patients and their families is no longer widely endorsed, “in some cases [lying], is still common practice today” (G. Davis 2017: n.p.; also see Driver 2017).

One of the proposed reasons for deceiving intersex patients is that they will not be able to handle the news; learning about their characteristics will apparently be too upsetting (Natarajan 1996; Ashley 1962; Money 1968; Money and Ehrhardt 1972). As expressed by David James Burrows Ashley, learning “the nature of his defect [...] may cause great distress” (1962: 289).

Anita Natarajan (1996) similarly claims, learning of one’s intersex diagnosis is too traumatizing, so withholding information is recommended. The paper in which Natarajan made this recommendation (ironically) won a medical ethics essay competition and was published in the Canadian Medical Association Journal. Dabbling in semantics, Natarajan attempts to distinguish between lying and deceiving: doctors who withhold information are “not actually lying: they are deceiving” (1996: 569-570). Whatever term one wishes to use, doing so is bad medical practice.

Withholding information is also, supposedly, a patient protective measure, a form of comfort. Doing so, it is assumed, prevents patients from feeling freaky or abnormal. “Sometimes,” J.D. Lantos states, “the best medicine might still be a comforting lie” (qtd. by Côté 2000: 199).
However, as many of the testimonies accounted for thus far demonstrate, repeated hospital visits, genital displays, dilation, HRT, and/or IGM unequivocally communicate that something is wrong, freaky, and abnormal. One need not be verbally told that they are pathologized and “freaky” – the treatment they endure communicates this quite effectively.

While learning about an intersex diagnosis can be “traumatic” (Groveman 1996: 1829), discovering that information was withheld later in life causes more harm (Karkazis 2008; G. Davis 2015a, 2017; Dreger 1998b; Coventry 1998, 1999). A.K. Edwin notes, “[d]espite the argument that the motivation behind this [secrecy] is often well meant, [...] it is more likely that misguided evasion or frank dishonesty may add considerably to a patient’s distress and prolong the necessary adjustment process thereby causing harm” (2008: 158). L.J. Fallowfield, V.A. Jenkins, and H.A. Beveridge’s study about medical disclosure and dis/honesty confirms: being honest with patients may cause emotional pain, but “deceit hurts more” (2002: 297). Deceit often results in a variety of body-mind issues: “a conspiracy of silence usually results in a heightened state of fear, anxiety and confusion” (Fallowfield, Jenkins, and Beveridge 2002: 297) as well as depression, drug abuse, and stress (2002: 301-302) – “not one of calm and equanimity” (2002: 297). Reflecting on his own experiences, Fr. Spencer St. John notes that deceit leaves “emotionally broken [intersex] adults in its wake,” not comforted ones (qtd. by Arana 2005: 45).

In addition to the body-mind disabilities noted above, deception can also contribute to the development or exacerbation of other disabilities and illnesses. Sherri Groveman (1996) was lied to by medical professionals about her AIS diagnosis. Like other intersex people who felt abnormal and sensed that they were being lied to (Creighton et al. 2002), Groveman discovered truths about her body-mind whilst conducting research about her experiences at a library.
Responding to Natarajan’s (1996) award winning medical ethics essay that endorsed deceiving intersex patients, Groveman recounts:

Learning the truth alone and scared in the stacks of a library is shockingly inhumane. [...] It is almost inevitable that the patient will learn the truth. The real question is how and when we want her to do so. When I discovered I had AIS the pieces finally fit together. But what fell apart was my relationship with my family and physicians. It was not [emphasis added] learning [...] that caused trauma [...]. I avoided all medical care for the next 18 years. I have severe osteoporosis as a result of a lack of medical attention. This is what lies produce. (Groveman 1996: 1822).

Groveman’s account effectively undermines Natarajan’s arguments. Her story of learning the truth and the pieces finally coming together can also be read as an instance of haunting: something unclear, ghostly, “comes into view” (Gordon 2011: 2). And, once in view, new spectres form and emerge: ruptured family ties, distrust and avoidance of doctors, and exacerbated illness.

In addition to Groveman (1996), other intersex people (see Mokoena in Interface Project n.d.; Goto in Arana 2005: 41) report that the distrust fostered by medical professionals led them to avoid seeking medical care when they needed it which compounded disabilities and illnesses. According to Cornwall, the trauma caused by lying is “crippling” (2010). Disability metaphors are often deeply problematic because they typically deny and erase the material, lived reality of people living with disabilities and they typically frame disabilities as inherent lack (Mitchell and Snyder 2013; Straus 2013; Baynton 2006; S. Rose 2005; Ben-Moshe 2005). However, the resulting trauma, embodied consequences, and compounded illnesses from lies are disabilities, not metaphorical disabilities. Hence, Cornwall’s comment on the “crippling” effects of lies and statements like, “It felt insane to be walled in by secrets” (K. Walsh 2015: 120), appear to be more than just metaphors and need to be taken seriously. Intersex people’s accounts illustrate the disabling effects of deceit.
Reproducing the idea that learning of one’s diagnosis would be too traumatic, medical professionals have mis/informed parents that if their intersex child learns of their intersex diagnosis and if “normalizing” interventions are not performed, their child may self-harm and/or experience suicidal ideation (Coventry 1998; C. Harper 2007: 136; Arana 2005: 23; Hester 2006: 54; Driver in Arana 2005). Angela Moreno’s parents, for example, were told that their intersex child would commit suicide (Moreno in Coventry 1998). However, Moreno explains, “[a]lthough the doctors had claimed that knowing the truth would make me self-destructive, it was not knowing what had been done to me – and why – that made me want to die” (Moreno qtd. by Coventry 1998: n.p.). Debbie Hartman’s experience of being a mother to an intersex child, Kelli, also complicates the idea that honesty and no medical intervention will cause the child unbearable distress. Hartman was not provided with enough information to make an informed decision about surgery and, when she asked to speak with other parents of intersex children or intersex people themselves, she was informed “there is no one” (qtd. by Arana 2005: 48). Due to being misinformed, Hartman assumed surgery was the right thing to do and agreed to the procedure. Kelli “has endured unnecessary pain, confusion and severe emotional and physical scarring,” Hartman describes (Hartman in Arana 2005: 48). “My child has tried to commit suicide twice in her 10 little years because she says she hates her body,” Hartman continues, “she constantly asks me why they…cut up her genitals” (qtd. by Arana 2005: 48). Hartman reports Kelli stating: “They thought I was no good, Mom” (qtd. by Arana 2005: 48).

In addition to unnecessary medical procedures and surveillance, repeated lies and misinformation that emphasize difference, teach shame, coerce people to agree to irreversible procedures, and create body-mind disabilities are what cause suicidal ideation and self-destructive behaviours. Many intersex people report attempting suicide and/or struggling with
suicidal thoughts (see Pagonis 2016d; Chase 1998b, 2006; L. Long 2015; Peterson 2015; St. John in Arana 2005: 45) and experiencing “shame, confusion, depression, anorexia, anxiety, insecurity, panic attacks, low self-esteem, explosive anger, lack of trust and feeling of safety” (seMbessakwini qtd. by Arana 2005: 34; also see Adams in Caplan-Bricker 2017; Anick in Strudwick 2017). While medical professionals have argued that such body-mind disabilities will arise if children learn of their intersex statuses or if their body-minds remain as they are, in fact, various disabilities stem from lies, medical practices, and discourses that communicate they are, in Kelli’s words, “no good” (qtd. by Arana 2005: 48).

All that being said, according to Arana’s investigation into intersex human rights violations, intersex people “did not disproportionately [...] attempt suicide” (2005: 12; also see Slijper and Drop 1998; J. Morgan et al. 2005). However, other studies suggest intersex people are at an increased risk of suicidal ideation (Mazur et al. 2004; Warne et al. 2005; Schützmann et al. 2009). At this moment, claiming intersex people are or are not more likely to commit suicide is difficult because there are too few long- and short-term studies that assess intersex people’s mental health. As Karsten Schützmann et al. write, “[e]valuation of psychological distress has received relatively little attention in research on persons with disorders of sex development (DSD). Results of previous studies varied considerably” (2009: 16). Additionally, as noted above, many of the studies that have been conducted (some of which have been discussed in this chapter) are methodologically dubious and highly problematic, in that, for example, many studies focus on the apparent function or cosmetic appearance of intersex people’s medically altered anatomical characteristics rather than seek to determine what intersex people want and need (Carpenter 2013c). Nevertheless, many intersex individuals’ testimonies are clear: the current and historical treatment of intersex are “medical abuses” (Koyama 2003: 2) and have
caused short- and long-term body-mind disabilities. Hence, as Arana advocates, “[a]dequate funding should be provided for services that support and protect intersex people, particularly youth, in suicide prevention, peer support, coming out, counseling, and housing services” (2005: 27; also see McDonald 2016).

Again, while some may argue that a comforting lie is the best medicine (Lantos qtd. by Côté 2000: 199), some of the lies told to intersex people and their families are not at all comforting. For example, some parents of intersex children have been told their children will develop cancer and, in order to prevent such a calamity, surgery is necessary. Some parents, who have been blatantly lied to or have been only told partial truths, are advised to perpetuate lies and tell their children that they had to undergo surgery because they had cancer (G. Davis 2015a: 115; G. Davis 2017; InterACT and Human Rights Watch 2017). Pidgeon Pagonis and their family were told such lies. As a child, Pagonis was told they were born with cancer.

Pagonis’ parents were told their child would develop cancer:

One of the first lies my mother told me was that I was born with cancerous ovaries [emphasis in the original] and that they were removed in a life-saving post-birth operation. You [doctors] instructed my parents to tell me this made-up story, and it became a root in my development. When I began asking questions about why I couldn’t get a period or have biological children, you told my mother to just stick to the cancer story [emphasis in the original] – and she did. Sad I wouldn’t be able to have kids, confused about the reason why, and scared the cancer would return, I began to retreat inward to a world of shameful silence. You didn’t tell my parents the same lie. Instead of telling them I was born [emphasis in the original] with cancer, you hyped the risk that my “underdeveloped ovaries” which you decisively referred to as “gonads” – and really were my undescended testes – would likely develop cancer if left intact. You noted in the records after my gonadectomy that the tissue samples came back negative and “no term other than gonad was used.” This manipulative tactic meant to induce willingness in scared parents is a byproduct of a culture that insists, sometimes by force, that humans only come in two polar opposite varieties. Instead of removing my undescended testes and causing a life-long dependency on hormone replacement therapy (HRT), you could have instead been honest with us and offered to

49 See Chapter 4 for further discussion of medical professionals conflating cancer with intersex variations as well as the eugenic practice of sterilization.
monitor them annually for signs of cancer. I know other Androgen Insensitive (AIS) intersex folks who still have their testes, and they wouldn’t trade them for the world. These types of decisions about our bodies belong to us and never to you. (Pagonis 2015a: n.p.; also see Pagonis 2015b; Weaver 2016; G. Davis 2017).

Lies about cancer are hardly comforting. As Pagonis aptly draws readers’ attention to, these lies are manipulative means to gain “consent” from parents for doctors to perform interventions that work to enforce and restabilize compulsory dyadism and able-bodiedness. And, ironically, in the attempt to enforce able-bodiedness, interventions often result in body-mind disabilities, hormone dependency, and sterilization. Similarly expressed by M. Joycelyn Elders, David Satcher, and Richard Carmona, “[a] gonadectomy can create a need for hormone replacement therapy, and may also preclude fertility […]. In short, surgeries whose purpose is to ensure physical and psychological health too often lead to the opposite result” (2017: n.p.).

Even though some medical professionals defend the idea that certain intersex people will inevitably develop cancer if their gonads are not removed, cancer is not as big of a risk as doctors claim. However, sterilization and a variety of disabilities are typically an inevitable risk when such a lie is perpetuated and results in surgery. Carpenter confirms,

Sterilisations are typically carried out on adolescents, on the basis of inflated claims of cancer risk with Australian studies quoting upper bound rates of 30% to 50%. Overseas studies quote risks from 0.8 to 5% in the case of AIS [Androgen Insensitivity Syndrome]. The lifetime risk of breast cancer in women is 12.2% according to the US National Cancer Institute – but we don’t routinely remove women’s breasts on the basis of that cancer risk. Sterilisation turns us [intersex people] into lifelong patients, even if it’s the only intervention carried out: we need HRT. (Carpenter 2013d: n.p.).

The logic of increased cancer risk is used selectively to justify disabling, or supposedly enabling, apparently disabled intersex people, effectively removing both anatomical attributes and possible life paths from them without their consent. Furthermore, the apparent risks of cancer are inconsistent and ought to be considered alongside the fact that everyone is at risk of developing
certain types of cancers, depending on, for example, anatomical characteristics, family history, life choices, and age. If cancer is truly a risk, rather than literally remove one’s possible life paths and disable them, routine cancer screenings can take place (see Döhnert, Wünsch, and Hiort 2017), similar to routine mammograms and papanicolaou tests.

Recalling Cameron’s experience of being coerced to take HRT (see above) and consulting various studies, one’s risk of developing cancer (e.g. breast cancer, gastric cancer) “markedly” increases because of long-term HRT (Ross et al. 2000: 328; Pizot et al. 2016; Weiss et al. 2002). HRT with one hormone (as opposed to two or more) can increase breast cancer risk by up to 10% for each five years of use (Ross et al. 2000). After 15 years of HRT, the risk is typically increased by 36% (Ross et al. 2000). Linda K. Weiss and colleagues report a pronounced increase risk of breast cancer in people who are on HRT and explains that this “[r]isk dissipates once use is discontinued” (2002: 1148). Many intersex individuals, however, do not have the choice to discontinue HRT because nonconsensual gonadectomies literally removed that choice; their health both depends on and may dissipate because of these hormones. Ultimately, in an effort to reorder the supposedly disordered intersex body-mind – to ostensibly “prevent” cancer – one’s risk of cancer increases due to the required HRT.

All of the injustices discussed thus far will continue if medical protocol is not altered immediately, if medical professionals refuse to acknowledge the harm caused. Intersex people’s testimonies demand acknowledgment and fundamental changes to medical care.

Medical Recognition (or Lack Thereof) of the Disabilities Created

Medical professionals, by and large (with some notable exceptions [Weber 2017; Bougnères et al. 2017; Elders, Satcher, and Carmona 2017; Diamond and Sigmundson 1997; Gregorio 2017a,
deny or refuse to explicitly acknowledge the extent of trauma and body-mind disabilities created by nonconsensual, “curative” interventions. However, the clinical term, “hypospadias cripple,” signals otherwise. Even though “cripple” is typically deemed an outmoded socio-medical descriptor and is not usually found in medical scholarship or uttered in clinical settings (Linton 1998; Kafer 2013; L. Davis, ed. 2013a), Katrina Roen notes that clinical texts “refer to intersex people in terms such as ‘hypospadias cripple’” (2009: 21). However, not all intersex people with hypospadias are labeled “crippled,” as Roen implies. Intersex people with hypospadias who underwent failed “normalizing” surgical procedures that resulted in various disabilities are deemed “crippled.” This term is a form of recognition of the disabling nature of IGM.

Hypospadias is the medical/izing term used to describe a cosmetic genital variation. The variation is characterized by the urethral meatus (or “pee-hole”) being situated on the underside of the penis. Depending on where the urethral meatus is located, the type of hypospadias may be medically referred to as distal or glanular (near the head of the penis but not at the tip of the glan), midshaft (middle or lower on the underside of the penile shaft), penoscrotal (where the penis and scrotum join), perineal (behind the scrotal sac). There are no worrisome medical or health concerns associated with hypospadias itself. When left alone, people with hypospadias are entirely capable of orgasming and urinating.50 Hypospadias is also quite common (Fichtner et al.

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50 Since infertility is often pathologized, concerns about in/fertility crop up in conversations about hypospadias. Hypospadias itself does not affect fertility (Asklund et al. 2010; “Hypospadias” n.d.). Nevertheless, some online, mainstream fertility sources claim fertility is affected and surgically relocating the urethral meatus will solve this problem. For example, according to Fertility Authority, “Hypospadias is a birth defect in which the opening of the urethra, which is normally found on the tip of the penis, is located instead on its underside. This is important when trying to conceive, since the urethra carries semen out of the body. [...] Fertility problems should no longer remain after the hypospadias is surgically corrected” (“Infertility Causes” n.d.). These sorts of sources misrepresent in/fertility. Most people with hypospadias have fertile sperm (Asklund et al. 2010). On rare occasions, cryptorchidism (undescended testicles) accompanies hypospadias and this structural variation can affect fertility, but hypospadias itself does not. These sources also downplay the plethora of medical risks and problems associated with
It is estimated that between 1 in 125 and 1 in 300 people born with a penis have hypospadias (Griffiths 2016). This oft-cited estimate is contestable, however. Jan Fichtner and colleagues, noticing the high prevalence (70%) of glanular and midshaft hypospadias in their pediatric hypospadias patients, decided to “study the meatal location in normal men [men never diagnosed with hypospadias] to investigate if meatal advancement [surgery] in all patients with anterior [glanular and midshaft] hypospadias can be justified when the wide variation of meatal locations in normal men are considered” (1995: 833).

If “normal” people’s meatal locations vary considerably, according to Fichtner et al., the necessity of surgery should be reconsidered. “[O]f the 500 ‘normal’ men” they observed, “the meatal location varied widely with only 55% [275 people] of all meatus at the tip of the glans” (Fichtner et al. 1995: 833). Hence, 45% of apparently “normal” people with penises are actually not “normal” by dominant medical standards. In fact, some of the undiagnosed people had “significant hypospadias” but they did not have “complaints about cosmetic or functional aspects” of their penises (1995: 883). Hypospadias, according to medical standards, may be very common, almost the “norm.” The authors conclude that surgical protocol ought to be reassessed.

surgery. All that being said, however, infertility is not inherently pathological or something that must be avoided or “fixed” (see Chapter 4).

51 According to Fichtner et al., we should “narrow our indication for meatal advancement [surgical interventions]” (1998: 834). Rather than simply narrow what hypospadias manifestations should prompt surgeries, we should wait until the patient is old enough to understand the risks associated with this kind of cosmetic surgery and consent to or reject such intervention. Fichtner et al. also claim that their findings indicate that “it remains unclear whether the tip of the glans truly is the normal site” of the urethral meatus (1998: 833). This study does not merely ask us to rethinking what anatomical formations are normal or where the normal site for a bodily structure is. This study demonstrates there is no “normal.” It calls us to divest ourselves from the “quest for normalcy” (Khan qtd. by Karkazis 2008: 1), the ideology, “tyranny,” or “empire” of “the normal” (see Fiedler 1996; Silvers 1994; Couser 2000; Rosenbaum and Gorter 2012). If we remain invested essentializing morphologies and in the idea of discovering what is normal, people deemed “abnormal” will be continually read as “medical crises that demand normalization” (Garland-Thomson 2005: 1567), even if said normalizing projects are disabling and medically unnecessary.
One of the primary ideologies that inform hypospadias “repair” is the cultural demand that assigned males must stand up to urinate. Given the location of the meatus, some assigned males with hypospadias must sit down to urinate (Griffiths 2016; “Program” 2016; see Lahood dir. 2012). Dreger summarizes:

Most hypospadias “repairs” performed by surgeons occur because of an untested, Freudian belief that you can’t grow up to be a “real man” if you urinate and ejaculate from somewhere other than the very tip of your penis. Urology texts of the past made it pretty plain: if you don’t “fix” hypospadias, a boy might be so messed up in his gender identity that he’ll grow up gay. Few urologists today seem to believe that sexual orientation is caused by how one pees, but many still think boys’ psychological health absolutely depends on being able to pee standing up. There’s no evidence for this. (Dreger 2013: n.p.).

The evidently queerphobic and sexist cultural demand for assigned boys and men to pee standing up has resulted in many nonconsensual surgeries. These surgeries are risky, and many of them result in short- and long-term body-mind disabilities.52

According to Christopher J. Long et al.’s study (2017), which analyzes the complication rates of hypospadias “repair,” complications are more frequent in midshaft, penoscrotal, and perineal repairs when compared to distal repairs, but the “overall complication rate was 56%” (2017: 852). 56% of people who were subjected to surgeries intended to repair their “disabled” penises dealt with various disabilities (also see Stanasel et al. 2015; Safwat, Elderwy, and Hammouda 2013; McNamara et al. 2015; Pippi Salle et al. 2016). Such a high statistic should “raise concern” (C. Long et al. 2017: 853) about why medical professionals attempt to surgically “repair” hypospadias. Some of the complications, disabilities, or impairments include, urethral

52 For a historical account of how hypospadias was regarded and treated since the 4th century B.C.E., see Ahmed T. Hadidi (2004), Durham E. Smith (1997), and Laïos Konstantinos, Marianna Karamanou, and George Androutsos (2012). In brief, “Aristotle, in the 4th century BC, was the first to describe it [hypospadias]. He pointed to the false impression that boys have of male and female genitalia due to the fact they urinate seated” (Konstantinos, Karamanou, and Androutsos 2012: E1). Galen (130-201 C.E.), introduced the term hypospadias: “hypo,” meaning under, and “spadon,” meaning fissure (Hadidi 2004; Konstantinos, Karamanou, and Androutsos 2012). “Treatment” during Galen’s time, 2nd century C.E., consisted of “amputation beyond the orifice” (Durham Smith 1997: 81). The part of the penis that went beyond the urethral meatus – the penis distal of the urethral meatus – was amputated.
strictures and urinary fistulas (also known as rectourethral fistulas), urethral hairballs and stones, and ventral curvature (Craig et al. 2014; Safwat, Elderwy, and Hammouda 2013; C. Long et al. 2017; Kampantais et al. 2012; Cinman et al. 2012; Devore 1999; Devore in Harrison dir. 2011). To clarify some of these medical terms, urethral strictures are scars that develop in the urethra. They narrow the urethra and can cause swelling in the penis, blood and discharge, pain in the pelvic area, and problems with urination, including pain upon urination or the complete inability to urinate. Urinary fistulas are holes that form between the urethra and the rectum. These holes can cause urine to pass through the rectum, infections, swelling, pain, and discomfort. Urethral hairballs occur when hair-bearing skin is used when reconstructing the urethra. They can cause pain and discomfort when urinating, chronic pain and swelling, chronic UTIs, and can contribute to urethral stone formation. Stones are hard masses that form in the urinary tract which can cause pain, bleeding, infection, and they can block urine flow. Ventral curvature is caused by scar tissue and makes the penis point or curve downward. It can result in erectile dysfunction, pain, and infection. All of these problems may necessitate additional operations, which carry their own risks. Intersex activist Cecelia McDonald explains, “failure means more surgery. Kids have ended up having 10, 20, 25 surgeries to correct what went wrong in the first one and in subsequent surgeries” (2016: n.p.).

In various medical texts and settings, people with hypospadias who have undergone failed surgeries and experience these sorts of disabilities are referred to as “hypospadias cripples” (C. Long et al. 2017; Gill and Hameed 2011; Amukele, Stock, and Hanna 2005; Sahin and Seyhan 2003; Adayener and Akyol 2006; Hrabovszky and Huston 2002; van der Werff and van der Meulen 2000; Hypospadias Foundation n.d.). Samuel A. Amukele, Jeffrey A. Stock, and Moneer K. Hanna explain: “hypospadias cripples” is a term reserved for people with
hypospadias who have undergone “at least 2 failed attempts at hypospadias repair” (2005: 1540). James R. Craig and colleagues similarly note, the term describes “individuals with remaining functional complications after multiple attempts at hypospadias repair” (2014: 196). The doctors associated with Hypospadias Foundation also use the expression whilst describing (and photographically depicting) surgical procedures performed on “cripples” (“A 14 years old boy - Hypospadias Cripple” n.d.). That is, not all intersex people with hypospadias are labeled “crippled.” People disabled by intersex mutilation are referred at cripples. In other words, “this ‘crippling’ isn’t caused by the hypospadias; it’s caused by the complications of surgeries to ‘fix’ hypospadias” (Dreger 2013: n.p.).

While some medical scholars suggest doctors “should probably” avoid the “somewhat pejorative” term “cripple” (Craig et al. 2014: 196), many medical professionals continue to use the term. In most circumstances, “cripple” is construed as an offensive and outmoded descriptor (Linton 1998; Kafer 2013; L. Davis ed. 2013); it is not merely “somewhat pejorative.” Expunging the term from medical discourses is wise, not simply “probably” a good idea. However, removing the term from medical discourse does not negate the fact that the development and deployment of the term is a blatant recognition of the disabilities intersex mutilation or “cure” causes. Or, since intersex is understood as a disability by medical professionals, interventions may further disable intersex people. Highlighting medical professionals’ recognition is a useful tactic in combating nonconsensual, medically unnecessary procedures in all its forms, especially given the fact that many medical professionals typically publically deny the harm caused. Underlining this recognition emphasizes how the curative medical approach, one that is supposed to heal and protect people, recognizes that it violently
disables intersex people’s body-minds and, nevertheless, continues to do so. Medical professionals effectively, violently, and knowingly create newly disabled beings.

Viloria’s account of being interviewed by 20/20 correspondents alongside a medical professional who endorses irreversible interventions also draws readers’ attention to another way in which medical professionals, perhaps inadvertently, admit to or recognize that these disabling procedures are for social, not medical, reasons. Viloria writes that the doctor is “condescending,” and in response to watching a clip of me saying how happy I am that I didn’t have a clitoral reduction surgery, he says he still thinks he could have helped me. Even better, when the interviewer asks him why he believes these surgeries are necessary despite what he’s heard from people who have experienced it and from me, he answers, ‘Society can’t accept people of different colors, and now we’re supposed to accept somebody with genitalia that don’t match what their gender is. I do not believe society is ready for it.’ […] I’m […] fascinated by how the doctor’s racism analogy reveals that social prejudice – not medical necessity – is what is truly at the heart of these procedures. It’s actually one of the most honest statements I’ve ever heard a doctor make about what we are subjected to. His analogy makes it easy to see why the practice is misguided; after all, would you ever say we should lighten the skin tone of people of color just so they’d be more acceptable to society?” (Viloria 2017: 193-194).

Viloria’s analysis of this doctor’s analogy is apt; it highlights the fact that some medical professionals understand that disabling interventions are for social reasons and are aware that intersex people testify to their harms yet continue to do so.

Furthermore, since medical professionals regard intersex people as disabled and knowingly “cripple” or (further) disable intersex people, intersex and disability scholarship and activism have good reason to align to combat coercive, unnecessary procedures intended to “cure” intersex people with (perceived) disabilities (see Spurgas 2009; Koyama 2006). Indeed, the term “hypospadias cripple,” is a means to open up a conversation about intersex-as-disability and the disabiling consequences of curative violence. In fact, “crip” or “cripple” could be

53 I address in Chapter 4, some bioethicists do in fact support using technologies to prevent the birth of people of colour as well as intersex, disabled, and queer people in the attempt to “spare” them from discrimination.
(re)claimed by some intersex people, if they so choose (see Shapiro 1994; Linton 1998; Kafer 2013; McRuer 2006; Peers 2015; Clare [1999] 2009).

**Conclusion: Disabling Practices: Medical Mistakes or Medical Malpractice?**

According to Adrienne Carmack, a urologic surgeon, most medical interventions performed on people with intersex variations have been mistakes:

> The approach by medical doctors to assign a gender, and then administer irreversible treatments to support that gender, is fundamentally flawed! No matter the original logic behind this treatment model, it is now apparent that in many cases it was a mistake [emphasis added]. Yet, surgeries are still being done based on what is thought to be the gender a child will relate to. (Carmack 2014: 67-68; also see G. Davis 2015a: 80).

Daniela Truffer’s doctor similarly conceptualizes the surgery performed on Truffer as a mistake:

> When I was two months old, and still in the hospital, doctors opened my abdomen and found healthy testes, which they threw in the garbage bin. According to my medical records, my parents had not provided consent. Further tests showed I am chromosomally male. Later the “castration” was declared a “mistake”: one doctor said I was a boy with hypospadas. As they had already removed the testes, however, they would have “to continue this way and the small patient must be made a girl.” (Truffer 2015: 111).

Are these procedures mistakes? Is “mistake” an appropriate or accurate characterization?

Considering these queries alongside the numerous testimonies explored in this chapter, intersex activism, and differentiating between mistake and maltreatment (Paget [1988] 2004), demonstrates that the disabling consequences cannot be construed as mistakes, no matter how good-intentioned initial interventions were. While all medical procedures have risks, the various disabling outcomes of medical interventions are unintended consequences; but, given that most of the procedures are medically unnecessary and performed on unconsenting infants and children, they constitute institutionalized medical malpractice, “medical abuses,” and, in some circumstances, sexual assault (Koyama 2003: 2). In other words, given the overwhelming
evidence that these procedures are harmful, the situation is not about “something we initiated went wrong” (Paget [1998] 2004: 12), but rather about that “something” is known to be violent, yet we continue to initiate it.

Paget explains that mistakes in medicine are inevitable and the fact that many medical mistakes are discovered retrospectively is unfortunate, sometimes even macabre ([1988] 2004). A quick look into past popular medical theories, diagnoses, procedures, and cures for various (perceived) illnesses, diseases, disorders, and disabilities demonstrates that medicine is precisely about learning from mistakes (Porter 1998; Claridge and Fabian 2005). Developing and espousing evidence-based medicine has been integral to avoiding many mistakes.54 Nevertheless, doctors still make mistakes. Mistakes are endemic to the practice of medicine. However, mistakes, unnecessary harm, medical malpractice, and recompense “are not identical issues” (Paget [1988] 2004: 8). Making a mistake is not the same as institutionalized, medical malpractice. A mistake is an adverse result of human error, a miscalculation of sorts. A doctor in conversation with Paget provides an example: a doctor unknowingly doubling the dose of a patient’s medication ([1988] 2004). Such a mistake could seriously harm a patient, cause death, and result in legal action, but it is not an example of institutionalized medical malpractice. Institutionalized medical malpractice or abuse is established, systemic discrimination, negligence, and/or denial of evidence which typically results in harmful, disabling, or poor medical care. Legal action can, in theory, also be taken to combat institutionalized malpractice.

The disabling procedures enacted on countless intersex people are not mistakes, they are institutionalized malpractice or “abuses” (Koyama 2003: 2) because: (1) for decades, intersex people and their advocates have clearly and unequivocally demonstrated that nonconsensual, 

54 For a timeline of the development of evidenced-based medicine see Jeffrey A. Claridge and Timothy C. Fabian (2005).
medically unnecessary procedures are harmful, disabling, and mutilating; (2) there is no evidence to suggest that nonconsensual, cosmetic treatments benefit intersex people or, in other words, “the medical treatment of intersex people remains devoid of evidence” (Carpenter in United Nations Human Rights 2017: n.p.); (3) for decades, NGOs as well as feminist, intersex, and queer studies scholars have urged medical professionals to cease such interventions because the evidence demonstrates that they are mutilating and tortuous; (4) medical professionals recognize and confront the “crippling” consequences of these procedures; and (5) despite all of these points, these practices continue. Systemically and systematically mutilating children and knowingly creating body-mind disabilities are not mistakes. These interventions are medical malpractices, not evidence-based medicine; they are instances of “curative violence” (Kim 2017).

Even though intersex people’s testimonies illustrate that these practices are medical malpractices, not all medical professionals can (or will) recognize intersex treatment as such. Not only do these doctors want to protect themselves, their careers, and the institutions they are a part of, their positionalities also can prevent them from fully recognizing the harm caused: “[i]nterpretation is a communicative relation” (Paget [1988] 2004: 11). Meaning, deciding if a medical practice is or is not harmful is an interpretative exchange (and sometimes a legal determination). Patients can claim a practice is harmful, disabling, and discriminatory – and evidence may even support that claim – but medical professionals may disagree and believe their practices are helpful, corrective, and curative. The medical maltreatment of intersex people is

55 Taking legal action against these practices is theoretically possible, but it is rare. As noted in a previous footnote, there is only one known legal case concerning a child subjected to surgery: Crawford v. Medical University Of South Carolina (2017; also see Albritton 2015; Baumgartner 2017; Tamar-Mattis 2015; Carpenter 2013b; Ghorayshi 2015, 2017; Marusic 2017; Readhead 2015; Koman 2015; Bennett-Smith 2015; Lambert 2017; “Intersex in the Courts” n.d.; Lambert 2017). Legal avenues are extremely costly and too time consuming for most people. Furthermore, I suspect many people not want to become embroiled in a long-term, possibly re/traumatizing and highly publicized legal battle.
often not recognized as such because according to many medical professionals, intersex is a disability, an “emergency” (Karkazis 2008: 96; G. Davis 2015a: 23; Gregorio 2017a: n.p.; Fausto-Sterling 2000b), that necessitates curative action. Framing intersex in this way allows doctors to “abandon medical ethics” (G. Davis 2015a: 23), thereby institutionalizing dyadism, able-bodiedness, and violent disabling practices. This discourse distorts or masks the harm caused. Consequently, medical professionals have been largely protected from mainstream criticism and legal action.

Doctors’ tremendous amounts of authority, power, and cultural capital also protects them from considerable criticism. “The problem is,” Viloria explains, “whenever intersex adults step forward to say they were harmed by these surgeries, doctors often respond that intersex people would have been worse off if they had been left as they were, and sadly, because of the social stigma against us is so strong, most people believe the physicians” (2017: 150). In addition to the stigma against people with intersex traits, medical professionals are typically regarded as all-knowing, god-like, truth-tellers. This expert reputation works to effectively silence intersex people who contradict “expert” claims (see Edwin 2009; L. Long in Arana 2005: 43; Cameron 2007; Chase 1999). Consider, Sean Wall’s experience meeting with the doctor who mutilated him. “The doctor had no regrets,” Wall explains: “he was very condescending. He [said] ‘you intersex activists don’t know what you’re talking about’” (in “What It’s Like To Be Intersex” 2015: n.p.; also see Viloria 2017: 194). This sort of exchange is not just a failed communication or an instance in which the trauma caused to Wall’s body-mind is denied or not recognized. This exchange is about power; it is about who has the power to tell “truths” (see van Heesch 2009). This doctor can easily exploit his position of power and claim authority over Wall’s body-mind, experiences, the theoretical futures he stole from Wall, as well as the entire intersex community.
Controverting the fact that intersex people (as well as other marginalized people such as people with disabilities, fat individuals, women, LGBTQ folks, and people of colour) have authority over their body-minds, experiences, identities, and futures has been and continues to be an enormous hindrance to rectifying institutionalized medical malpractices (see Grabham 2007; Beasley and Bacchi 2005; Bonham 2001; B. Hughes 2000).

In addition to being “medical abuses” (Koyama 2003: 2), various medical practices and procedures outlined in this chapter constitute “ritualistic sexual abuse of children” (Koyama 2003: 2; also see Driver in Arana 2005; Arana 2005; Astorino 2010; T. Alexander 1997; Schützmann et al. 2009; Tosh 2013; Guillot, Bauer, and Truffer 2016). Koyama explicates:

Adult intersex people’s stories often resemble that of those who survived childhood sexual abuse: trust violation, lack of honest communication, punishment for asking questions or telling the truth, etc. In some cases, intersex people’s experiences are exactly like those of child sexual abuse survivors: when they surgically “create” a vagina on a child, the parent – usually the mother – is required to “dilate” the vagina with hard instruments every day for months in order to ensure that the vagina won’t close off again. (Koyama 2003: 2).

Medical practices like dilating a child with a medical dildo-like device are not simply like sexual abuse, they are “institutionalized sexual abuse” (Driver in Arana 2005: 31; also see Guillot, Bauer, and Truffer 2016). Taking the idea that medical professionals have systematically sexually assaulted intersex people seriously, Schützmann et al. (2009) conducted a study. Highlighting the fact that intersex people and women who have endured sexual abuse both report being touched and examined against their will, they compared and contrasted the mental health of intersex people and women who have experienced abuse. They report that both groups of people exhibit similar self-destructive behaviours and mental health disabilities (e.g. depression and anxiety).
In acknowledging that various “treatments” and practices are sexual abuses, it is important to remember that intersex people are construed as disabled by medical professionals and draw attention to the fact that people with disabilities – children and adults – are at increased risk of being subjected to sexual assault and chronic sexual abuse (Sobsey and Doe 1991; Kvam 2008; Gorey and Leslie 1997; Putnam 2003). Some studies estimate that children with disabilities are at a 2-3 times greater risk of being sexually abused than children without disabilities (Kvam 2008; Gorey and Leslie 1997). Children with disabilities are particularly vulnerable to abuse because, for example, they are dependent on others, they may be institutionalized, and they are often in literally and metaphorically vulnerable positions in medical(izing) settings (Putnam 2003). Hence, many offenses are committed by health and service providers and occur in medical contexts. Such abuses are infrequently reported and seldom result in conviction. In fact, sexual abuse is rarely even recognized as sexual abuse unless it is “quite obvious” (Kvam 2008: 1073). Abuse is often not “quite obvious” because children with disabilities are not seen as credible sources, they may not have access to certain discourses to express their experiences, they may have troubles effectively communicating to adults, and/or, as is the case with intersex children, the medical protocol or prescription is the act of sexual assault. That is, dilating a child so a prospective penis will be able to fit inside of said child is not seen as sexual abuse because it is narrated as medical care, as a medical necessity.

The culture of silence, abuse, shame, and unquestioned medical authority surrounding intersex is changing because of the Intersex Rights Movement and growing mainstream media attention. Carpenter describes: there is “a global and decentralized intersex movement” that engages with “local, national, and international human rights systems” which has resulted in a number of wins which included the development of new legal attributes that better capture our [intersex people] experiences and Malta was the first country to
protect people from discrimination on the grounds of sex characteristics [i.e. Malta outlawed intersex genital mutilation]. UN treaty bodies have condemned human rights violations in medical settings as harmful practices. Major challenges remain [...]. Human rights violations persist, deeply imbedded in [...] a deliberate history of silencing. (Carpenter at UN Human Rights 2017: n.p.).

All of the intersex human rights violations and the disabling consequences will continue and continue to haunt, however, as long as medical professionals retain the status of all-knowing infallible experts (see Edwin 2009).

Altering the expert status of medical professionals – recognizing that intersex people are the predominant authorities on intersex and their own experiences, desires, and needs – and changing the medical response to and construction of intersex (and disability) – no longer relying on unethical, unsubstantiated, and disabling notions of “care” – are the shifts that the testimonies accounted for in this chapter require. Framing the institutionalized abuses and malpractices as violently disabling intersex people’s body-minds provides another means to justify and institute these changes. Shifting the discourse to “curative violence” (Kim 2017) and “body-mind disabilities” also holds doctors accountable in a new way. I am not suggesting that discourses of mutilation and torture, for example, are inaccurate or should be done away with. I think these narratives can be complemented by the discourses of created disabilities and “curative violence” (Kim 2017) because claims of mutilation and torture are easier for authoritative doctors to dispute. Claims to mutilation and torture seem and are discredited as sensationalized (see Chase 1998b). While incorrect, the general sentiment in the Global North is that genital mutilation happens “over there” not “over here” (Chase 1998b). The Global North “cures” and “heals;” the Global North does not mutilate and disable. Naming the practice “curative violence” and explicitly framing the consequences as disabling may, in certain circumstances, better highlight the paradox: in an effort to fix, cure, and enable the apparently disabled, diseased, or disordered
intersex person – in an effort to exorcise the intersex phantasm – medical professionals violently create newly disabled beings. The very institution that claims to cure, heal, and safeguard people contributes to creating disabled intersex subjects and experiences. Ultimately, considering the outcomes of curative mutilation as disabling underlines that an intersex politic rooted in disability is imperative moving forward.
Chapter 3

The Racialized Intersex Spectre: Sex and Dis/ability Segregation in Sport

What makes a lady? Does it mean if you’re wearing skirts and dresses you’re a lady? No. What kind of a lady is that? Yeah I’m a lady. There’s nothing I can say, yes, I’m a lady. I have those cards of being a lady. (Caster Semenya in Ginnane, dir. 2011)

Introduction


The idea that intersex haunts non-intersex individuals, however, is arguably a rather unnecessarily emphatic proposal. In fact, it is potentially politically dangerous. As I outline in more detail below, when I speak of intersex here, my conceptualization is not identity based. I claim that the possibility of having anatomical traits categorized as intersex – the possibility of being subjected to “the process of intersexualization” (Eckert 2009: 64) – haunts all people, but I do not argue that everyone should claim intersex as an identity. Rather, I come from a place that challenges the notion of essential, distinct body-mind classifications and recognizes that theorizing about the precariousness of embodiments (and identities) remains politically and
personally useful insofar as doing so can be liberatory (McRuer 2006; Butler [1993] 2011; C. Davis 2005, 2007; Clare [1999] 2009; Woltersdorff 2011). This sort of theorizing enables us to un/do, perform, and think of new modes of relating, organizing, and becoming different gendered, sexed, dis/abled, queer, and racialized subjects. In some ways, I am echoing Robert McRuer’s statement that it is theoretically and politically “important to raise issues about what it means, for the purposes of solidarity, to come out as something you are – at least in some ways – not” (2006: 57).

As noted in previous chapters, intersex always “haunts” intersex people, often alongside or in the form of disabilities, even if they were surgically and/or hormonally altered (O’Rourke and Giffney 2009; Spurgas 2009). The intersex “phantasm” (Holmes 2002: 175) always threatens to resurface; the intersex body-mind is always contested and, therefore, is routinely surveilled and managed (Roen 2009; Butler [1993] 2011; Spurgas 2009). Expanding on this claim, I illustrate that the spectre does not haunt just pre-/post-operative or hormonally inscribed intersex individuals. The fact that one can discover one has intersex traits at any stage in one’s life suggests that the phantasm haunts us all. One can be subjected to “intersexualization” (Eckert 2009: 64) and medicalization at any point throughout one’s life. Intersex is an elusive, queering, cripping ghost. Our body-minds are not objectively or definitively sexed or dis/ordered (Fausto-Sterling 2000a, 2000b; Karkazis 2008; van Dijck 2005). “What you are and what you are not,” what you think you are or will become, and what you think you are not and will not become, “[fold] into each other” (McRuer 2006: 71). The spectre is not and cannot be contained; everyone is always and already contested. People who seem to embody compulsory dyadism are merely temporarily seemingly embodying said mandate.
That being said, it is vital to examine the historical and cultural construction and representation of intersex (Magubane 2014; Reis 2005, 2009; Dreger 1999; Kessler 1998) and take stock of how and why intersex is imagined to haunt certain people and nations more than others in order to understand, deconstruct, and resist the inequitable power relations involved in the maintenance of interphobia and other forms of oppression. Tracking sex testing in sport, but more specifically who is tested and publicized as hiding the spectre, is one way to deconstruct and resist these power relations. Moreover, as Viloria rightly notes, sport sex testing practices remind intersex studies scholars, intersex activists, and advocates that intersex issues will not be over once infant intersex mutilation ends (2017: 230). Interphobia manifests in numerous ways. As a result, this chapter attends to the controversy around sex testing athletes.

If intersex haunts all people it apparently does not haunt all people equally. The ongoing institutional and mainstream media focus on and fascination with alleged intersex athletes suggests that the broader cultural imaginary assumes and represents intersex as overwhelmingly haunting elite athletes. However, Zine Magubane reminds, feminist scholars must:

[look] more closely at the intersection of race and nation in the production and reproduction of intersex bodies [...] because [...] the lack of attention that feminist scholars have given to the role of race and nation in determining which bodies are marked as intersex and what is done about those bodies means that they have missed an important opportunity to understand the role of race and nation in the production of what Jennifer Germon (2009) calls “ontological gender.” (Magubane 2014: 761-762).

Scholars concerned with intersex issues and compulsory dyadism must analyze and historicize the role race and nation have played and continue to play in the cultural production of sexual “ambiguity,” intersex, Disorders of Sexual Development (DSD), or, in O’Rourke and Giffney terms, “hauntological” gender (2009: x). In doing so, I identify that the phantom is currently represented as haunting female athletes of colour from colonized nations in the Global South,
most notably Caster Semenya (1991-) from South Africa, but also Santhi Soundarajan (1981-) from India, Pinki Pramanik (1986-) from India, Francine Niyonsaba (1993-) from Burundi, Margaret Wambui (1995-) from Kenya, and Dutee Chand (1996-) from India.56 And, as the literal and/or symbolic violence enacted on these women suggests, they haunt and deceive the apparently honest and fair athletic world. The idea that these women deceive the sports community is a contemporary iteration of the old trope that “hermaphrodites” are “deliberately deceptive or shady character[s]” (Reis 2005: 412; also see Reis 2009). Rather than mislead or seek an unfair advantage, these athletes simply want and deserve to compete without violent commentary and invasive body-mind intervention.

Adding to Magubane’s call for a more intersectional and historical analysis of intersex and how the construction of sexual “ambiguity” relates to current sex testing practices, I push this intersectional analysis further and consider the role dis/ability plays in the discursive construction of intersex surrounding sex testing protocol. Centering disability in a discussion of elite sport may appear strange because Olympians and racialized people are generally read as hyper-able (see Entine 2000; Hoberman 1997). However, according to medical professionals and sport governing bodies, intersex is a disorder, disability, or disease (Holmes 2008; G. Davis 2015a; Mitra 2014a). Analyzing sex testing and the presumed hyper-ability of Olympians and racialized individuals through a disability framework reveals that intersex and the embodied

56 As far as I can tell, Wambui and Niyonsaba have not been forced to undergo sport sex testing. Questions of Niyonsaba and Wambui’s sex and accusations that they are men, intersex, or hermaphrodites float around public media forums (see Gugala 2016; Blatchford 2016). These accusations have increased since Niyonsaba won silver and Wambui won bronze in the 800m race at the 2016 Olympics (see J. Parker 2016; Blatchford 2016). Pramanik’s sex accusations and testing arose in 2012 after she was accused of raping a woman (Mitra 2014a). Moreover, while many scholars and journalists assume and impose intersex and DSD on these women, none of the athletes listed above have publically claimed intersex or DSD. Respecting these women’s narratives and identities is important whilst acknowledging the interphobic, racist, and sexist violence they experience. As I discuss below, imposing identity or diagnostic categories on these athletes is a colonial act.
effects of intersex are constructed differently depending on who is presumed to be intersex, what
that person looks like and is capable of doing, and where that individual performs.

To tease out and historicize these intersections and complexities, I must begin this
chapter by elaborating on my claim that intersex haunts all people. Once I do so, I map the
history of sport sex testing and identify who, when, and which nations have been
overwhelmingly understood as hiding the spectre and subjected to sex tests. Even though the
intersex spectre is indiscriminate, the ghost is represented as haunting certain people and nations
depending on the broader cultural climate. I determine, presently, the phantom is represented as
haunting women athletes of colour from the Global South. Hence, sexism, interphobia, racism,
colonialism, and imperialism converge on these women and, further, these discriminatory models
are institutionalized by sport legislation. Ultimately, I argue, sex testing has been and is used as a
political tool and, currently, it functions as a colonial tool.

Coming to this conclusion, I then explore the reasons put forth by sport governing bodies
for sex testing and emphasize that the ideologies underpinning these reasons are discriminatory
and scientifically unfounded. Since these discriminatory beliefs are the scaffolding that upholds
this practice, sport must be decolonized (Appadurai 2015; Hayhurst 2014; Hern 2013; Darby
2002, 2017; Malcolm and Waldman 2017; Darnell and Hayhurst 2011; Nauright 2013; Bale
2002). We must deconstruct this framework. A means to this end is exploring sport sex
desegregation. Next, given that intersex people are deemed disordered or disabled, I analyze
sport sex testing through a disability studies lens and consider sport dis/ability segregation. By
synthesizing relevant literatures on intersex, disabled, and racialized people in/outside of sport, I
identify a discrepancy: intersex is pathologized and defined as a disorder or disability by medical
professionals in and outside of sport contexts, but in the context of sport, intersex traits are
represented as an advantage whereas outside of sport they are represented as inherent, disordered lack. Identifying this contradiction and discursive shift opens up a conversation about how, when, and why the supposed effects of intersex/disability change. Once this contradiction is identified and untangled, I explore how the supposed hyper-able, or, perhaps, “supercrip” (Clare [1999] 2009; K. Hall 2011) suspect intersex athlete undermines medicalizing and ableist assumptions about intersex-as-lack and disorder-as-lack. While critics of sex testing have proposed sex testing and sex segregated sport creates a false and oppressive binary that primarily negatively affects women, trans individuals, and people with intersex traits, considering disability within the context of sport opens up a conversation about the presumably justified dis/ability segregation and Olympic/Paralympic binary in sport (Peers 2009; Goggin and Newell 2000; Heilpern 2016; “Has disability sport lost” 2015; D. Rose 2012). In opening up this conversation, I highlight that sport is not as sex or dis/ability segregated as it is presumed to be.

Teasing out how disability and disorder center in this conversation about intersex athletes allows me to place the maltreatment and exclusion of (disabled) intersex people and people with disabilities in sport on the same continuum. Theorizing intersex and disability together in this context provides us with the opportunity to reimagine sport policies and the organization of sport by complicating the relationship between disability and (inter)sex and further blurring the line of Olympian and Paralympian. The line between Olympian and Paralympian is already blurring, at least in part, because of the controversy surrounding Oscar Pistorius competing as an Olympian.57 Alison Kafer elucidates: “This distinction between disabled people and ‘ordinary’

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57 It must be noted that Pistorius was charged with murdering his girlfriend, Reeva Steenkamp, in 2014. He was deemed not guilty of murder, but guilty of the culpable homicide of Steenkamp as well as reckless endangerment with a firearm. His sentence was three years in prison. After just a year in prison, it was decided that Pistorius would serve out the rest of his sentence under house arrest. During this time, the prosecutors appealed the conviction. The Supreme Court overturned the ruling in December 2015 and Pistorius was found guilty of murder. He was sentenced to six years in prison. In November 2017, his sentence increased to thirteen years and five months.
people surfaces in the raft of news stories covering Oscar Pistorius’s attempt to compete alongside nondisabled runners in the 2008 summer Olympics” (2013: 108). He became the first double-amputee athlete to compete at the Olympics in 2012. (Suspect) intersex Olympians further blur this distinction because intersex is construed as a disorder or disability by medical professionals. Hence, (suspect) intersex athletes call us to reconsider what (perceived) disorders and disabilities qualifies one as Olympian or Paralympian. By critically analyzing the narratives that surround disordered intersex and disabled individuals’ body-minds, I reveal dubious ways discourses about disability, disorder, and intersex shift from disadvantaged, pitiable, lack to unfairly advantaged, cheat, cyborg when disability, disorder, and/or intersex are attached to athletes. In identifying this shift, I prove that sport can never successfully be organized around sex and dis/ability binaries because people do not fit into dichotomous categories or fully embody compulsory ways of being. Moreover, the attempt to segregate sport remarginalizes and restigmatizes the most marginal groups: women, intersex people, trans individuals, people with disabilities, people of colour, and individuals from colonized nations. I conclude this chapter by emphasizing that anti-ableist, anti-colonial, and anti-interphobic analyses show us that sport segregation is not the only organizational model. We have the potential and tools to decolonize sport (Appadurai 2015; Hayhurst 2014; Hern 2013; Darby 2002, 2017; Malcolm and Waldman 2017; Darnell and Hayhurst 2011; Nauright 2013; Bale 2002) which can lead to the eradication of myriad forms of discrimination and create new possible worlds where spectres knowingly and welcomingly haunt.
Intersex Haunts Ostensible Dyads

As briefly noted above, seemingly universalizing intersex – claiming that intersex haunts non-intersex people – is potentially politically dangerous. I do not support all people claiming they are intersex or assuming they are intersex. Further, when I speak of intersex here, my conceptualization is not identity based. I claim that the possibility of having intersex anatomy haunts all people, but I do not argue that everyone should claim intersex as an identity. I also do not maintain people with intersex traits must identify as intersex. Indeed, many people with intersex variations do not identify with/as intersex (Viloria 2017; G. Davis 2015a). I celebrate intersex identity and identification, yet I acknowledge that claiming an identity (or embodiment) is a personal choice. However, doing so is also not merely a personal choice. Un/welcomed identities are imposed on all of us and claiming an identity is an ethically complicated decision (Mollow and McRuer 2012; Linton 1998). Doing so requires accountability and a critical examination of the social, material, historical, and political power relations that mold the identity. It requires examining the experiences, political movement, and embodiments associated with the identity in question. One need not look beyond the controversy surrounding Rachel Dolezal’s transracial identity claim (see A. Jones 2015; Attakora-Gyan 2015; Tuvel 2017; Singal 2017; Thomsen 2016a) or the emerging conversation about seemingly dyadic people identifying as intersex (see Viloria 2017) to understand my point. Nevertheless, these conversations about the precariousness of body-minds, classification systems, and identities help us imagine and construct new, less oppressive worlds.

Exploring the idea that people are temporarily non-intersex and only ostensibly embody compulsory dyadism is perhaps troubling and potentially risky. However, I think doing so is worth the risk because it helps me move away from dichotomous reasoning. The language of
hauntology is particularly helpful here. The language enables me to demonstrate how intersex, like gender (Butler [1990] 2006), moves through time and space. Who we think is or is not intersex is, and always has been, complicated and contested (Dreger 1999; Reis 2005, 2009; Magubane 2001, 2014). Employing the discourse of hauntology is not intended to diminish or ignore people’s lived experiences of interphobia by only functioning within the theoretical realm. Although I employ the language to highlight that all body-minds are contested, I also, and arguably more importantly, use hauntology to highlight how interphobic violence and compulsory dyadism circulates.

The fact that one can discover one has intersex traits at any stage in one’s life suggests that the phantasm haunts all seemingly non-intersex people:

Though we speak of intersex as an inborn condition, intersex anatomy doesn’t always show up at birth. Sometimes a person isn’t found to have intersex anatomy until she or he reaches the age of puberty, or finds himself an infertile adult, or dies of old age and is autopsied. Some people live and die with intersex anatomy without anyone (including themselves) ever knowing. (“What is intersex?” n.d.: n.p.).

For those who have not been medically diagnosed, subjected to nonconsensual HRT, medical displays, and genital mutilation, for those who do not know they were diagnosed and were lied to by medical professionals and family members, for those who (will) learn something new about their anatomical attributes later in life – for all people – intersex is a ghost that is “neither present nor absent, neither dead nor alive” (C. Davis 2005: 373). There are countless testimonies of medical professionals withholding diagnoses and lying to people about their intersex traits, what was done to their anatomy, and why it was done (Chapter 2; G. Davis 2013, 2015a, 2015b; Holmes 2008; Holmes ed. 2009; Kessler 1998; Dreger ed. 1999; Pagonis 2015; Garcia 2015;

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58 This excerpt is from Intersex Society of North America. ISNA closed its doors in 2008 after the advent of Accord Alliance (G. Davis 2015a). For other intersex organizations and resources see “Intersex Links” provided by Organization Intersex International: United States (n.d.).
Quinn 2015; Truffer 2015; Zieselman 2015; Anick in Strudwick 2017). For example, Karen A. Walsh writes,

Truthful disclosure didn’t come to me about my biology and what was done to me as an infant until I was 33, when I forced the issue by removing my medical records from my endocrinologist’s office. I learned that there was never full disclosure to my parents either, and therefore there was no informed consent for the “corrective” surgeries performed on me as an infant. My parents were only told that their little girl would get cancer and would not have a normal development as a girl unless her “deformed ovaries” were removed, and that they should never discuss these problems with me. Thus, after having presented with an inguinal hernia and having exploratory surgery at the age of 16 months, my intra-abdominal testes were removed in a second surgery two months later. I was pronounced a “male pseudohermaphrodite,” a diagnosis that was shared neither with my parents or me. (K. Walsh 2015: 120).

Like Walsh, many other people discover they have/had intersex characteristics later in life, a discovery that often contextualizes medical trauma and body-mind disabilities (Chapter 2; G. Davis 2013, 2015a, 2015b; Holmes 2008; Kessler 1998; Dreger ed. 1999; Pagonis 2015; Garcia 2015; Quinn 2015; Truffer 2015; Zieselman 2015).

Some people, however, who discover they have intersex traits have different experiences. Consider the thirty-seven-year-old “ordinary bloke,” Rob (a pseudonym), who found out, after undergoing cancer screening, that he, as described in the National Post, has a “full set of female reproductive organs” (Sawer 2015: n.p.). “‘Ordinary bloke’ prepares for hysterectomy after doctors discover womb during bladder cancer test,” Patrick Sawer reports (2015: n.p.). Understandably, this discovery was shocking to the apparently “ordinary businessman” (Sawer 2015: n.p.), the “regular red-blooded guy” (Rob. qtd. by McDermott 2015: n.p.). Rob explains:

the diagnosis came as a bombshell. I’ve never seen myself as anything but an ordinary bloke who has a normal sex life. I was shocked when the consultant said I had a fully functioning set of women’s reproductive organs, and I was even having periods. It appears I could even potentially get pregnant. But I’ve been told by the doctors I’ll be having a hysterectomy in the next few weeks. Bizarrely, that could lead to menopause. (Rob qtd. by Sawer 2015: n.p.).
Indeed, Rob was not as “normal” as he thought. He houses a ghost that will be cast out via a hysterectomy. Whether or not the procedure is medically necessary, however, is not really explained. Nevertheless, Rob clarifies elsewhere that he wants to undergo the operation: “it appears I could get pregnant. But much as I would like a baby, getting pregnant would feel too weird. Instead I hope that getting the female reproductive removed [sic] will improve the quality of my own sperm and I have a baby as a man” (Smith-Squire 2015: n.p.).

Rob’s experience reminds: intersex is an elusive queering, crippling ghost that tells us our body-minds are not transparently, objectively, or definitively sexed or dis/ordered (see Fausto-Sterling 2000a, 2000b; Karkazis 2008; van Dijck 2005). Employing McRuer’s language, “what you are and what you are not,” what you think you are or will become, and what you think you are not and will not become, “[fold] into each other” (2006: 71). There is no sexed, gendered, or body-mind category, no geographical border, that contains the spectre. We are all always already contested inter/sexed, dis/ordered, dis/abled non-/citizens. As a result, people with supposed non-intersex anatomies – people who apparently embody compulsory dyadism – are only ever temporarily evading pathologization, enfreakment, “intersexualization” (Eckert 2009: 41), and “intersex citizenship” (Grabham 2007: 29).

My argument echoes Morgan Holmes’ claim: “In a sense, ‘intersexuality’ is nothing more than a perpetually shifting phantasm in the collective psyche of medicine and culture” (2002: 175). Holmes continues, “[w]hen we appreciate that the difference

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59 This case was recounted in and circulated by many online magazines and newspapers, including Cosmopolitan (R. Rose 2015), The Sun (McDermott 2015), The Voice (“Man Born With Womb” 2015), and others (Smith-Squire 2015; “Shocked’ businessman” 2015). Rob’s experience is represented as unnatural, freaky, and even funny. For example, the article about Rob’s experience featured in Cosmopolitan is accompanied by an image from the 1994 romantic comedy, Junior (Reitman dir. 1994), depicting Larry Arbogast (Danny DeVito) rubbing Alex Hesse’s (Arnold Schwarzenegger) pregnant stomach. Rob is effectively enfreaked. He is deemed a freakish, comedic, “Wonder womb man,” as The Sun describes him in tradition side-show style (McDermott 2015: n.p.).
between intersex and not intersexed can be only millimetres it seems clear that no one is truly intersex, but we are all, in our infinite differences from each other, intersexed” (2002: 175; also see Kessler 1998). When we appreciate that one can go decades, even an entire lifetime, without knowing one has intersex traits and is presumably “normal,” it seems clear that no one is truly intersex, dyadic, or normal, “but we are all, in our infinite differences from each other, intersexed,” not normal (2002: 175). Abnormality, intersex, and dyadic embodiments are perpetually shifting discursive phantasms attached to certain people’s body-minds.

Indeed, what “counts” as intersex anatomy is, and has historically been, hotly contested (Kessler 1998; Dreger 1999). This point is illustrated by the now closed ISNA’s response to the query, how common do intersex traits manifest?:

[t]o answer this question in an uncontroversial way, you’d have to first get everyone to agree on what counts as intersex – and also to agree on what should count as strictly male or strictly female. That’s hard to do. How small does a penis have to be before it counts as intersex? Do you count “sex chromosome” anomalies as intersex if there’s no apparent external sexual ambiguity? (“How common is Intersex” n.d.: n.p.).

Similarly explained by Viloria through a more identitarian lens,

there has always been confusion and debate over which variations should be considered intersex. For example, there’s a variation called Mayer-Rokitansky-Küster-Hauser syndrome, or MRKH, in which people are born with bodies that look typically female but have a small or absent uterus and a short or absent vagina. I had wondered whether these people should be considered intersex, or would they want to be, and I learned that most of them didn’t because they identified as women. Conversely, I learned that there are people who don’t [emphasis in the original] have visibly androgynous sex anatomy and do [emphasis in the original] consider themselves intersex. [...] So yes, it’s confusing trying to figure out who and what is intersex, but to me, that’s okay. (Viloria 2017: 204).

The apparently distinct category “intersex” breaks down when one scrutinizes what characteristics count as intersex, female, and male (Fausto-Sterling 2000b). Trying to contain
these leaky categories in an indisputable or unproblematic way is impossible; yet, many scholars and medical professionals continue to draw (inconsistent) ideological, literal, and statistical lines between intersex and normate (Kessler 1998; Dreger 1998a, 1998b; Fausto-Sterling 2000a, 2000b). We cannot draw these lines because people’s anatomies are, as Holmes eloquently put it, infinitely different. And, moreover, we cannot draw these lines because biological sex is a social construction wherein gender subsumes sex (Butler [1990] 2006, [1993] 2011, 2004). Therefore, who is (not) classified as intersex can and does vary depending on who is looking and what ideologies inform the gaze. Suzanne Kessler explains: “[h]ow hard one looks at genitals and what one ‘sees,’” or does not “see,” “is not constrained by the optic nerve but by ideology” (1998: 44-5). Or in Sara Ahmed’s terms (2006), what we perceive depends on how we are orientated (also see Orr and Watson forthcoming). The very instability of the category demonstrates, intersex as identity and biological category “is a historical and cultural construction rather than a simple biological phenomenon” (Holmes 2002: 175; also see Viloria 2017; G. Davis 2015a; Warnke 2011; Fausto-Sterling 2000b; Vigneault 2011).

Like many seemingly timeless and universal categories, such as homosexuality and heterosexuality and blackness and whiteness (Katz [1995] 2007; Foucault [1978] 1990; Somerville 2000; Laqueur 1992; Wahrman 2004; Magubane 2001; Padgug 1979), intersex and Disorders of Sex Development (DSD) are relatively recent, historically situated biological, diagnostic, and/or identity categories. The terms “intersex” and “intersexuality” are just barely one hundred years old (see Goldschmidt 1917, 1938) and DSD nomenclature was instituted just over a decade ago (G. Davis 2015b; Greenberg 2012b; Viloria 2017; Karkazis 2008).

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60 It is also crucial to note, as I explain in more detail below, time and place in which these observations are made have an impact on these evaluations. For example, it is probable that intersex births are reported or “seen” more frequently in places where pregnancies are monitored by medical professionals closely, where people tend to give birth in hospitals rather than, for example, in the home, and in locations where the criteria of what constitutes male and female anatomy is very strict.
The intersex spectre haunts all people. Nevertheless, the spectre is not represented as such.

Looking towards sport policies, particularly sex testing, as I do for the remainder of this chapter, clearly highlights this representational discrepancy. During the Cold War, female athletes from the Soviet Union – most notably, Polish sprinter Ewa Klobukowska (1946-) – were not just accused of doping, but they were also sex suspect. These athletes, including Klobukowska, were often publicly disqualified from competitions, information about their sexual anatomies was leaked to the media, and, as a result, these women were slandered by the press (Pieper 2014, 2016; Wackwitz 1996, 2003). They were presented as doping, masculine cheats and gender-deceiving freaks: steroid “Übermenschen” and “ball-bearing females” (Beamish and Wagg 2007: 11). And “suddenly they were not women any more, nor were they considered men” (Martínez-Patiño et al. 2010: 315). For example, Neil Allen, the Times’ Athletic Correspondent at the time, reported that Klobukowska was disqualified from the European Cup in Kiev because she “failed a sex determination test for women’s athletics” (1967b: 5; also see N. Allen 1967a). Even decades later, Klobukowska’s sex is discussed and shamed in the media. In the news article, “Girls will be girls at Olympics – sex tests will prove it,” published in 2008 before the Beijing Olympics, Jane Maccartney and Hattie Garlick discuss “[s]uspicious-looking female athletes” and note, “Klobukowska [...] was the first athlete to be unmasked as a man when she failed an early form of chromosome test in 1967” (2008: 35). After Klobukowska was forced to retire and was publicly defamed, she experienced severe depression, broke off contact with the sports world, and decided to undergo surgery and HRT “to reassess her sex as woman” (Martínez-Patiño et al. 2010: 315; also see Carlson 2005).
In addition to slandering individual women, the media exploited (inter)sex speculation to disparage communism and Soviet conceptions of femininity that did not reflect America’s investment in capitalism and American notions of femininity, namely, the idea that women belong in the home and are innately quieter, weaker, smaller, and less muscular than men (Pieper 2014, 2016; Cole 2000). That is, sex testing was used as a political tool of war to further stoke anxieties and fear around communism and as a political tool to “naturalize” traditional gender roles. Sex testing alleged “ball-bearing” (Beamish and Wagg 2007: 11) Soviet women, Rob Beamish and Stephen Wagg clarify, bolstered American images “of normalized gender and sex roles [...], centering heterosexuality, the nuclear family, and ‘gender-appropriate,’ ‘biologically natural’ behaviour” (2007: 19). In other words, America’s “super-heterosexualized Cold War family ideal was used as a ‘psychological fortress’ against the fear of communist aggression” (2007: 19). Targeting Soviet women for sex testing was means to protect and strengthen the psychological fortresses around traditional American gender roles, anti-communist ideals, and capitalism.

After the collapse of the Soviet Union, similar to Soviet women athletes, women athletes from the People’s Republic of China excelled in international track and field and became suspect. These women were deemed fraudulent and unnatural (Pieper 2014, 2016; Plymire 1999). Lindsay Parks Pieper explains this shift:

with the collapse of the Soviet Union in 1991, the divisions between Cold-War-East and Cold-War-West somewhat dissipated. The People’s Republic of China, however, emerged as a new global enterprise that challenged countries of the geographic-West. China’s increased economic authority and improved international influence created new political and geographic tensions. This threat extended into sport as Chinese teams achieved unprecedented success and dominated international competition. Tellingly, the Chinese female athletes emerged in the 1990s as the new “other.” (Pieper 2014: 1560).
China’s growing economic power (Xuetong 2006) threatened the West and, since it was a communist nation, China was easily rendered suspect in the Western imaginary. Sex testing supposedly gender deceiving Chinese women athletes was a way in which Western forces could exploit communist anxieties in the attempt to destabilize China’s emerging economic power whilst also restabilizing the sex and gender binaries. The destabilizing project succeed in establishing Chinese women athletes “as the racial and gendered ‘other’ in the realm of sport” (Pieper 2016: 168).

This gender/sex fraudulence anxiety extended to other racialized Eastern women athletes (Pieper 2014: 1566). For example, at the:

1990 Asian Games held in Beijing, an Indian female hockey player was reportedly expelled after failing the requisite gender verification test. Three years later, during the South East Asian Games, four women experienced similar expulsion. Kong Chuan, head of the Games’ medical committee, reported that the discoveries not only resulted in the immediate removal of the athletes, but that two women “did not know they were not females until they were told.” (Pieper 2014: 1566).

Put simply, the intersex spectre was imagined as residing in racialized, Asian women along geographic-Eastern borders soon after the Soviet collapse because of the economic and political threat the East posed.

Mapping these shifts illustrate that anxieties about gender roles and sex always shift and expand with changes in economic and political uncertainties. And, these anxieties continue to manifest in new ways in sport. Today, the intersex spectre is predominantly imagined as residing in women athletes of colour from colonized nations in the Global South. In particular, women of colour from Africa and India – Caster Semenya (1991-) from South Africa, Santhi Soundarajan (1981-) from India, Pinki Pramanik (1986-) from India, Francine Niyonsaba (1993-) from Burundi, Margaret Wambui (1995-) from Kenya, and Dutee Chand (1996-) from India – have
been targeted, rendered suspect intersex, subjected to sex testing, and publicly slandered.

Payoshni Mitra, a gender studies researcher, activist, and intersex athlete advocate, confirms: “athletes from developing nations are targeted” for sex testing (2014b: n.p.; also see G. Davis 2015a: 152; Karkazis 2016b).

Soundarajan was tested after winning silver at the Doha Asian Games in 2006. The fact that she “failed” the test became public knowledge. The silver medal she won at those Games was taken away from her and remains withheld. Semenya was tested in 2009 after her victory at the Berlin Games. She was banned from sport for about a year. Her test results were not officially made public but numerous news sources, such as UK’s The Telegraph (S. Hart 2009), New York’s The Daily Telegraph (Hurst 2009), and Sydney’s Daily News (Yaniv 2009), claim to know intimate details of her biology (Viloria 2017). Questions of Semenya’s sex remained in the news when she won silver at the 2012 Olympics. Her sex was also questioned when she married long-time girlfriend, Violet Raseboya. Semenya’s apparently innate masculinity or intersex anatomy was supposedly confirmed by her lesbian relationship and wedding negotiations. As Stephen Green comments, calling into question Semenya’s sex, gender, sexuality, and marriage to Raseboya:

The story gets murkier. [...] Semenya ‘married’ a woman [...] Semenya and her/his long-time girlfriend, Violet Raseboya, held a ceremony in Ga-Dikgale in the Capricorn district of Limpopo. [...] Semenya, 24, sent her parents to Raseboya’s family in Polokwane to negotiate lobola (dowry). An insider revealed at the time both families were happy to negotiate lobola, with Semenya’s family paying R25,000 [...] Dowry in Africa is paid by the man’s family to the women’s. That fits, because sadly, Caster Semenya, you are not a woman. (S. Green 2016: n.p.).

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61 Chand’s case, outlined below, is arguably the most noteworthy because a crucial policy concerning intersex characteristics was suspended. Yet, Semenya has garnered the most attention in Western media and scholarship and she has become a, albeit contested, household name.
Semenya’s sex continued to concern the public as she was on track to compete in the Rio de Janeiro 2016 Olympics. “Even now,” Katrina Karkazis notes before the Games, “six years on, as she prepares for Rio, nearly every report on Semenya’s race times doggedly refers to this [sex test] investigation” (2016a: n.p). After she won gold for the 800m at the Rio Games, the media continued to question and slander her (Karkazis 2016a, 2016b).

In 2014, in line with International Olympic Committee (IOC) and International Association of Athletic Federations (IAAF) regulations, Chand was dropped from the Commonwealth Games because she “failed” a sex test. The test became public knowledge and she was banned from sport. The Indian government appealed to the Court of Arbitration for Sport (CAS) to contest Chand’s exclusion and a long case between Chand and the IAAF ensued. In July 2015, CAS suspended the rules that exclude intersex athletes, specifically women with the intersex variation (or DSD) hyperandrogenism, which is characterized by naturally high levels of androgens. The androgen testosterone is of primary concern to sport policy makers. CAS provided the IAAF two years to submit evidence to justify excluding these women athletes. The final date to submit evidence was initially 24 July 2017. The IAAF submitted inconclusive, methodologically unsound evidence before this date. The date to submit evidence was then moved to 28 September 2017 [Court of Arbitration for Sport 2017; A. Brown 2017]). Unless new evidence convinced the court that these athletes have an unfair advantage within this timeframe, “the Hypoandrogenism Regulations will be declared void” (Court of Arbitration for Sport 2017). Commenting on the situation, Joanna Harper, an advisor on gender issues to the IOC, noted that IAAF’s lawyers “are working to reverse that verdict. Since I am involved in with the case, I will have no further comment on it” (qtd. by Tucker 2016: n.p.). Yet, commenting further, she reveals that, “[i]f the IAAF ultimately loses the case, I believe they will try to come
up with some other way to place limits on who gets to compete in women’s sport. I don’t care to speculate publicly on what that method might be” (qtd. by Tucker 2016: n.p.; also see Karkazis 2016b). Not only does J. Harper believe that intersex women should be excluded from participating, she reveals that even if evidence demonstrates that these women should not be barred, the IAAF will work to bar them anyways.

In relation to the suspended rule, in 2016 Outsports leaked information that the Olympics would loosen restrictions concerning trans athletes and women athletes with hyperandrogenism (Zeigler 2016b). There were two potential changes. First, the new guidelines would not mandate compulsory sex reassignment/confirmation surgery for trans athletes or “normalization” surgery for intersex athletes. This guideline was instituted, but before it was mandated, Jordan-Young, Peter H. Sönksen, and Karkazis (2014) report, several women athletes with intersex traits were forced to undergo medically unnecessary partial clitorectomies and/or gonadectomies to become “proper” women and, therefore, “properly” competition-ready. Second, while trans men would be able to compete without restriction, trans women and women with hyperandrogenism would be required to maintain testosterone levels below 10nmol/L by taking HRT to disrupt their natural hormone levels for at least 12 months prior to competition.

According to the IAAF, normal men have levels at or above 10.5 nmol/L and normal women have levels that range from 0.1-2.8 nmol/L. Even if these are statistically average levels, it does not follow that men and women who naturally fall outside of them “fail” their gender or are inherently abnormal, unfairly advantaged, or pathological. Even though the apparent normal range for women is 0.1-2.8 nmol/L, the IAAF decided women must maintain levels below 10 nmol/L because women with Polycystic Ovary Syndrome have an average testosterone level of 4.5nmol/L. To represent extreme outliers, they considered raising the level to 7.5 nmol/L.
Further research revealed that if this level was the instituted standard, 16 out of 1000 women athletes would be required to undergo HRT for 12 months prior to competition. That number seemed much too high so they settled on 10 nmol/L, a level supposedly “just below the bottom end of the normal male range” (Tucker 2017: n.p.). The research presented to the IAAF clearly illustrates that women’s testosterone levels vary considerably and the 10 nmol/L cut off is quite arbitrary. Despite these facts, the IAAF is ultimately invested in the idea that to be a “real” woman one must have certain biological formations (see Sudai 2017).

As the two-year suspension drew near and the possibility of loosened restrictions seemed imminent, a methodologically dubious study (Bermon and Garnier 2017) was published. The authors, Stéphane Bermon and Pierre-Yves Garnier, claim women athletes with high levels of testosterone have an unfair advantage. Of the 43 athletic events tested in the study, there were apparently 5 events in which women with higher levels of testosterone had a statistically significant advantage. Not only is the study steeped in evident conflicts of interest – it was funded by the IAAF and one of the authors, Bermon, works for the IAAF – the study is also methodologically unsound and, therefore, the findings are invalid (Karkazis and Meyerowitz-Katz 2017). When the authors ran their statistical analyses, they failed to perform an “adjustment for multiple comparisons” to check whether the significance is real or an “artifact of chance” (Meyerowitz-Katz 2017: n.p.):

There is a good chance that this [the results] was just down to luck. So I went through the paper and ran […] a Bonferroni Correction. What this basically does is raise the bar for statistical significance according to the number of tests that had been done. According to these results, none of them are actually significant. […] [In the study] you’ll notice that there are 16 insignificant results many of which had women with low [emphasis in the original] levels beating women with high levels. From these results we could just as easily conclude that, for the majority of athletic events, testosterone levels had no impact on performance whatsoever. (Meyerowitz-Katz 2017: n.p.).
Similarly expressed elsewhere, “[n]one of these results were statistically significant, but they nevertheless show that ‘significant competitive advantage’ was not evidenced across the board” (Karkazis and Meyerowitz-Katz 2017: n.p.). Even though the study is highly problematic, it is “ratcheting up what it takes to be a woman athlete” (Orr and Watson forthcoming; also see Kelner and Rudd 2017; AFP 2017; Beswick 2017; Tucker 2017; Bloom 2017; A. Brown 2017).

The 28 September 2017 deadline for conclusive evidence drew near. Before the deadline, Andy Brown reports, the IAAF “submitted additional evidence to the CAS in support of its Hyperandrogenism Regulations. Whether that will be enough [...] remains to be seen” (2017: n.p.). In fact, what that evidence is remains to be seen by the public. When the deadline arrived, there was no public ruling. And, as of January 2018, there still has been no public announcement about a definitive ruling. The jury is still out, seemingly waiting until they can assert that women with hyperandrogenism are unfairly advantaged. One can only assume, as J. Harper predicted, dates have been pushed once again because the IAAF are “try[ing] to come up with some other way to place limits on who gets to compete in women’s sport” (qtd. by Tucker 2016: n.p.).

All that being said, the IOC needed to speak to the policies for the 2018 PyeongChang Olympic Games. The IOC declared: “With regard to the Hyperandrogenism in female athletes, there were no regulations in place at the Olympic Games Rio 2016 and there will be no regulations in place at the Olympic Winter Games PyeongChang 2018 as we are still awaiting the resolution of the Dutee Chand case” (IOC qtd. by Carr 2017: n.p.). While concerns about sex testing seem to vanish from cultural consciousness during the Winter Games (Orr 2018), this was undoubtedly good news for some athletes who participated at the PyeongChang 2018 Games. Nevertheless, since the case remains unresolved, the false belief that testosterone has bearing on
athletic performance is perpetuated and, when the Summer Games draw closer, women will be targeted and slandered again.

Many people maintain that testosterone is not only a marker of people’s “true” sex (or pathology), but also a marker of their athletic capabilities or, as is the case with women, potentially unfair capabilities. Nevertheless, this piece of “common knowledge” is misinformed. “Testosterone is not the master molecule of athleticism. One glaring clue,” Rebecca Jordan-Young and Karkazis (2012) verify referencing Joe Leigh Simpson et al.’s study (2000), “is that women whose tissues do not respond to testosterone at all are actually overrepresented among elite athletes. As counterintuitive as it might seem, there is no evidence that successful athletes have higher testosterone levels than less successful ones” (Jordan-Young and Karkazis 2012: n.p.; Karkazis 2016b). Another glaring clue is that, according to Bermon and Garnier’s study (2017), women with low levels of testosterone often beat women with high levels. One cannot reduce one’s athletic ability to testosterone. There is no evidence to suggest that athletic abilities are purely a matter of, or exclusively extend from, sex (however sex is defined) (Dworkin and Cooky 2012; Zaccone 2010). Ultimately, barring intersex or trans women athletes from participating if their physical attributes do not conform to cissexist, transmisogynistic, sexist, and interphobic standards of femininity is discrimination. The phrase “gendered ableism” can be employed to describe this particular manifestation of discrimination. Oppressive ideologies regarding what women are apparently innately physically incapable of doing (e.g. incapable of being as good as or better than men at sport) is an essentialist, ableist issue. In sport, gendered ableism is at the crux of interphobic sex testing and transmisogynistic regulation.

Returning to the fact that the intersex spectre has shifted through time and space and, currently, women athletes of colour from colonized nations in the Global South are currently
targeted for testing, illustrates that Olympic sports, indeed all “sport mega-events” (Horne 2012: 31), were, and remain, a domain for political battles. Sex testing is a political tool that does more than maintain systemic dyadism, interphobia, sexism, transmisogyny, and gendered ableism. Sex testing is used to maintain or shift inequitable global, economic, as well as gender, sex, and racial power relations. Through interphobic accusations of housing the spectre and cheating sport, not only are certain athletes treated as intersex (non)citizens (Grabham 2007), but sex testing particular athletes from particular nations also functions to shame and admonish these nations. By exploiting and exporting Western notions of sex, gender, femininity, masculinity, pathology, and DSD (see Pieper 2014; Reis 2009), sport sex testing is used as a tool to limit, control, and impose sexual citizenship, intersex citizenship and, if intersex is understood to be a disorder or disability, disability citizenship (Snyder and Mitchell 2010). Analyzing how the phantom is currently imagined to reside in women athletes of colour from colonized nations in the Global South also reveals that sex testing is used as a racist, colonial, imperial tool. And, it must be noted, this violent tool is, and always has been, exerted on already marginalized people: female, intersex, trans, racialized, and colonized individuals.

Sport mega-events like the Olympics, are global events that function to undermine and exert control over certain nations and citizenships. As explained by Amanda D. Watson, Heather Hillsburg, and Lori Chambers, the Olympics are “a site of global citizenship recognition […] in which host nations, spectators, sponsors, and fans exalt and admonish particular citizenship performances” (2014: 86). Similarly, Gerard Goggin and Christopher Newell suggest that, “the modern Olympics have been increasingly central to the hegemonic formation of nation-states, via the valorisation of certain sorts of exemplary individuals and disciplining of citizenry through sporting spectacle” (2000: 78). The attempt to contain intersex across certain national,
citizenship, gender, and/or racial boundaries via accusing certain athletes of hiding the spectre, functions to admonish and render suspect specific nations, citizenships, people, and athletic and gender performances. Sex testing certain athletes is, to borrow from Anne-Marie Fortier, an “[accusation] of national shame” (2005: 559). This feeling of national embarrassment was evident in India when Soundarajan was questioned and subjected to sex testing. There was a “sense of national shame,” Mitra explains (2014a: 387). Indian news outlets, sports officials, Federations, and politicians “deserted her” and “discussed her case calling it ‘mysterious’ or ‘strange’” (2014: 387; also see Cooper 2010: 250; Sullican 2011; Dreger 2010; Kalra, Kulshreshtha, and Unnikrishnan 2012).

**Why are Athletes Sex Tested?**

I suggest above that fairness is currently the main justification for sex testing women athletes. In this section I historicize and elaborate on the various reasons sex testing was and, unless the ruling is permanently overturned, remains instituted. When the Olympic Games first began in the seventh or eighth century B.C.E., women were not permitted to participate. Women could not compete as athletes or engage as spectators. To ensure women did not compete, athletes competed naked to “prove” they were men (Wackwitz 2003; Cooper 2010). Sex testing for sport mega-events in the twentieth century, beginning in 1960, was not to exclude women athletes from participating. The practice was meant to ensure men did not “masquerade” as women (Cooky and Dworkin 2013; Wackwitz 1996, 2003). There is, however, only one case of a man, Hermann Ratjen, masquerading as a woman in the 1936 Berlin Olympic Games (Cooky and Dworkin 2013; Pieper 2014). Nazi Germany hoped that the Games would be a political showcase of their superiority (Pieper 2014: 1560). With the aim of winning the most medals, the
Nazi Regime told Ratjen, a Hitler Youth member, to live and compete as a woman. Adopting the name Dora Ratjen, he lived and trained as a woman for three years. At the Olympics, he did not win Germany a medal; he placed fourth (Pieper 2014: 1561).

When sex tests began in 1960 to ostensibly detect masquerading men, only and all women were tested. The prospect of a woman masquerading as a man and winning was supposedly out of the realm of possibility. The tests consisted of humiliating “nude parades.” In the name of protecting women from male impersonators who, it is implied, are innately physically superior to women and therefore would inevitably win, women athletes were required to “parade nude in front of a panel of doctors” (Cooper 2010: 246; also see Donnellan 2008).

Justified via this “protectionist discourse” (Dworkin and Cooky 2012: 22; also see Jordan-Young and Karkazis 2012), women’s privacy was invaded with impunity. Rather than accept this protectionist discourse that justifies sex testing and sex segregated sport, Shari L. Dworkin and Cheryl Cooky point to the fact that sex segregation in sport was put forward historically when women outperformed men at athletic performances. For example, Jackie Mitchell, the first woman to sign a professional baseball contract, struck out both Babe Ruth and Lou Gehrig in 1936 [...]. The commissioner of baseball was so perturbed that he banned women from professional baseball and they have been banned from the sport ever since. Softball, which is perceived as inferior due to the larger, slower ball, was then further developed as a sport specifically for women. (Dworkin and Cooky 2012: 22).

Sport sex segregation, and the subsequent institutionalization of sex testing, was not established to reflect physical capacities, but rather to construct and preserve “images of male superiority” (McDonagh and Pappano 2008: 17; also see Cahn 1994; M. Cohen 2009; Kane 1995). Sex(ist) segregation has led to decades of literal and symbolic violence against women athletes: underfunding women’s sport, markedly less women’s sport coverage, sexist and objectifying sport commentary, inequitable gendered pay, and, of course, sex testing (Adams and Leavitt
In 1966, nude parades ceased and gynecological exams took their place (Simpson et al. 2000; Cooper 2010). Again, only women were subjected to such tests. After women athletes spoke out about how humiliating and intrusive these tests were, the tests changed in 1968. Women were then required to undergo a chromatin test to ensure they had XX “female” chromosomes (Simpson et al. 2000; de la Chapelle 1986). The aim was to test for “male pseudohermaphroditism.” Due to many complaints about the test and mounting evidence that suggested sex cannot be reduced to chromosomes and sex is not definitely or objectively definable or dichotomous, the IAAF stopped sex testing female athletes in this manner in 1991.

In 2000, the IOC followed suit. Testosterone levels, as explicated above, then became, and remain to be, the focus. While not all women athletes are tested, they are urged to “out” themselves if they know they have hyperandrogenism (A. Brown 2017). Further, the IOC and IAAF retained “the right to examine female athletes that raise suspicion” (Cooper 2010: 247; A. Brown 2017). As IAAF’s policies indicate, an investigation can be initiated at any time if there is “reasonable grounds for believing that a case of hyperandrogenism may exist” (2011: 3). According to Karkazis, “[t]he violation of privacy has taken place in ways horrifying and yet predictable” (2016: n.p.; also see Karkazis and Jordan-Young 2012). Given that privacy is “implicitly reserved for socially-privileged groups (male, white, heterosexual), and that living outside these interlocking privileges means inhabiting a body that is always, to some extent, ‘public’ and available for scrutiny, probing, and coercion,” the fact that women athletes’ privacy is consistently violated is unsurprising (Karkazis and Jordan-Young 2012: n.p.). In addition,
these athletes’ identities, athletic achievements, and careers have been publically challenged and disparaged.

Finding and aiming to destroy or level the intersex spectre is allegedly the central goal of sex testing suspect women. The spectre apparently must be found and levelled to ensure fairness (see IAAF 2011). And yet, numerous studies and scholars demonstrate that sport has never been, and never could be, a level playing field (Cooky and Dworkin 2013; Zaccone 2010; Sage 1998; McDonagh and Pappano 2008; Buzuvis 2010; Messner 2002; Camporesi and Maugeri 2016; Milner and Braddock 2016; C. Sullivan 2011). According to Cooky and Dworkin, “sport as a level playing field is neither an organizational reality nor a possibility, given the historical and contemporary social, economic, and cultural arrangements of sport” (2013: 107). There is no concern with fairness when certain athletes from wealthier countries have greater access to expensive training, technology, nourishing food, equipment, and healthcare. Likewise, sport is never a level playing field because committees do not and cannot police all the “myriad physical advantages that are not available to nor attainable by all athletes” (2013: 107). Such physical advantages include, extreme tallness (diagnosed as acromegaly) (e.g. Kenny George), a long wingspan (e.g. Michael Phelps [Cooper 2010]), or increased hemoglobin levels and oxygen capacity (diagnosed as congenital polycythemia) (e.g. Eero Mäntyranta [Cooky and Dworkin 2013]). There is no concern with fairness when it comes to these sorts of “disorders” or advantages. Concern spikes when assumed advantages come from one’s “disordered” sex, as is the case with Semenya. That is, concern spikes when the sex binary, gendered ableist ideas, and sex segregation are challenged. Concern also spikes, as I elaborate on below, when one’s assumed advantage comes from one’s disability, as is the case with Oscar Pistorius when he
competed as an Olympian rather than a Paralympian (Kafer 2013). In other words, concern also spikes when dis/ability segregation is challenged.

We can see this disquiet clearly when one considers the fact that Phelps’ advantage of a long wingspan is celebrated, whereas Semenya’s assumed intersex advantage and Pistorius’ assumed disability advantage from his blades is scorned and punished (Cooper 2010: 233). Phelps’ advantage is indisputable, yet admired (Cooper 2010). Pistorius’ advantage is disputable, yet scorned. Semenya’s supposed advantage cannot be proven, yet she is disparaged. And, given that sport governing institutions and viewers of sport only appear to be invested in fair play when it comes to gender, sex, and disability – not, for example, embodied advantages like tallness or economic disparities between teams, competitors, and countries – suggests that the discourse of fair play and equality functions primarily as a guise for numerous exclusionary and discriminatory ideologies.

**Discriminatory Ideologies Underpinning Sex Testing**

Sex testing promotes and relies on interphobia, cissexism and transmisogyny (Cavanagh and Sykes 2006), compulsory dyadism (see Daston and Galison 2007; Jordan-Young 2010; Laqueur 1992; Oudshoorn 1994; Hird 2000; Herdt 1994; Fausto-Sterling 2000b; Jordan-Young and Karkazis 2012), and racist, Eurocentric notions of femininity (Pieper 2014; Kane 1995). Sex testing is critiqued because the practice is not uniform and this lack of uniformity reveals the discriminatory ideologies that underpin it (Cooky and Dworkin 2013; Dworkin and Cooky 2012; Travers 2008; Cahn 1994). For instance, only women were tested and, currently, only women who appear “too” muscular, “too” manly, or are “too” athletically able are tested (Cooper 2010: 235; Pieper 2014; Karkazis 2016b). In other words, women who excel in sport and do not
conform to oppressive standards of dyadism, femininity, and feminine beauty are presumed to be not “real” women and are required to undergo invasive and humiliating procedures to “confirm” their sex.

Male athletes never provoke such outrage. Men are never questioned or tested because “all men in sport are assumed to be ‘real men’ at the outset” (Dworkin and Cooky 2012: 21). Men are expected to be capable, athletic, dynamic, and muscular. It is clear sex tests function to maintain “[o]ne of the most central and coveted beliefs in sport,” namely, men have inherently superior athletic abilities and body-minds compared to women (Dworkin and Cooky 2012: 21; Cooper 2010). Or, in Vikki Krane’s terms, “[t]he underlying message is that athleticism and femininity are contradictory” (2001: 115). Athleticism and femininity are understood to be, and are typically represented as, antithetical. The institutionalization of the idea that men have superior abilities and morphologies via sex testing practices and sport sex segregation is gendered ableism.

Nor is sex testing uniform across national borders, citizenship status, or race, as elaborated on above. This lack of consistency suggests that intersex haunts certain women and places; sex “deceivers” are presumed to come from certain geographical locations (presently, the Global South) and look a certain way (not white). Given that women athletes from colonized nations in the Global South are currently targeted (Mitra 2014b; G. Davis 2015a: 152; Karkazis 2016b), sex testing is evidently informed by intersecting racist, cissexist, sexist, gendered ableist, and colonial logics (Hargreaves 1994, 1997; Nyong’o 2010; Cooky, Dycus, and Dworkin 2013; Munro 2010; Magubane 2014).

Why women of colour? Patricia Hill Collins’ insights are instructive. Speaking specifically of Black women – hence, the reader can keep Semenya in mind here – Collins
explains that Black women “by definition, cannot achieve the idealized feminine ideal because the fact of Blackness excludes them” (2004: 199). Idealized femininity is white. Embodying hegemonic femininity is not merely about not looking or acting like men, but it is also about looking, being, or passing as white (Collins 1990, 2000, 2004). Black women, and women of colour in general, do not and cannot achieve idealized femininity or be read as “real” women and, therefore, become suspect women or are not understood or recognized as women at all (Pieper 2014, 2016; Somerville 2000; Kane 1995). Given these ideologies, Semenya’s Blackness already renders her not-quite-woman or suspect woman. Moreover, her muscular, athletic (“manly”) physicality, supposed “unfeminine” gender presentation, queer sexuality, and amazing athletic (“manly”) hyper-abilities render her double, triple, suspect (see Orr and Watson forthcoming). Her body-mind and way of being in the world, and what she does with her body-mind, challenges and threatens views about what “real” women look like, desire, and are capable of doing. Hence, questioning Semenya’s femininity and sex testing her is a means to re-stabilize hegemonic white femininity, dyadism, and heterosexuality, and to reemphasize the notion that Black women are not and cannot be real women.

Len Anderson draws attention to the racism in sport sex testing practices and hegemonic femininity in The Sowetan, one of the largest South African newspapers. Speaking of Semenya, L. Anderson states, “[i]t is very clear that the IAAF used Western stereotypes of what a woman should look like as probable cause [for sex testing] and that is racist and sexist” (2009: n.p.). He continues, “those making the determination [about sex testing] are fat and ugly European men” (2009: n.p.). While the comment “fat and ugly” is problematic, L. Anderson is correct: mostly white European, Western men from the Global North decide who is properly feminine. Informed
by oppressive ideologies, they decide who might be hiding the spectre and haunting sport; they
decide where the phantom resides and which body-minds to investigate.

Western, European men imagining and placing the spectre “over there” in racialized
women – or “intersexualizing” the Other (Eckert 2009: 62) – is not new. Representing the
phantom in African women, particularly South African women like Semenya, is also not new.62
There is a long Western, colonial, imperial, and scientific history of labelling African women’s
genitals ambiguous, primitive, and abnormal (Magubane 2001, 2014; Reis 2009; Pieper 2014;
the seventeenth century (Magubane 2014: 769), sometimes citing Western, European, male
colonizers’ traveling texts and tales of “discovery” (Flower and Murie 1867; Beck and Beck
1860: 176), European, American, and South African medical texts maintained that “malformed
or ambiguous genitalia [...] were particularly common among women of African descent – a
‘fixed peculiarity of race’” (Magubane 2014: 769; also see Waitz 1863; Beck and Beck 1860,
1863; Flower and Murie 1867; Velpeau 1845; Cuvier 1817; Otto 1816; Müller 1834; von
Luschka et al. 1868). These writers did not necessarily deny that European women also can have
“unusual formations of the generative organs [emphasis in the original],” however, they
emphasized, “[i]t is not common in Europe, but is quite frequent in warm climates” (Beck and
Beck 1860: 175-176). Or, in slightly different words, “This malconformation rarely occurs in
temperate climates” (1860: 176). The specific “ambiguities” or “malconformations” (also known
as “Hottentot aprons”) these writers apparently viewed were “excessive” clitoral length and/or

62 One could also consider the guevedoche or guevedoce of Dominican Republic (Warnke 2011). Guevedoche is a
third sex identity category that Westerners repeatedly “discover,” misrepresent, pathologize as DSD or “5-alpha
reductase deficiency,” and attempt to cure. There are numerous mainstream articles like the Advocate’s
“Discovering the Guevedoces: The Fascinating Story of Boys Raised as Girls” (Ennis 2015), that impose
dichotomous Western notions of gender, sex, and DSD and reproduce white saviour narratives. That is, the Western
colonial imaginary is particularly invested in imagining the spectre “over there” in racialized peoples that apparently
ought to be cured.
labia minora visibility (Somerville 2000: 26; McClintock 1995: 42; Magubane 2014: 769). Many scientists claimed that these “malconformations” were literal markers of these women’s innate, perverse, insatiable sexuality, degeneration, and primitivism (Gilman 1985: 90). Roen verifies, there is a “long-standing belief that large, visibly protruding female genitalia signal deviance” (2009: 18). As a result, an African woman “becomes her genitalia;” she is reduced to her alleged “ambiguous” genitalia (Gilman 1985: 121). We witness this process happen to Semenya. News headlines like, “Caster Semenya ‘is a hermaphrodite’, tests show” (S. Hart 2009) and “Caster Semenya has male sex organs and no womb or ovaries” (Hurst 2009), and the content that scrutinizes her supposed sex characteristics reduce her to her sex (Cooky, Dycus, and Dworkin 2013; Viloria 2017).  

Some European, American, and South African medico-scientific texts published well into the twentieth century continued to perpetuate the idea that African and Black women are more likely to be sexually “ambiguous” or, in less pathologizing terms, have intersex traits (Magubane 2014; Charlewood 1956; Ramsay et al. 1988). Western nations as well as South Africa during apartheid were, and arguably still are, invested in biological racism and white supremacy.

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63 When I speak of race and African and Black people here I am not conflating Blackness with African identity or citizenship and I am not merely retrospectively applying contemporary understandings of Black, White, race, or racism onto historical contexts. Race, Whiteness, and Blackness have been constructed very differently through time and space (Magubane 2001; Schiebinger 1993; McClintock 1995; Goldberg ed. 1990; Stoler 1997; Willis ed. 2010). Race categories were and, in many respects, remain unsteady. Indeed, “skin color and hair textures were not stabilized as markers of racial difference until fairly late in the nineteenth century” (Magubane 2001: 823). When I speak of the historical construction of many African women’s physical attributes and genitals I do not suggest they understood themselves to be or thought themselves Black or that they were necessarily understood to be Black by others. Nevertheless, the shift in racial/racist discourses and beliefs that rooted blackness in, for example darker skin and hair texture, occurred alongside the maintenance of the belief in sexually ambiguous African women and African women were constructed as Black. That is, my aim here is to trace the ideological construction and imposition of sexual ambiguity to contextualize how this construction and imposition is articulated through current sex testing practices.

64 As cited by Magubane (2014), in Bantu Gynaecology, Godfrey P. Charlewood asserts that intersex congenital “abnormalities” are more frequent in “Negroes and related races” (1956: 12). Michele Ramsay and colleagues similarly claim that there is a “high frequency” of “true hermaphroditism” and external genital “ambiguity” “among southern African black” (1988: 4). Ramsay et al. continue: “In southern Africa ambiguous genitalia seems to be much more common in blacks than in whites” (1988: 9).
systems that are underpinned by and rely on dyadism and interphobia. Sex testing is one way by which these discriminatory views and oppressive consequences currently manifest.

This brief historical account draws attention to the way the spectre of supposed degenerate genital and sexual ambiguity was, and remains to be, imagined and constructed by colonial and imperial forces across gender, racial, national, and geographical lines. The spectre of intersex has been and continues to be used as a colonial and imperial tool to render certain people and nations degenerate and suspect and to justify various forms of violence. Addressing the history of the construction of genital ambiguity, as Zine Magubane (2014) demonstrates, helps us understand how race and nation play a key role in determining what body-minds are labelled sexually ambiguous, where the spectre supposedly haunts, and how citizenship statuses and nations are admonished. This history reveals how various forms of oppression literally and symbolically converge on and shape certain people’s body-minds and nations. It contextualizes the violence enacted on Semenya and demonstrates that the institutionalized violence she endured, and continues to endure, must be read as a contemporary iteration of the ambiguously sexed African woman (Magubane 2014; Munro 2010).

Decolonizing and Desegregating Sport

John Horne (2012) speaks of “the four Cs” needed to analyze sports mega-events like the Olympics: capitalism, connections, citizenship, and contradictions. However, it is vital to take another C into account: colonialism. Doing so helps us acknowledge and address how colonialism shaped and shapes these events and the nations that and citizens who participate. Taking colonialism into account reveals that sex testing is a colonial, imperial practice (Cooky, Dycus, and Dworkin 2013; Magubane 2014; Munro 2010) because it imposes and “promotes
Western notions of biology, gender and race” (Pieper 2014: 1558; Warnke 2011; Vigneault 2011). Abolishing sport sex testing practices and questioning sex segregated sport (Dworkin and Cooky 2012; Cooky, Dycus, and Dworkin 2013; McDonagh and Pappano 2008; Travers 2008), would be decolonizing projects that would help protect many marginalized athletes, nations, identities, and citizenships.

Imposing strict, dyadic Western biological categories and ideologies through sex testing is a colonial act that delegitimizes people’s identities, subjectivities, and experiences. Such imposition also contributes to the erasure and replacement of many culturally specific identities and social formations that do not reproduce the idea that sex and gender are dichotomous or institutionalize compulsory dyadism (Vigneault 2011). Whilst remaining cognizant of the fact that Soundarajan and Chand have always identified as women, consider the sex tests imposed on these Indian women and the broader implications. Drawing from extensive historical literature, “[s]cholars and historians have argued that the binary sex model was not as integral to the cultures of traditional Indian societies” (Mitra 2014a: 389). The notion that “bodies are naturally completely one sex or another” was not prominent in these societies (Mitra 2014a: 389). Western colonial, orientalist, and imperial forces decimated these traditional systems (N. Menon 2011; Mitra 2014a; Reddy 2005; Atluri 2012; Lugones 2007).

Past and present, various Indian cultures recognize/d a “third sex:” hijras, aravanis, kinnar, kothi, shiv-shakthis, and jogti hijra (Johari 2014; Mposo 2017).65 Hijra appears to be the, arguably problematic, general term used to name all of these various groups and identities. At the current moment, hijra is a marginalized, yet institutionalized sex in India (Reddy 2005; Khan et al. 2009; Preves 2003). “Hijras have been labeled as trans, India’s lady boys, India’s third sex,

65 See Aarefa Johari (2014) and Paulina S. Mposo (2017) for the specific geographical and unique cultural differences between each group.
drag queens, and a whole host of other English terms” by people in the West (Atluri 2012: 727).

Yet, these English descriptors are insufficient. They do not capture the cultural contexts, identities, or citizenship status. They also do not reflect the body-mind or cultural diversity of the communities. Moreover, the contexts in which these English terms are typically used often erase the complex, colonial history. These terms also function to impose (1) Western, dyadic ideas of sex and gender, (2) Western DSD, intersex, and gender identity disorder discourses onto “backwards” India, and/or (3) supposedly liberal, progressive Western notions of LGBTQI liberation and rights (Atluri 2012). Colonization, imperialism, and orientalism delegitimized and pathologized hijra identities, practices, expressions, and communities (Reddy 2005; Atluri 2012). Western views about sex and gender dyadism were imposed and institutionalized in India and, as Nivedita Menon explains, some nationalist elites throughout the nineteenth and twentieth centuries embraced “colonial modernity,” including dyadic notions of sex and gender (2011: n.p.).

Considering this context, suspecting female athletes from India and imposing Western understandings of sex, gender, intersex, pathology, and DSD through sport sex testing not only undermines fundamental aspects of these athletes’ identities as women, but doing so also continues the colonial work of erasing, renaming, and pathologizing hijras. Through the discourses of fairness, scientific progress, scientific objectivity, or even LGBTQI rights/liberation, imposing Western iterations of sex through sport continues the colonial process of limiting and controlling Indian sexual citizenship. In other words, this practice is a problem of who has the power to name body-mind characteristics and name and erode culturally specific identities. Indeed, intersex, women, and colonized peoples alike have struggled, and continue to struggle, to gain the right to name and control their body-minds, identities, and modes of being in
the world on their own terms (see Loomba 2015; Kessler 1998; G. Davis 2014; Feder and Karkazis 2008; Grabham 2007; Holmes ed. 2009).

As explained earlier in this chapter, coining the phrase “intersex citizenship,” Grabham (2007) demonstrates that folks with intersex anatomy are not treated as proper citizens because their body-minds are presumed to be out of control, abnormal, disordered. However, as the experiences of suspect intersex athletes demonstrate, people need not be medically confirmed as having a DSD before being treated as intersex (non)citizens. Suspicion is enough – having a body-mind, sex, gender, race, citizenship, and nationality deemed suspicious by Western, colonial ideologies and institutions was enough for Semenya, Chand, and Soundarajan to be stripped of their autonomy, respect, career opportunities, income, and hard-won titles and medals. Suspicion is built into IOC and IAAF’s sex testing guidelines: they retain “the right to examine female athletes that raise suspicion” (Cooper 2010: 247). Semenya illustrates this reality in the 2011 television documentary, Too Fast to be a Woman? The Story of Caster Semenya: “I don’t have rights. Let’s put it this way: in athletics, I don’t have rights. I’m just a competitor” (in Ginnane dir., 2011). Being a competitor with suspect or incongruous characteristics ought not and need not involve exclusion or the denial of rights, privacy, and self-determination. Yet, she is not just a competitor, as she states in the above quotation. Likewise, Soundarajan and Chand are not just competitors. By institutionalizing dyadism and forcing Western ideas about body-minds onto these athletes, they become (potential) vehicles for those ideals to be further entrenched in their nations and the globe at large.

In the face of this Western imposition, South African media outlets, politicians, family members, and fellow citizens supported Semenya (Magubane 2014; Cooky, Dycus, and Dworkin 2013; Munro 2010; Orr and Watson forthcoming). While Western media outlets slandered and
questioned Semenya and assumed she was a man, not a real woman, intersex, disordered, or a hermaphrodite, South Africa came together and defended Semenya’s female identity and right to body-mind autonomy (Magubane 2014; Cooky, Dycus, and Dworkin 2013; Munro 2010; Klein 2016). Many of the arguments defending Semenya were rooted in nationalist, anti-imperialist discourses. Defending Semenya’s female identity and right to body-mind integrity was a means to oppose imperial forces that seek to define and name South Africans. While some Western commentators and scholars claim that Semenya, her family, and her nation’s rejection of the labels intersex, DSD, and hermaphrodite is interphobic, backwards, or anti-science, such a claim neglects the colonial, imperial context (Magubane 2014; Munro 2010; Orr and Watson forthcoming). Such a claim reproduces the historical dismissal of Black women’s narratives of their body-minds and of colonized nations’ own narratives as a whole. Moreover, such a claim, at least in part, overlooks the fact that Semenya and her nation’s support for her expand the strict confines of femininity and challenge the dominant ethos that authentic femininity is frail, unmuscular, less able or athletic than men, thin, and white (Orr and Watson forthcoming).

Semenya explicitly speaks to this challenge when she asks, “What makes a lady? Does it mean if you’re wearing skirts and dresses you’re a lady? No. What kind of a lady is that? Yeah I’m a lady. There’s nothing I can say, yes, I’m a lady. I have those cards of being a lady” (in Ginnane, dir. 2011). Much like Sojourner Truth’s (1851) famous address, Semenya is essentially asking, “Ain’t I a Woman?” And she passionately declares that she is indeed.

I endorse immediately abolishing sex testing for the numerous reasons explored above. However, does abolishing the practice mean we must abolish sex segregation in sport as well? Dworkin and Cooky note that sex testing and sex segregation cannot be “disentangled” (2012: 21); they are “mutually constitutive” policies (2012: 22). Further, as demonstrated, sex testing,
sex segregation, and colonialism cannot be disentangled (Cooky, Dycus, and Dworkin 2013; Magubane 2014; Munro 2010). However, would an equitable sport system emerge from abolishing both sex testing and sex segregation at this moment in time? According to Ann Travers, institutional powers should “entirely eliminate sex as an organizational category in sport” (2008: 90):

Queer postmodern feminism’s deconstruction of the two sex system as ideological rather than natural [...] supports an argument for the elimination of sex segregated sport. This argument can be summed up as follows: First, differences in men’s and women’s athletic performances can be attributed to social, political, economic, and psychological discrimination rather than biological factors. [...] Second sport is implicated in translating the ideology of the two sex system into the material reality of bodies that conform to sexist expectations (Young, 1998). [...] Third, the very separation of the girls from boys and women from men constitutes gender injustice. (Travers 2008: 90).

Travers’ arguments are convincing. Yet, Jordan-Young and Karkazis’ proposal is also compelling: “[s]ex segregation is probably a good idea in some sports, at some levels and at some moments. But it is time to refocus policy discussions at every level so that sex segregation is one means to achieve fairness, not the ultimate goal” (2012: n.p.). Sex segregation might be a good idea in particular contexts largely because of the concern that, if sport was suddenly desegregated without any other policy discussions, women would be pushed out. This possibility cannot be overlooked.

We must ask: what does desegregation mean for women’s sport? Would women be negatively affected or pushed out? What would sport look like without sex segregation? Acknowledging that desegregating sport is worth considering, Eric Vilain notes if it happened now, “female athletes would lose most, if not all, elite competitions. For all the brouhaha around Semenya [...], one should remember that her time in the 800 meters at the world championships [...] would not have even qualified for the men’s final” (2012: n.p.). Would desegregation
ultimately help men continue to dominate the sports world and further marginalize women? J. Harper maintains that “[a]llowing these [intersex] athletes to compete in women’s sport […] threatens the very fabric of women’s sport” (qtd. by C. Bennett 2016: n.p.). Whilst J. Harper’s views are undeniably interphobic, the concern for women’s sport is a genuine issue that scholars must grapple with as this conversation continues. In line with Jordan-Young and Karkazis’ position, I maintain, at this moment, “[e]nsuring gender equity through access to opportunity” (2012: n.p.), funding, pay, coverage, as well as abolishing sex testing are more feasible goals and promising stepping stones to future legislative changes concerning women’s sport, decolonizing sport, and sex desegregation.

Unfairly Advantaged Yet Disordered Intersex and Disabled Athletes

Adding colonialism to Horne’s (2012) list of Cs needed to analyze sporting events (i.e. capitalism, connections, citizenship, and contradictions) is not enough. In addition to many other terms readers could add to his list, I suggest dis/ability is required to analyze sport mega-events, sport organization, and sex testing. The presumed hyper-ability of (suspect) intersex athletes and racialized people, coupled with the presumed in/abilities of women, sheds light on how intersex is constructed differently depending on where one is from, what one looks like, and when and where one performs. A disability perspective on sex testing reveals some contradictory narratives about intersex, intersex athletes, disability, athletes with disabilities, the organization of sport, and, in turn, the (il)logic of dichotomous thinking.

Sport mega-events analyzed through a disability lens may, at first glance, seem like a wayward impulse because, for example, elite athletes and Olympians are typically assumed to be enabled, hyper-abled. Nonetheless, athletes with disabilities and Paralympians are too often
rendered invisible and reduced to inspirational objects (Goggin and Newell 2000). Consider Brazilian *Vogue*’s 2016 Paralympic campaign that featured photo-shopped able-bodied models to look like disabled Paralympians. “The campaign,” Fernando Carneiro remarks, “is even more outrageous because the magazine had two actual Parathletes at the photo shoot ‘as inspiration,’ but were not the subject of the campaign” (2016: n.p.). Moreover, there is not nearly as much media coverage of the Paralympics as the Olympics (Goggin and Newell 2000). As a result, British Paralympian Ryan Raghoo notes, Paralympians who are world record holders and medalists are not household names; “the same value is not given to the same achievement” (Raghoo qtd. by Heilpern 2016: n.p.). Rick Hansen, Canadian Paralympic gold medalist, activist, and philanthropist, echoes Raghoo by acknowledging that athletes with disabilities are not provided with the same opportunities as enabled athletes (Migneault 2016).

When there is coverage of disabled athletes, the “tragedy of disability” (Peers 2009: 653) is often emphasized. The athletes are typically represented as passive and pitiable (DePauw 1997; Goggin and Newell 2000). In contrast to passive, pitiable, tragic representations, the trailer for the 2016 Paralympics, “We’re the Superhumans” (Channel 4 [UK Paralympic Broadcaster]), reproduces another common disability trope: the overcoming inspirational supercrip (see Clare [1999] 2009; Peers 2015; Hardin and Hardin 2004; Garland-Thomson 2005; Goffman 1963; Shuttleworth 2012; Wendell 1996; Orr 2016a). Kim Sauder, a blogger also known as crippledscholar, writes of the trailer, “[i]t’s ironic how closely the term Superhuman is to the term Super crip” (crippledscholar 2016: n.p.). The irony became even more palpable after media outlets were cautioned against overusing terms like “superhuman,” “brave,” and “heroes” in Paralympic coverage and reporting because the terms are contentious among and offensive to some Paralympians and members of the disability community (Connelly 2016).
In the “We’re the Superhumans” trailer, all the athletes remain nameless. Athletes cannot become household names if they are not named. In an article (Khaleeli 2016) full of praise for the trailer, however, I found a few of the Paralympians’ and other people’s names featured in the trailer. In the article, their names were accompanied by a list of some of their accomplishments and also often accompanied by a brief “origin story” (Peers 2012, 2015) of how they acquired their disabilities or, as explained in one story, “deformities” (Khaleeli 2016: n.p.): Alvin Law, Canadian drummer; Bartek Ostalowski, Polish racing driver; Jessica Cox, American pilot, dancer, and taekwondo black-belt; Ellie Simmonds, British Paralympic swimmer, medalist, and world record holder; Natalie Blake, British Paralympic powerlifter; Hannah Cockroft, British Paralympic wheelchair racer, world record holder, and medalist; Matthew Phillips, British ParaClimber; Aaron “Wheelz” Fotheringham, American wheelchair stuntman and motocross athlete; Evan Ruggiero, American tap dancer; and Tony Dee, Australian singer. Dee sings the Sammy Davis Jr. track, “Yes I Can,” throughout the trailer. The song’s lyrics, “‘gee, I’m afraid to go on,’ has turned into, ‘yes I can,’” are given new meaning. These athletes, or so the narrative proposes, were “afraid to go on” because of the “tragedy of disability” (Peers 2009: 653), but they changed their fearful attitudes and declared, “yes I can,” and now they are superhumans. The athletes, as well as the other talented individuals featured in the video, are framed as overcoming their disabilities via a change in attitude. Like so many ableist neoliberal success stories, they supposedly individually overcame their disabilities. This narrative effectively erases the institutionalized ableism these people face and it erases the interpersonal circumstances and labour that helped these people reach such elite levels.66 While the athletes are active in the

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66 Such interpersonal circumstances and labour is often emphasized in sexist coverage about and interviews with women athletes who are enabled (Daddario 1998). Women athletes’ coaches and/or husbands are often credited for the athletes’ achievements, effectively discrediting the women’s achievements. For example, when Hungarian swimmer Katinka Hosszú beat the 400 meter medley world record at the Rio Olympics in 2016, an NBC
trailer – they are seen performing their sports – they are nameless, objects of inspiration (see Clare [1999] 2009). They become “in-spite-of” stories that reproduce the narrative that one can independently overcome their disability if they just shift their perspective – “yes I can!”

This trailer is an example of “inspiration porn” (S. Young 2012: n.p.) or, in Clare’s words, it is “supercrip crap” ([1999] 2009: 3). Stella Young, the late journalist and disability activist, describes “inspiration porn” as “feel-good tools” that cater primarily to enabled viewers. Framed by motivational rhetoric (e.g. “yes I can;” “The only disability in life is a bad attitude” [S. Young 2012, 2014]), these representations “create unrealistically high expectations of what all [emphasis in the original] disabled people should accomplish” and, subsequently, “serve to justify the vilification of particular disabled people who do not manage to overcome, often writing them off as stubborn or lazy and therefore deserving of the poverty or lack of care that they may experience” (Peers 2015: 332). Put differently, inspiration porn and supercrip crap erase ableism and compulsory able-bodiedness, invalidate the difficulties people with disabilities experience, and function to inspire enabled people. To explain further, “[t]hat quote, ‘the only disability in life is a bad attitude,’” according to S. Young,

the reason that’s bullshit is because it’s just not true… No amount of smiling at a flight of stairs has ever made it turn into a ramp. Never. You know, smiling at a television screen isn’t going to make closed captions appear for people who are deaf. No amount of standing in the middle of a bookshelf and radiating a positive attitude is going to turn all those books into braille. (S. Young 2014: n.p.)

Employing Samantha King’s term, inspiration porn is infused with and relies on “the tyranny of cheerfulness” (2010: 286). Disabled people are expected – demanded – to radiate positivity. Yet, a positive outlook cannot erase ableism and compulsory able-bodiedness; it cannot literally alter inaccessible aspects of society. Promoting the idea that people with disabilities can overcome

commentator said that her husband and coach, Shane Tusup, was “the person responsible for her performance” (qtd. by J. Miller 2016: n.p.; also see Mei 2016; Bogart 2016; Park 2016).
their disabilities, be happy, perhaps even transform stairs into ramps, and even become elite athletes if they shift their attitudes – if they just declare, “yes I can,” or “draw on their own inherent energy and power” (McWhorter 1999: 155) – encourages enabled individuals to think of disability as a personal issue or choice, not an instituted socio-political issue that they influence. Inspirational supercrip crap porn, therefore, helps enabled people to remain complicit in reproducing ableist structures. Considering the “We’re the Superhumans” trailer illustrates the need for a critical disability approach to sport and athletics.

Goggin and Newell (2000) also demonstrate the need for a disability approach to sport by challenging the Paralympian-Olympian divide. To provide a bit of history, while organized sport for people with disabilities can be traced back to well over one hundred years ago, it was not popularized until after World War II (“Paralympics - History” n.d.). Intended to abet and rehabilitate, sport was organized for the large numbers of war veterans and civilians who were disabled by the war. Named after the British hospital that opened a spinal cord injury centre and encouraged rehabilitation sport, The Stoke Mandeville Games took place on the hospital grounds on the same day as the Opening Ceremony of the London 1948 Olympics (International Paralympic Committee [IPC] n.d.; “Paralympics - History” n.d.). The same year sex testing was instituted, 1960, was the first year the Mandeville Games took place in the same city as the Olympics, Rome, Italy (IPC n.d.). Those Games, while not called the Paralympic Games at the time, “have gone down in history as the ‘First Paralympic Games’ [...]”. The word Paralympic was originally a pun combining ‘paraplegic’ and ‘Olympic’” (IPC n.d.: 1). Since the inclusion of many other types of disabilities, the “para” now refers to “parallel” (Goggin and Newell 2000: 74; IPC n.d.: 1; A. Hughes 1999). “Para” implies that the Olympics and the Paralympics are not divided, but occur in tandem, together, “side by side” (IPC n.d.: 1). However, they do not really
occur together, Goggin and Newell note: “[i]n reality, [...] the Paralympics are very much a separate event held almost three weeks after the Olympics finish” (Goggin and Newell 2000: 74). There are a few notable exceptions (Heilpern 2016; D. Rose 2012; Springer 2016), but this separation – this ableist dis/ability segregation – “is not questioned” (Goggin and Newell 2000: 71).

Since Goggin and Newell penned their observations in 2000, circumstances have not improved. The 2016 Olympic and Paralympic Games remain segregated. The Olympics took place from 5-21 August whereas the Paralympics took place from 7-18 September (Heilpern 2016). The 2018 Olympic and Paralympics Games remained segregated. The former ran from 9-25 February and the latter ran from 8-18 March. In addition to this segregation, Paralympians receive far less funding and (problematic) media exposure compared to Olympians (Goggin and Newell 2000; Gibson 2016; Heilpern 2016; Springer 2016). While the segregation between the Games and athletes is presumed natural because of the apparent body-mind differences, abilities, and talents, a closer examination of the discourses that surround Olympians and Paralympians demonstrate the segregation is narrated as needed and just.

Similar to the narratives around sport sex segregation, underpinning the assumption that dis/ability segregation is necessary and fair is the ableist and paternalistic idea that Olympians’ abilities and body-minds are inherently better than Paralympians’ abilities and body-minds. The events apparently must be segregated for Paralympians’ “own good” because they will inevitably lose. This protectionist discourse was challenged most recently at the 2016 Paralympics when four Paralympians ran the men’s 1500m faster than anyone at the Olympics that took place weeks before: Fouad Baka, Algeria, placed fourth finishing in 3:49:84; Henry Kirwa, Kenya, finished in 3:49:59 and won bronze; Tamiru Demisse, Ethiopia, was awarded silver after
finishing in 3:48:49; and Abdellatif Baka, Algeria, won gold after running the 1500m in 3:48:29 ("Athletics Men’s 1500m - T12/13 Final" 2016). Maxwell Strachan reports: “even the fourth-place [Paralympic] finisher would have won gold” if they competed at the Olympics (2016: n.p.). The Olympic 1500m gold medalist, Matthew Centrowitz Jr. of the United States, finished with a time of 3:50:00.

Alison Kafer (2013) critiques the ostensibly needed and fair segregation by analyzing the media response to Oscar Pistorius’ attempt to compete as an Olympian with a “paradigmatic” disability (see McRuer and Mollow 2012: 12), rather than a Paralympian, in at the 2008 Beijing Olympics. He ended up competing at the 2012 London Olympics. Kafer observes, Pistorius complicates the distinction between enabled and disabled athlete because he attempted to compete, and successfully competed, as an Olympian. However, Pistorius, nicknamed “Blade Runner” (Eveleth 2012b: n.p.), was represented as a cyborg by mainstream media, which functioned to re-solidify the dis/abled binary and the idea that enabled and disabled athletes must remain segregated. I quote Kafer at length:

With his gleaming high-tech prosthetics, Pistorius perfectly embodied the cultural understanding of a cyborg; he was one with his machine. […] [W]hat I want to highlight here is the way in which news writers presented Pistorius as a definitive cyborg and, therefore, almost of a different species than his fellow runners. Anna Salleh, writing for an Australian news outlet, described the Pistorius case as one involving “the competing rights of cyborgs and non-cyborgs.” Bloggers from both sports and technology sites described the case in terms of the arrival of the “cyborg athlete” […]. Not only was Pistorius’s cyborgization taken for granted in these stories, but so, too – and relatedly – was his difference. As Swartz and Watermeyer note, doping can also be seen as cyborg technology, but athletes accused of doping are not described in those terms; physical disability and its attendant technologies render one cyborgian in a way nothing else can. The cyborg/noncyborg distinction points to a problematic assumption underlying popular conceptions of the cyborg. Although Haraway intended the figure to critique dualistic understandings of nature and culture or of humans and machine, too often it serves only to reify such binary logic. In these news stories, “cyborg” represents the melding of pure body and pure machine; there is an original purity that, thanks to the assistive technology, has only now been mixed, hybridized,
blurred. To return to the Pistorius case, the athlete is simply a body; when it gets mixed with the prosthetic machine, it becomes impure, mixed, cyborg. A nondisabled runner, in other words, is natural, unmixed, unadultered. [...] the “cyborg” concept thus serves to perpetuate binaries of pure/impure, natural/unnatural, and natural/technological; rather than breaking down binaries, it buttresses them. (Kafer 2013: 108–109).

Presenting Pistorius as a cyborg “naturalizes” the natural/unnatural dichotomy and justifies Paralympic-Olympic segregation. Competition can only be fair, the narrative proposes, if Paralympians and Olympians are segregated. Akin to representing Pistorius as an unfairly advantaged, impure cyborg, naming the 2016 Paralympians “superhumans” (Channel 4 [UK Paralympic Broadcaster]) – unnatural, unbelievable, cyborgian – functions to also reinforce the “naturalness” of Olympian-Paralympian segregation.

Before Pistorius challenged what being a Paralympian (and Olympian) means in mainstream conversation, who is or can classified as disabled and can therefore compete as a Paralympian has been challenged and has shifted within the Paralympic institution:

Although this group [Paralympian] was initially restricted to those with spinal cord injuries, it later came to include athletes with cerebral palsy, amputations, restricted sight and various other medicalized physical conditions listed under the umbrella term les autres [the other]. Athletes with intellectual disabilities did compete for medals in one Paralympic Games (2000), but were disqualified from further competition shortly thereafter. (Peers 2009: 662).

People with intellectual disabilities eligible to compete again years later and did so at the 2012 London Paralympics. Ultimately, though, certain medicalized and medically classifiable paradigmatically disabled and disordered athletes can compete as Paralympians (Peers 2012, 2009; “Classification” n.d.). The shift in who is eligible and qualifies to compete occurs because it is difficult, arguably impossible, to create a definitive classification system to determine who is disabled enough or disabled in the “right” way (Peers 2012; Brown and Corday 2016). Stephanie Dixon, CBC Paralympic commentator and former Paralympian, explains, “it’s really difficult to
draw the line,” hence, there is some level of arbitrariness involved in classifying athletes with disabilities (qtd. by Brown and Corday 2016: n.p.). The fact that people’s disabilities may manifest differently through time and space, assessment day makes things even more difficult. For example, Amy Burk, a Team Canada goalball player with a visual impairment, has been excluded from competitions because her impairment on various occasions was not “severe enough to qualify her as a disabled athlete” (Brown and Corday 2016: n.p.). Burk explains that her vision varies day-to-day and lighting in a room, for example, can influence her vision. As a result, one day she could be classified as disabled enough to compete and other days she may not (Brown and Corday 2016: n.p.).

Drawing from her own experiences, Peers (2012) notes that getting re/classified as a Paralympian is a long, difficult, objectifying, and invasive process that re/creates the category disability. (Re)classifying as a Paralympian requires one to repeatedly demonstrate that one has a definitively medically diagnosable disability and certain body-mind in/capacities via various performances that include, but are not limited to, displaying medical documents, retelling origin stories (e.g. an accident, born this way), physical movements that highlight the disability but do not jeopardize one’s “supercrip” status, movements that satisfy enabled onlookers, and movements that satisfy fellow athletes. Drawing from Foucault’s analyses of self-/surveillance ([1978] 1990, 1991, 1979), Peers describes her complicated performances of properly disabled, supercrip, Paralympian before she became, in her words, a “revolting gimp,” one “who either cannot or will not inspirationally overcome disabling circumstances” (2015: 332):

I meticulously trained myself out of every possible sign of “gimpy” fatigue or pain that would call into question the legitimacy of my supercrip status. I simultaneously trained myself out of leg movement and other signs of ability that would call into question the legitimacy of my disabled status. Strangers, too, actively policed my inspiration disabled status insofar as their inspired looks often changed to looks of disapproval – which were sometimes even accompanied by
angry accusations that I was a “faker” – if and when I moved my legs, stood up from my wheelchair, or switched from my wheelchair to my crutches, and vice versa. I came to learn that the capacity to inspire is linked to the capacity to act as if I were a stereotypical disabled subject with a complete spinal cord injury. (Peers 2015: 335).

Diagnosed with a progressive, genetic myopathy, Peers’ disability and re/classifiable status as a Paralympian shifted throughout her athletic career depending on who was looking, how she behaved, what origin story she told and when she told it, what she was in/capable of doing (2012, 2015). Through enough successful performances, she became disabled; she became a supercrip. In Peers’ words, “disability stories produce disabled subjects” (2012: 186). Comparable to (inter)sex classifications in sport that “construct sex difference” rather than reflect body-minds (McDonagh and Pappano 2008: 15), who is classifiable as properly disabled in sport is not as clear-cut as one might assume. These binaries are fragile and, therefore, require constant maintenance and surveillance.

All that being said, bringing in a disability lens to sex testing practices may still seem out of place. In the introduction to Kim Q. Hall’s edited collection, Feminist Disability Studies, speaking of Semenya, K. Hall contends that intersex is a disability issue even if “at first glance it may seem strange to discuss the controversy surrounding Semenya’s victory in [...] a book about feminist disability studies” (2011: 3). Semenya “neither self-identifies as nor is widely perceived to be disabled” (2011: 3), but she is pathologized and apparently innately abnormal, disordered, disabled, or diseased. Consequently, drawing from Clare ([1999] 2009), K. Hall posits, Semenya’s remarkable athletic abilities and accomplishments may exemplify the overcoming, supercrip narrative (2011: 3).

The crux, I believe, of the apparent strangeness of analyzing the controversy around Semenya and sex testing in disability terms is that sex and disability are often conceptualized and
treated as separate issues. As Alexandre Baril (2015a) describes, when sex enters a conversation about disability, the issue is presumably no longer about disability. Drawing connections between trans and disability theories, Baril writes:

If research exploring the lived experiences of people lacking a particular ability or limb is worthwhile, how can the exclusion of individuals who lack specific genitalia be justified? If the implications for a person’s sexuality of having only one leg are a suitable subject for disability studies, then I submit that the experiences of trans men without penises, among others, are as well. The critical point here is that disability studies are concerned with bodies that differ from ableist norms, but stop short at markers of sex/gender; a bodily difference involving the hand, back, and so on, is the domain of disability studies, but the moment genitalia are involved, these differences become the concern of trans, gender, and sexuality studies. (Baril 2015a: 38).

Drawing from Baril and echoing K. Hall (2011), Koyama (2006), Cornwall (2009, 2013, 2015), among others, I highlight that theorizing intersex and disability together is vital if we do not want to “stop short” (Baril 2015a: 38). From there, we can continue reimagining the organization of sport beyond the dissolution of sex tests and sex segregation. We can, drawing from, for example, Goggin and Newell (2000) and Raghoo (in Heilpern 2016), think of other ways to organize sport that are not dependent on dichotomous fe/male and dis/ability (il)logic.

Many scholars (Fausto-Sterling 2000a, 2000b; Kessler 1998; Dreger ed. 1999; G. Davis 2015a, 2015b; Karkazis 2008; Preves 2003; Butler 2004) have demonstrated that intersex anatomies challenge the female-male sex binary. As a result, intersex traits are pathologized and deemed disordered, disabled or diseased. According to bioethicist Robert Sparrow, intersex traits are “analogous” to (paradigmatic) disabilities such as “leglessness or deafness” (2013: 34). With this in mind, Semenya’s suspected disordered or disabled intersex anatomy coupled with her remarkable athleticism complicates the assumed distinction between dis/ability as well as fe/male abilities. This should prompt us to think of sex and disability together.
Consider, for instance, IAAF spokesperson Nick Davies’ comments about Semenya “suffering” from a medical disorder. His commentary points to the tension between ability, hyper-ability, and disability whilst reproducing what Fausto-Sterling refers to as the “rhetoric of tragedy” (2000b: 47). Comparable to the “tragedy of disability” discourse (Peers 2009: 653; also see Dudley-Marling and Paugh 2010), the rhetoric of tragedy masks or justifies interphobic sex testing through ableist discourses. Speaking about Semenya on 20 August 2009, Davies remarks, whilst unofficially outing Semenya, “It’s [Semenya’s intersex trait is] seen as a medical condition. That’s a point to stress. It’s clearly not her fault. It’s who she is physically” (in Ginnane, dir. 2011). Further explained in the pejoratively titled news piece penned by Alastair Jamieson, “Caster Semenya gender row: what is a hermaphrodite?,” Davies notes that Semenya may “suffer [emphasis added] from a genetic disorder which means she has both male and female chromosomes” (Davies qtd. by Jamieson 2009: n.p.). This rhetoric of tragedy, or medical discourse of suffering from an intersex disorder, often centers in conversations about intersex traits despite the fact that the vast majority of medical issues and disabilities many intersex people experience come from the socio-medical response to their intersex traits, not the traits themselves (G. Davis 2013, 2015a; Fausto-Sterling 2000b; Dreger 2013; Danaon and Krämer 2017). This rhetoric functions to elicit pity from (temporarily) non-intersex, enabled individuals and implies there is a need for medical intervention and surveillance (G. Davis 2015a; Danaon and Krämer 2017). In the context of sport, this narrative elicits pity and, if Semenya is determined to be “suffering,” we must find the root of suffering (i.e. the intersex spectre) and remove it. In other words, violence and medically unnecessary procedures are narrated as necessary medical aid.
The idea that Semenya suffers from her physicality is difficult to come terms with because her supposed intersex trait does not cause her evident pain or suffering. Rather than suffer from her assumed intersex anatomy, she suffers from the violent societal response to her physical morphology, gender performance, and sexuality (Ginnane dir. 2011; Karkazis 2016a; Magubane 2014; Cooky, Dycus, and Dworkin 2013). This is clear given that, amidst the accusations, Semenya bluntly states, “I don’t give a shit about athletics anymore” (in Ginnane, dir. 2011). Soundarajan, found in the same situation just years before Semenya, attempted suicide because she was suffering from violent and invasive treatment and inter/national rejection, not her apparent intersex trait (Cooper 2010: 250; Mitra 2014a; Sullican 2011; Dreger 2010). The narrative of suffering masks the fact that these athletes, according to dominant ideologies about gender, sex, gendered ableism, and dis/ability have “unruly” (Fausto-Sterling 2000b: 8) body-minds, not inherent medical problems.

The idea that Semenya suffers from an intersex disorder is also difficult to reconcile when we consider the fact that she is, by most standards – indeed by IOC, IAAF, and International Paralympic Committee (IPC) standards – not disabled. She would not qualify as a Paralympian. Rather, she is read as able-bodied, hyper-able, and (unfairly) advantaged. Hence, in addition to exploiting the ableist rhetoric of tragedy that claims Semenya is pitiously disordered and must be fixed, she is simultaneously framed as unfairly advantaged and, as a result, ought to be excluded from sport until the advantage is levelled. The unfairly advantaged narrative justifies discriminatory exclusion. The media often appeals to this discourse. “There are screams of unfairness that publications like *Sports Illustrated* [SI] have amplified,” Cyd Zeigler writes; “in his latest piece for *SI*, Tim Layden [2016] lays about a bunch of nonsensical fear-mongering from people about Semenya, allowing one person to say her advantage is so huge and so unfair
that it’s like watching the Super Bowl when one team is so much better, you already know the winner” (Zeigler 2016a: n.p.; Layden 2016). In addition to the Super Bowl comparison, Layden emphasizes her “unfeminine” characteristics to bolster his argument: “She is 5’10” and weighs 161 pounds, with muscular arms, broad shoulders and narrow hips. She has a severe jawline, hard and strong, and a competitor’s unflinching eyes” (2016: n.p.). Layden implies these characteristics are antithetical to femininity and women athletes.

After Semenya won the gold medal for the 800m at the 2016 Olympics, the notion that she is unfairly advantaged continued to crop up. Articles, such as The Telegraph’s “Caster Semenya destroys rest of the field to claim easy [emphasis added] gold in women’s 800m final - can anyone beat her?” (Bloom 2016), maintain she is so unfairly advantaged that her win was easy to achieve (also see Tucker 2016). The author, Ben Bloom, asserts that Semenya won with “minimum effort” (2016: n.p.). Acknowledging that athletes have beat Semenya, Bloom presumptuously rationalizes the fact that she did not break a world record because “she prioritised gold over records” (2016: n.p.). Her incredible achievements, steadfast training, numerous sacrifices, and dedication to the sport are effectively erased and delegitimized (Karkazis 2016b). I am reminded of Raghoo’s statement: “the same value is not given to the same achievement” (qtd. by Heilpern 2016: n.p.).

Often, both narratives – Semenya is pitiably disordered and unfairly advantaged – are employed simultaneously. Owen Bowcott, penning an article for The Guardian, explains that Semenya has an “intersex disorder” (2009: n.p.) and, quoting Peter Bowen-Simpkins, a consultant gynecologist, states that she has “an advantage” over other (apparently “real”) women (qtd. by Bowcott 2009: n.p.). This article – undeniably misinformed, discriminatory, and misrepresentative – employs both narratives. In doing so there is an albeit unintended
consequence: the article undermines the notion that a disabled or disordered person as inherently disadvantaged. It points to a contradiction.

On the one hand, the medical community, and institutions like the IAAF and IOC that rely on medical authority, pathologize intersex traits and construe them as disordered, disabled, diseased, disadvantaged, and wrong; these traits must be “fixed.” On the other hand, intersex traits, in the context of sport, are construed as inherently advantaged, powerful, and hyper-able. Narrating a person as disordered and advantaged counters dominant, ableist understandings of the embodied effects of pathologized morphologies and draws our attention to the failings of binary thinking. This apparent contradiction reveals the logical shortcomings of Western dichotomous thinking about sex, gender, dis/order, and dis/ability. Claiming Semenya is both better and worse for supposedly having intersex anatomy, draws attention to the il/logic powerful institutions appeal to in order to justify, uphold, and institutionalize discriminatory ideologies and practices. Since the logic cannot hold, ironically, the supposed hyper-able intersex athlete undermines interphobic and ableist assumptions that the embodied effects of disorders, disabilities, and/or intersex traits are always undesirable, painful, insufferable, and/or disadvantaged.

To expand, the claim that intersex is embodied disadvantage changes depending on who is marked as intersex, what one does with their body-mind, and where they perform. If intersex is attached to or is suspected of haunting a female athlete, that athlete is assumed to be hyper-able and her achievements are admonished and delegitimized. If intersex is attached to a racialized, Black, or Black African woman athlete who is often already construed as unfairly advantaged due to persistent biological racist ideas that claim racialized (particularly Black people) have essential biological attributes that predispose them to be better in sport (Entine 2000; Hoberman
1997; Harrison and Lawrence 2004; P. Miller 1998), that athlete is assumed to be hyper-able and possibly doubly, triply unfairly advantaged. That athlete’s achievements are never legitimate.

These views are evident in Poland’s Joanna Jóźwik’s comments after the 800m race at the 2016 Olympics. Jóźwik finished fifth in the event. Semenya (South Africa) won gold, Francine Niyonsaba (Burundi) was awarded silver, and Margaret Wambui (Kenya) won bronze. Jóźwik stated: “I’m glad I’m the first European, the second white” to cross the finish line (qtd. by Karkazis 2016b: n.p.); “I feel like a silver medalist” (qtd. by M. Adam 2016: n.p.; also see Critchley 2016); “I saw Melissa Bishop who was very disappointed, she improved her personal best and was 4th. It’s sad, and I think she should be the gold medalist” (qtd. by Critchley 2016: n.p.) Jóźwik’s comments are, Karkazis remarks, “unsporting behaviour” (2016b: n.p.). “It’s impossible not to note the optics of this controversy,” Karkazis notes, “the three black women from sub-Saharan Africa ebullient on the podium and the three white global north women feeling they should be there instead” (2016b: n.p.). Plainly put, Jóźwik’s remarks are interphobic, racist, and smack of white entitlement.

There are accounts of Jóźwik and Lynsey Sharp (Great Britain), who placed sixth, publically expressing this racist, “unsporting” behaviour and stating the race was unfair (see J. Parker 2016; T. Morgan 2016; Flanagan 2016; Kanayama 2016; Critchley 2016). However, contrary to Karkazis’ suggestion, Melissa Bishop (Canada), who placed fourth, did not publically voice this concern. Rather, Bishop stated: “Me missing the podium is because I didn’t run fast enough, not because of who was in the race. The only thing I can do is keep competing and keep doing what I love” (qtd. by J. Parker 2016: n.p.). To be clear, the focus was not solely on Semenya. Niyonsaba and Wambui were also rendered suspect intersex and publically questioned in media (see J. Parker 2016; Blatchford 2016). Jóźwik, for example, stated, “the three athletes
who were on the podium raise a lot of controversy. [...] These colleagues have very high testosterone levels, similar to a male’s, which is why they look how they look and run like they run” (qtd. by Critchley 2016: n.p.). In the attempt to repudiate these athletes’ achievements and deny, what many commentators named, their “black excellence” (see Phala 2016; Klein 2016; Essack 2016), Jóźwik’s remark reproduces essentializing interphobic, sexist, gendered ableist, and racist narratives.67

Pistorius also challenges dominant assumptions that disability is always a disadvantage as illustrated by, for example, Smithsonian’s article “Does Double-Amputee Oscar Pistorius Have an Unfair Advantage at the 2012 Olympic Games?” (Eveleth 2012a). The article reads, “science shows that Pistorius uses less energy than his competitors, rising questions about whether or not he should be allowed to compete in London,” the 2012 Olympics (Eveleth 2012a: n.p.). Like (suspect) intersex athletes, in the context of sport, Pistorius’ disabled and allegedly inherently disadvantaged morphology becomes an unfair advantage. The seeming illogic – Pistorius is disabled and advantaged – undermines the ableist narrative that people with disabilities are always and already disadvantaged. This contradiction also challenges the protectionist narrative that athletes with disabilities must be segregated from (temporarily) enabled athletes for their own good. The idea that disabled athletes must remain segregated because people without disabilities would inevitably win due to their innately superior morphologies and abilities is

67 In response to all of the slandering remarks and articles coming from the West, particularly about Semenya, after the 800m race, hashtags, such as, #BlackExcellence (“#BlackExcellence n.d.; also see Mushimiyimana 2016; Danez Smith 2016), #HandsOffCaster (“#HandsOffCaster n.d.), and #BlackGirlMagic (“#BlackGirlMagic n.d.) began trending. Alyssa Klein recounts some of the tweets in her article, “South Africans on Twitter Defend Caster Semenya Against U.S. Media” (2016): “The threat of black excellence creates stupidity from the white world #HandsOffCasterSemenya #HandsOffCaster” (@Thabo_Shinange qtd. by Klein 2016: n.p.); “#HandsOffCaster because Black women shouldn’t have to hold back their greatness to coddle your insecurities & bigotry” (@Kmoeti qtd. by Klein 2016: n.p.); “Whiteness so fragile, questioning whether Caster Semenya should run with women, GTFOH [get the fuck out of here]! #HandsOffCaster #WeLoveCaster” (@KaZihlandlo qtd. by Klein 2016: n.p.). In another article about the terrible and objectifying ways in which Western media was treating Semenya during the 2015 Games, Mbali Phala notes that Semenya’s still “serving black excellence despite the ridiculous amount of bull she’s had to go through” (2016: n.p.).
undermined. The similarity in contradictory, dichotomous discourses used to justify excluding both Pistorius (from competing as an Olympian) and Semenya (from competing unless her body-mind is surveilled and altered) prompts me to think of Pistorius and Semenya on the same continuum even though (suspect) intersex athletes are not necessarily legibly disabled or disordered.

An ostensibly non-intersex competitor’s fear of competing against the “unfairly advantaged ‘hermaphrodites’ who [apparently] regularly defeated ‘normal women’” (Cahn 1994: 111) and insisting that they cyborgize to become “natural” points to another inconsistency in the way sport is presumably organized. That is, in order to “make things fair” and “natural,” women athletes with intersex variations have been subjected to cyborgization (e.g. ingest synthetic HRT to “naturalize” the body-mind and irreversible surgeries to “reorder” the body-mind) so they can compete as “natural” Olympians. At the same time, some argue Pistorius must compete as a Paralympian precisely because he is a cyborg (Kafer 2013). It is clear, narratives used to justify exclusion are selectively chosen to maintain sex and dis/ability segregation and maintain Western ideologies and dominance.

Institutions and people invested in dichotomous, protectionist (Dworkin and Cooky 2012: 22; Jordan-Young and Karkazis 2012) sport sex, non/cyborg, and dis/ability segregation and the colonial export of DSD nomenclature benefit from these logical inconsistencies. And these institutions and people do not face enough mainstream bio/ethical scrutiny. Drawing from Giorgio Agamben’s notion of “a state of exception” (2000, 2005), G. Davis posits,

Medical professionals who frame intersex as an emergency are creating a state of exception that allows them to abandon medical ethics that warn against performing medically unnecessary surgery on children. Once the intersex trait is presented as an emergency and the state of exception is established, medical providers tend to inundate parents with information about intersex. However, the information they present focuses on the alignment of sex, gender, and sexuality as
essentialist characteristics of the body, laying the groundwork for justifying medically unnecessary interventions notably irreversible surgical procedures that many doctors continue to, even today, recommend without any hesitation to parents of newly diagnosed children. (G. Davis 2015a: 23).

G. Davis brilliantly points to how medical professionals “abandon medical ethics,” and therefore commit medical malpractice, by establishing a state of exception. In line with G. Davis’ reasoning, I argue that, with the help of sensationalist media and misrepresentative science, IAAF and IOC policies (e.g. retaining the right to sex test suspect athletes and preventing suspect athletes from competing until tests are conducted) establish a similar state of exception and, in turn, abandon scientific and medical knowledge, medical ethics, and ultimately institutionalize unethical, discriminatory sport practices. As Italy’s Elisa Cusma, a finalist beaten by Semenya in Berlin, claimed Semenya is a man – “She is a man,” Cusma bluntly accused (qtd. by Dimanno 2016: n.p.) – when a woman athlete is accused of being intersex, a hermaphrodite, or a man, she might be prevented from competing until invasive tests are done and analyzed. She is also possibly stripped of her titles and she is publicly slandered for being a gender deceiving freak (Dimanno 2016; Pape 2016a, 2016b; Karkazis 2016). Madeleine Pape, who once had similar views as Cusma, but recently and publicly “stand[s] with Caster Semenya,” describes this state as “nothing short of a modern-day witch-hunt” (2016b: n.p.), a comparison that is eerily apt and reminiscent of the haunting analogy that runs through this dissertation: people with (potential) intersex traits are treated as if they house a spectre that must be found, killed, cast out, exorcized.

When this state of exception is created, scientific evidence that demonstrates sex is neither binary nor an objective, identifiable category is abandoned. The fact that scientific evidence cannot support the claim that athletes with intersex anatomy are unfairly better at sport is ignored (Simpson et al. 2000; Jordan-Young and Karkazis 2012; Karkazis 2016b). The fact that there is no evidence to suggest that athletic abilities are purely a matter of, or exclusively
extend from, sex (however sex is defined) is disregarded (Dworkin and Cooky 2012; Zaccone 2010). And while coercive policies regarding the medical interventions needed to re/enter competition are still being debated and may change, people in positions of power are still fighting for coercive, medically unnecessary policies that (re)solidify compulsory dyadism. To emphasize the coercive aspect, consider HRT. If policies surrounding HRT are reinstated many athletes may not really have a choice to simply reject HRT and leave sport. For many athletes, sport prize money and corporate endorsements are a main source of income for themselves and their families. Hence, the “choice” to undergo HRT or not compete in sport does not really seem like a choice at all. Coercing athletes to undergo unnecessary procedures does not align with medical ethics. Outside of sport, there are arguments and policies made that endorse coercing patients to undergo life-saving medical treatments (Glick 2000; Conly 2014; O’Neill 2003), but coercing athletes to undergo unnecessary and irreversible procedures to make their morphologies conform to the false sex dyad cannot be ethically justified.

Nevertheless, sex testing and coercive policies are narrated as precisely that: fair and ethical. Sport governing bodies that abandon medical ethics are construed as acting ethically because these tests and practices are in the name of fairness. They abandon medical ethics and, as is the case with the IAAF, their own Code of Ethics: “[t]here shall be no discrimination in Athletics on the basis of race, sex, ethnic origin, colour, culture, religion, political opinion, marital status, sexual orientation, or any other unfair or other irrelevant factor” (IAAF 2015: C2.17) and “all forms of harassment in Athletics, be it physical, verbal, mental or sexual, are prohibited” (2015: C3.19). The code clearly prohibits discrimination, but athletes with intersex traits, women athletes, athletes of colour, and trans athletes have been, and remain, discriminated against, harassed, subjected to violence, and coercively cyborized in the name of fair play.
Referring back to Nick Davies’ assertion that Semenya “suffers” from a genetic medical condition and Sparrow’s proposal that intersex traits are “analogous” to other disabilities, namely “leglessness or deafness” (2013: 34), if one took these assertions seriously one must acknowledge that sport is not and cannot be sex, dis/ability, non/cyborg segregated. That is, in the context of sport, women athletes with (suspect) intersex traits do not just threaten the sex and gender binaries, they also threaten deeply rooted sexist beliefs about the in/abilities of women and the divide between dis/abled, ab/normal, un/natural, non/cyborg, and Paralympian-Olympian. When narrated as medically disordered or understood as falling under the category disability, intersex calls us to reconsider what qualifies one as a Paralympian or Olympian and to rethink how sport ought to be organized. Intersex challenges what we assume athletes with disabilities look like, what Olympians and Paralympians may look like. Considering the IOC and IAAF’s response to the intersex spectre – working to maintain coercive policies that require athletes to be subjected to various “technologies of gender” (Preciado 2013: 387) so they perform a specific kind of “biodrag” (2013: 191) – alongside Kafer’s (2013) analysis of the cyborg athlete, draws attention to the fact that cyborgs are not always (legible) Paralympians.

**Conclusion**

Intersex studies scholars, activists, and advocates rightfully remain critical of the institutionalized discriminatory treatment of (suspect) intersex athletes and compulsory dyadism. Similarly, disability studies scholars, activists, and advocates rightfully remain critical of the treatment and representations of athletes with disabilities. Nevertheless, the discriminatory treatment of athletes with disabilities and athletes with (suspect) intersex traits are presumed to be, and are treated as, distinct academic, social, and human rights issues. Drawing connections
between both non-normate embodiments, embodiments that haunt all people, helps avoid “stigmaphobic distancing” (McRuer 2006: 85) between both groups. And, when theorized together in the context of sport, the seemingly justified segregation between, male-female, Paralympian-Olympian, and non-cyborg blurs; the fact that these distinctions are rooted in Western colonial, imperial ideologies about body-mind morphologies becomes evident. This theorizing productively draws links between intersex and disability studies and movements and points to a location where both studies and movements, in addition to anti-colonial and anti-racist studies and movements, can productively align to contest systemic, intersecting oppressive policies.

Theoretically, I maintain that sport ought not be sex or dis/ability segregated, dichotomously or otherwise. I like to imagine creative, inventive sports arenas where all sorts of cyborgian, dis/abled, dis/ordered, inter/sexed, gendered, and racialized people come together to reimagine how we play, move, and compete. I like to imagine a future in which sports arenas actually strive to and fulfill the modern Olympic goals of cultivating and “promot[ing] peace,” “unit[ing] all people and build[ing] bridges between all cultures” and treating “all people” as “equal[s], regardless of their ethnicity, gender or faith,” or race, dis/ability, sex, or cyborgian state (“Support #Olympicpeace” n.d.: n.p.). If the goal is to break down barriers by building figurative bridges, creating and reinforcing barriers by segregating sport prevents this goal from manifesting. Reinforcing barriers does not just affect specific individual athletes, doing so is a colonial practice. Sex and dis/ability binaries and segregated sports represent a very specific cultural approach, namely a Western colonial approach, to classifying, organizing, thinking about, and treating people. This approach is not only inapplicable in the context of international sport because it does not reflect the diversity of body-minds or numerous communities and
countries, but it also naturalizes and institutionalizes myriad forms of violence. Sex and
dis/ability segregated sport is ethically intolerable.

My argument, at least in part, echoes some people with disabilities who maintain that
“the notion of a Paralympics is ethically unacceptable:”

For some people with disability – a minority – the notion of a Paralympics is
ethically unacceptable, even if in the real world it does give some people with
disability the opportunity to achieve in sport. For these, the existence of a special
event for people identified as having disability is a painful reminder of inequity
and injustice, and its presence perpetuates the discourse of “special needs” and
“special events” – excluded from the moral community. It occurs in a world
where oppression and segregation have been the collective experience of people
with disabilities (Abberley, 1987; Barnes et al., 1999). [...] It is certainly
remarkable that the claims of people with disability for participation in
mainstream society stand in stark and unremarkable contrast to a sporting event
where a select few medically defined disability types are organised into yet
another special or separate event. (Goggin and Newell 2000: 75).

Segregation and “special” events (see Clare [1999] 2009; Berger 2013; Linton 1998; Wendell
1996; Omanksy Gordon and Rosenblum 2001; Kleege 1999; Koch 2004; McRuer 2006) are
normalized and deemed necessary. Yet, they are, according to some people with disabilities,
exclusionary. Since Goggin and Newell’s statement that a minority of people with disabilities
demean the Paralympics unacceptable, a survey was conducted that reveals this view is now
more widespread (“Scope Paralympics Survey” 2011). Of the 386 people with disabilities who were
consulted, 65% of participants support jettisoning the Paralympics entirely and, instead, allowing
athletes with disabilities to compete in the Olympics. Rick Hansen (2010) agrees and proposes
that the two Games merge. The resulting Games, Hansen (2010) imagines, could draw from the
ways the Paralympics and even the Olympics currently organize sport based on people’s body-
minds and capacities. Jonathan Migneault reports on his interview with Hansen: “Some sports,
like boxing, [...] segregate athletes based on their size and weight. [...] Hansen said it would not
be a big jump to acknowledge the differences between able-bodied athletes, and those with
Recognizing the numerous logistical problems with a merger, namely accommodating thousands more athletes in the same space and at the same time (Heilpern 2016), the IPC stated that they are “very keen” at the prospect and they “would maintain the number of athletes” (qtd. by D. Rose 2016: n.p). They would ensure the number of athletes with disabilities would not shrink with a merger. Similar to J. Harper’s concern for “the very fabric of women’s sport” (qtd. by C. Bennett 2016: n.p.), Paralympian Baroness Tanni Grey-Thompson worries that, if merged, the Paralympics would “disappear off the face of the earth” (qtd. by D. Rose 2016: n.p.). Athletes with disabilities would likely be pushed out of most competitions and the rich history of the Paralympics could be erased, lost.

It is time to start reimagining sport differently and contesting the ideological underpinnings of sport sex and dis/ability segregation. However, even if it were possible at this moment, I am not sure it is time to entirely institute sport desegregation because women and people with disabilities would likely be remarginalized and excluded. Before we proceed with desegregation, we need to institute changes that ensure, to add to Jordan-Young and Karkazis’ proposal (2012), gender, sex, racial, national, and disability equity through, for instance, equal access to opportunity, resources, healthcare, and training, as well as equal media coverage, prohibiting sex testing, and funding redistribution. “[I]t is time to refocus policy discussions at every level so that sex segregation,” as well as dis/ability segregation, are “means to achieve fairness, not the ultimate goal” (Jordan-Young and Karkazis 2012: n.p.; also see Milner and Braddock 2016). A good place to start is entertaining the idea that the Paralympics take place before the Olympics. The local bid leaders for the Boston 2024 Games are doing just that.
After the 2016 Olympics, yet before the Paralympics took place, there were “cuts to venues, workforce, and transportation plans;” “[t]icket sales were abysmal” and “[d]elays in travel-grant payments by Rio organizers put the participation of athletes from 10 countries in jeopardy. […] [S]peculation spread that the […] troubles might force the cancellation of the Paralympics” (Springer 2016: n.p.; also see Gibson 2016; Heilpern 2016). Having the Paralympics before the Olympics would ensure the Paralympics would not be an afterthought and Paralympic competition would not be placed in jeopardy (Springer 2016).

Anti-ableist, anti-colonial, and anti-interphobic analyses show us that sport segregation is not the only organizational model. Decolonizing sports mega-events ought not be limited to ensuring that countries in the Global South have access to events (see Appadurai 2015; Hayhurst 2014; Hern 2013; Darby 2002, 2017; Malcolm and Waldman 2017; Darnell and Hayhurst 2011; Nauright 2013; Bale 2002). Decolonizing sport requires us to rethink and reorganize binary models. There are other ways of thinking about disability, body-mind diversity, sex, race, nationality, and gender and various scholars and other cultures give us alternative, less oppressive and pathologizing options. For example, recall India’s traditional non-dichotomous sex model that was decimated and undermined by Western colonial and imperial forces (N. Menon 2011; Mitra 2014a; Reddy 2005; Atluri 2012). We can also look towards the over 130 North American Indigenous communities that historically and/or currently recognize third or fourth gender and/or sex categories because they acknowledge and structure their lives around various genders, sexual anatomies, and sexualities (Roscoe 1992, 1998; W. Thomas and Jacobs 1999; Vigneault 2011; Warnke 2011; W. Williams 1992). The two-sex model is not inevitable. That said, current organizations and the people in power cannot merely look towards or draw from different models and communities. As Raghoo explains, “whatever happens” – Paralympic-
Olympic merger, hosting the Paralympics before the Olympics, dissolving the Paralympics, or dissolving the Olympics – “the athletes [with disabilities] have to be at the very centre of whatever decision is made” (qtd. by Heilpern 2016: n.p.). Equally, athletes from all participating nations, athletes of colour, and women, intersex, queer, and trans athletes must be a central to the reorganization process. We have “the potential to extend beyond the sex/gender binary in sport” (Cooky, Dycus, and Dworkin 2013: 50) and the dis/ability binary in sport which can lead to “the eradication of sex, gender, race, and sexuality” and disability injustice (2013: 51). Equally, we have the potential and tools to decolonize sport that can extend to the eradication of myriad forms of discrimination and create new possible worlds where spectres knowingly and welcomingly haunt.
Chapter 4

Contemporary Eugenics: Preimplantation Genetic Diagnosis and Interphobia

Intersex is [understood to be] an undesirable outcome of pregnancy and [this] is visible in medical technologies such as PGD [...] and may lead to the erasure of intersex in society. (Miriam van der Have at United Nations Human Rights 2017: n.p.)

Introduction

Morgan Carpenter (2016b), intersex activist, consultant, and co-executive director of OII Australia, observes a trend in which fertility clinics sponsor LGBTQI events in Australia. These clinics provide and promote a reproductive technology – Preimplantation Genetic Diagnosis (PGD) – capable of detecting (some) intersex variations in embryos so (prospective) parents can select for non-intersex embryos to implant via in vitro fertilization (IVF). Originally developed to circumvent life-threatening genetic diseases (e.g. Tay-Sachs)68 (Behrmann and Ravitsky 2013), PGD can be and is used to test for hundreds of characteristics, including non-fatal but culturally devalued morphologies like Down syndrome, deafness, blindness, and a variety of intersex variations “such as Androgen Insensitivity Syndrome (AIS), Congenital Adrenal Hyperplasia (CAH), and sex chromosome differences such as 47,XXY [Klinefelter Syndrome] and 45,XO [Turner Syndrome]” (Carpenter qtd. by Amato 2016: 17; also see Carpenter 2014b; Holland 2003). In other words, the embryo can be preemptively screened for queer, crip, disabled, and intersex spectres so potentially pregnant people will not house and gestate such a ghostly “monstrosity.”69

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68 I must note, the ethical implications of selecting against Tay-Sachs is not straightforward; it is debated and contested (see Saxton 2006; Shakespeare 1998; Holland 2003).
69 It is often assumed that only women can get pregnant, as various quotations throughout this chapter illustrate (see, for example, Crowe 2000: 176). However, as Erin Leigh Courtice and I note elsewhere (Orr and Courtice 2017), given that many intersex, trans, genderqueer, and non-binary people can and do also get pregnant, throughout this chapter I use the more inclusive and representative expressions “pregnant people” and “(potentially) pregnant people.”
A representative from City Fertility Centre, for example, spoke at the “LBQ Women’s Health and Wellbeing Conference” in 2016, held by the Victorian AIDS Council. The representative endorsed using PGD to screen out “genetic abnormalities” such as the intersex variation Klinefelter Syndrome (47,XXY) (Carpenter 2016b: n.p.). Rainbow Fertility also sponsored a conference on “LGBTIQ” inclusion in higher education at the University of Western Sydney in June [2016]. Rainbow Fertility provides services for “the LGBTI community” [...] The organisation also supports or provides “preimplantation genetic diagnosis” to eliminate “severe genetic disorders” including Turner Syndrome. Turner Syndrome is a chromosomal [intersex] variation. (Carpenter 2016b: n.p.).

Put simply, fertility clinics that sponsor, support, and speak at LGBTQI events, provide and promote a technology that can select against the “I” in LGBTQI.

This practice is not unique to Australia. Using PGD to detect intersex traits is legal in Canada (O’Neill and Blackmer 2015). In fact, PGD “remains unregulated” in Canada (O’Neill and Blackmer 2015: 10). Further, many of the fertility clinics that provide PGD in Canada promote themselves as LGBTQI friendly (see, for example, LGBTQ Parenting Network’s “Directory” of Assisted Reproductive Services). This paradoxical promotion is especially concerning in Ontario, Canada. More Ontarians than ever before are seeking out IVF (Blackwell 2016; Church 2015) because, in December 2015, Ontario Health Insurance Plan (OHIP) began covering one round of IVF services to all Ontarians under the age of forty-three with fertility issues, “regardless of sex, gender, sexual orientation or family status” (Ministry of Health and Long-Term Care 2015: n.p.).

70 Many Ontarians are learning about and are confronted with PGD

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70 That being said, many people who apparently do not have fertility issues “must still pay for IVF” such as “[g]ay men who use their own sperm, a surrogate and egg donor,” “[l]esbian women who wish to have one woman carry the child while the other partner contributes her egg” and trans men “who retain the reproductive ability to carry a child, but can only become pregnant through an embryo transfer” (“Ontario Government to Fund IVF” 2014). “Fertility issues” is narrowly defined and, as a result, the OHIP coverage excludes some queer people who desire to be biologically related to their children. Even though the rhetoric used to promote the IVF coverage seems inclusive – “regardless of sex, gender, sexual orientation, or family status” (Ministry of Health and Long-Term Care 2015:
as they take advantage of the recent IVF coverage. Even though not all people who engage with IVF will engage with PGD, providing more IVF access to Ontarians, particularly (some) LGBTQI Ontarians, is ironic when juxtaposed with the interphobic usage of PGD.

While some intersex studies scholars, activists, and advocates critique reproductive technologies like PGD and are concerned with the eugenic implications of anti-intersex selection (G. Davis 2013; Carpenter 2016b; Preves 2003; Costello 2014c; Astorino 2015; Bauer, Truffer, and Plattner 2014; Orr 2015, 2016b), there is “little written” (Sparrow 2013: 30) on this issue compared to other intersex bioethical matters (e.g. IGM). In addition to voiced concerns about PGD and interphobic selection (Carpenter 2016b; G. Davis 2013), scholars and activists are also troubled by the experimental drug, Dexamethasone (DEX). DEX, a drug prescribed to a person who is pregnant with a fetus with CAH, is intended to avert genital and behavioural “masculinization” or “virilization” of the fetus (see Chapter 2). Even at the risk of the pregnant person and fetus’ safety, DEX is prescribed to prevent the development of nonfatal variant genitals and to reduce the chance of the infant looking or acting “unfeminine” and developing “lesbianism” or “bisexuality” (Dreger, Feder, and Tamar-Mattis 2012; “Dreger, Feder and Tamar-Mattis on Dex” 2012; Reis and Kessler 2010; James 2012; “On the use of Dex” 2010; Sytsma 2006b). In addition to a smattering of published articles that focus on intersex and reproductive technologies (Holmes 2008b; Dreger, Feder, and Tamar-Mattis 2012; James 2012; Orr 2016b), there is only one volume, published by The American Journal of Bioethics (vol. 13, no. 10), devoted entirely to PGD and anti-intersex selection. Given that PGD and anti-intersex selection is actively promoted and PGD is used all over the world, in this chapter, I attend to the

n.p.) – a number of LGBTQI individuals cannot access this IVF coverage. Some queer family formations are, therefore, prevented.

71 Even a very brief visit to a fertility clinic’s website reveals a great deal of information about PGD. For instance, one of the ten listed “fertility options” on Ottawa Fertility Centre’s website is PGD (“PGD and PGS” 2014: n.p.).
use of PGD for anti-intersex selection and aim to add to the relatively scarce literature on this seemingly niche matter.

While there is limited literature on this topic, it is important to note that intersex studies scholars and activists are, relatively speaking, quite new to debates about the eugenic potential of reproductive technologies. In contrast, disability studies scholars and activists have been engaged in debates concerning reproductive technologies – amniocentesis and chorionic villus sampling (CVS), state-sanctioned sterilization, ultrasounds, abortion, PGD – and their eugenic implications for decades (Hubbard 2013; Shakespeare 1998; Magnet 2013; J. Green and Statham 1996; Stapleford 2014; Henry 2013; Davidson 2012; L. Davis 1995, 2012, 2013a; L. Davis, ed. 2013; Lamp and Cleigh 2011; Waldschmidt 2015; Wasserman 2009; Hull 2009; Parens and Asch 1999; Parens and Asch eds. 2000; Kaposy 2013, 2014, 2015; Kaposy and Downie 2008).

“[R]eject[ing] approaches to disability that seek to eradicate it” (Berger 2013: 14), disability studies scholars and activists outline the history of (ableist) eugenics, examine current reproductive technologies as new forms of eugenics, analyze discourses around reproductive technologies that extol able-bodiedness, and critique reproductive policies for excluding the perspectives of people with disabilities. Essentially, they challenge the ableist idea that disabled embodiments are sites of “no good future[s]” (Kafer 2013: 3). It is assumed that people with disabilities should not be born “for their own good” because they presumably would have insufferably low qualities of life (Kafer 2013; Goodley 2011, 2014; Linton 1998; Abberley 1987; 72 A recently developed test known as “MaterniT21” is now on the market. Intended to replace amniocentesis and CVS, MaterniT21 is noninvasive, does not carry the risk of miscarriage, and can accurately diagnose Down syndrome sooner (Kaposy 2013). Jaime L. Natoli and colleagues (2012) report that women terminate their pregnancies 60-90% of the time when their fetus is diagnosed with Down syndrome. Chris Kaposy (2013) believes “that the introduction of MaterniT21 will likely increase the overall incidence of abortion after prenatal diagnosis of Down syndrome” (2013: 300). Women typically refuse invasive screening tests because of the possibility of miscarriage, “not because they were opposed to the idea of prenatal testing or to abortion” (Kaposy 2013: 302; also see Rapp 1999). MaterniT21 is noninvasive; it does not pose risks. As a result, women will be more likely to agree to MaterniT21; termination rates will likely increase.
Nevertheless, employing reproductive technologies to prevent people with disabilities from having children or to prevent the implantation/gestation/birth of embryos/fetuses/people with disabilities and disordered traits remains intuitively benevolent to many bioethicists, medical professionals, and the general public (see Sparrow 2013; Trafimow 2013; Savulescu 2001, 2007).

Given disability studies scholars’ contribution to the study of reproductive technologies and their eugenic implications, I draw from this body of literature and advocate that future work on anti-intersex PGD employment integrate disability frameworks and theories. Indeed, of the few texts that address PGD and intersex, only a few consider disability (Holmes 2008b; Sparrow 2013; Trafimow 2013; Orr 2016b) and only a couple (Holmes 2008b; Orr 2016b) endorse anti-ableist frameworks. Disability studies provides invaluable analytical tools. And, more importantly, a disability lens is imperative because, “the medical presupposition that intersex characteristics are inherently disabling to social viability remains the take-for-granted truth from which clinical practice proceeds” (Holmes 2008b: 169). Intersex characteristics are presented as innately disabled, diseased, and disordered by medical professionals, certain bioethicists, and in Canadian policies (see O’Neill and Blackmer 2015; Sparrow 2013; Trafimow 2013; G. Davis 2015a; Mitra 2014a). For example, Robert Sparrow claims that intersex is analogous to “leglessness” and “deafness” and insists these morphologies deviate from “species-typical functioning” (2013: 32). Thus, according to Sparrow (2013), using PGD to select against intersex, like leglessness and deafness, is ethical, “perhaps even morally required” (2013: 34). Or, in other terms, doing so is an act of “procreative beneficence” (Savulescu 2001: 413; also see Savulescu 2007). This ableist delineation of intersex variations underlines the relationship between intersex and disability as well as compulsory dyadism and able-bodiedness; it highlights
the contemporary integration of intersex into conventional, ableist notions of disability. To explore this relationship, this chapter analyzes the use of PGD for anti-intersex selection through a disability studies lens and provides a critical discourse analysis of the pertinent bioethical literatures whilst weaving in analyses of Canadian policy and fertility clinic documents.

Questions guiding this chapter include: is this practice eugenic? What ideologies underpin interphobic PGD usage? How is anti-intersex selection justified? How do we reconcile reproductive freedom with this potentially eugenic technology? To answer these questions, I first explain in more detail what PGD is and what intersex variations can be detected by the screening technology. Then, drawing from disability studies literature, I consider whether or not using PGD to select against intersex is eugenic. Next, providing a literature review of *The American Journal of Bioethics* volume 13, number 10 (2013), the only entire volume dedicated to intersex and PGD, I outline the current state of the debate. Critically analyzing the arguments for and against anti-intersex selection, I identify that the justifications for anti-intersex selection are problematically rooted in consequentialist logic, an outdated (Shildrick 2005) mode of ethical reasoning that relies on “objective” dichotomous equations of pleasure-suffering to determine one’s quality of life.

Many scholars demonstrate that violent medical and social responses to intersex are fueled by queerphobia (Behrmann and Ravitsky 2013; G Davis 2015a; Rapp 1999; Karkazis 2008; Feder 2014). For example, intersex is often assumed to cause, or is conflated with, gay, lesbian, bisexual, trans, queer, and gender nonconforming identities, performances, and desires (Feder 2014: 41; Holmes 2000: 85). As a result, I consider whether interphobic employment of PGD may also be rooted in medical professionals’ and (potential) parents’ queerphobia. Put differently, perhaps PGD is used as a tool to mitigate deviancy from compulsory heterosexuality
and dyadism. Next, I analyze the ableist discourses that appear in literature about PGD and anti-intersex selection. I assess the ableist discourses as a means for medical professionals to “reclaim jurisdiction” over intersex (G. Davis 2015a: 88) and promote compulsory able-bodiedness.

If anti-intersex selection via PGD is a form of eugenics, the legacy of institutionalized eugenics inside and outside of Canada continues (see Hansen and King 2001; Grekul, Krahn, and Odynak 2004; McLaren [1990] 2014). If this interphobic eugenic practice is rooted in or justified via queerphobia and ableism, this practice seeks to eradicate not only intersex, but also queerness and disability. And, this technology is ironically promoted to LGBTQI folks. Hence, LGBTQI communities not only need to be aware of the paradox here, but, this proves good reason for LGBTQ people to more actively align with intersex and disability activism and intersex activism to more actively align with disability. We must remind ourselves that queerphobia, interphobia, and ableism are not fundamentally distinct from each other. Therefore, we must remain vigilant to the ways that all of these intersecting marginalized communities are targeted for eradication especially when liberal, tolerant, homonational, and inclusive discourses appear to dominate mainstream discourse (see W. Brown 2006; Puar 2007, 2013a; E. Chen 2013; Dryden and Lenon eds. 2015).

PGD: Confronting, Exorcising, and Eliminating Intersex

“Confronted with the spectre of intersex, modern medicine makes choices available to parents and physicians” to cure or rid the body-mind of the spectre (Sparrow 2013: 29). In addition to, for example surgery and HRT, one of those “choices” presented to (prospective) parents is PGD. PGD would prevent the potentially pregnant person from housing and birthing the phantasm. PGD was originally developed to avoid life-threatening genetic diseases (Behrmann and
Ravitsky 2013: 39). However, PGD can test for hundreds of “undesirable,” “disabled” genetic variations that are “undesirable simply because they fall outside the scope of what is considered by some to be ‘normal’” (Behrmann and Ravitsky 2013: 39). Society allegedly cannot invest its “reproductive futurism” (Edelman 2004: 3) in non-normate, spectral body-minds; such morphologies are not wanted in the future since “the value of a disability-free future is seen as self-evident” (Kafer 2013: 3). The intersex traits PGD is used to detect include, for instance, CAH, Klinefelter Syndrome, Androgen Insensitivity Syndrome (AIS), Partial Androgen Insensitivity Syndrome (PAIS), and Turner Syndrome (Amor 2012; Carpenter 2014b; Carpenter in Amato 2016: 17). PGD cannot detect all intersex characteristics. Not all intersex traits are genetic. Many intersex variations arise spontaneously and are influenced by in utero environmental conditions (Amor 2012; Lanfranco et al. 2004; Sparrow 2013; Gupta and Freeman 2013). The possibility of employing PGD to select against intersex depends on the intersex variation in question and its etiology.

PGD is costly. So, relatively few people access the technology, namely affluent, highly educated, white women/couples (Couture et al. 2013; Jain and Hornstein 2005).\(^73\) Hence, it is reasonable to assume that using PGD to select against intersex is, currently, relatively rare.\(^74\)

\(^{73}\) The cost of PGD varies. For example, in 2001, Joep P.M. Geraedts and colleagues report, “[t]he charges for PGD [in Europe] vary between about €600 and €4000 depending (among other reasons) on the number of embryos diagnosed and the type of disease involved. This sum is sometimes higher for the first treatment cycle than for subsequent cycles. [...] In a number of centres the charges levied on people from abroad are higher than those for local patients” (2001: 1091). Similarly, “[t]he cost of PGD,” as articulated on the Government of Canada website, “will depend on the specific test” and “may vary across Canada” (“Genetic testing and screening” 2013: n.p.) Looking at Ottawa Fertility Centre, PGD costs vary between $350 and $3,200; such costs exclude logistics, courier, IVF, and other possible additional fees (e.g. embryo freezing) (“Fees” n.d.: n.p.).

\(^{74}\) Statistics concerning how common PGD is used to detect and select against intersex variations are not available. However, there are some statistics concerning how frequently people choose to abort a fetus diagnosed with an intersex trait. A meta-analysis of fetal termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, Turner syndrome (an intersex variation), and Klinefelter syndrome (an intersex variation), concluded that, on average, 58% of fetuses diagnosed with Klinefelter syndrome were terminated and 72% of fetuses with Turner Syndrome were terminated (Mansfield, Hopfer, and Marteau 1999). Céline M. Girardin and Guy Van Vliet compiled the rates of pregnancy termination following prenatal diagnosis of Klinefelter syndrome (an intersex variation) from various places (2011). Some statistics include: in British Columbia, Canada, from 1971-1997, 88%
That said, we cannot underestimate the possible future ubiquitous use of PGD and its broader eugenic implications. Technologies advance and spread quickly. Many reproductive technologies that were previously available to only wealthy people are now more readily accessible (e.g. contraceptives, ultrasounds, amniocentesis, IVF). While PGD is not, for instance, covered by provincial healthcare plans in Canada and it is not typically covered by private insurance providers (Canadian Association of Genetic Counsellors 2009), future PGD coverage is conceivable. Looking south, it is also rare for American insurance providers to cover PGD. However, one can easily access online forums to learn about strategies regarding how to persuade insurance providers to cover PGD costs (see Sherbahn n.d.; Haney 2012). Some scholars believe that PGD may be standard practice in the near future. According to Jason Behrmann and Vardit Ravitsky, “PGD may soon become an integral part of in vitro fertilization” and, “as this happens, many more conditions may ‘creep’ into the screening process” (2013: 39; also see Couture et al. 2013). As a result, a bioethical analysis of PGD and the ideologies that

of the diagnosed fetuses were terminated; in Switzerland from 1980-2001, 74% were terminated; in California, USA, from 1983-2003, 70% were terminated; in Germany from 1989-1998, 17% were terminated; in Denmark from 1970-2000, 70% were terminated (Girardin and Van Vliet 2011: 918; also see Bauer, Truffer, and Plattner 2014). The second edition of the World Atlas of Birth Defects published by the World Health Organization, which compiles data from 1993-1998, indicates, for example, in Alberta, Canada, on average, 20% of fetuses prenatally diagnosed as “indeterminately sexed” were terminated; in Switzerland, 47% were terminated; in Australia, 16.68% were terminated (2003: 123; also see Bauer, Truffer, and Plattner 2014).

75 For example, in Ontario, in addition to the recently expanded IVF coverage, OHIP covers one complete and one limited ultrasound for “low risk” or “normal” pregnancies (“Fact Sheet: Ultrasound for Pregnancy” n.d.) and OHIP will cover amniocentesis and/or CVS for “high risk” pregnancies (“Prenatal Diagnosis Testing” n.d.). Some of the risks associated with IVF include miscarriage, premature delivery and low birth weight, ovarian hyperstimulation syndrome (i.e. one’s ovaries become swollen and painful), ectopic pregnancy, stress, and egg-retrieval procedure complications (e.g. bleeding, infection, damage to bowel, bladder or blood vessels). There are no known risks associated with ultrasounds. Some of the risks associated with amniocentesis and CVS include miscarriage, infection, and Rh sensitization, in which the pregnant person’s Rh-negative blood mixes with the fetus’ Rh-positive blood and produces antibodies that attack the fetus’ red blood cells.

76 In addition to intersex already “creeping” into screening processes, we may see other culturally devalued characteristics and disabilities creep into PGD screening, such as autism and cleft lip or palate. The genetic factors for clefting and autism have not been determined. However, speaking of autism, Sher Institute for Reproductive Medicine, an American institute with numerous fertility clinics, claim “this could all change in the next few years with the rapid advancement in genetic research” (“An Update on Autism” 2015: n.p.). Likewise, Marie M. Tolarova and Lateefa Al-Kharafi describe, “with rapidly advancing knowledge in medical genetics and with new DNA diagnostic technologies, more cleft lip and palate anomalies are diagnosed” (2015: n.p.). Sebastiaan Mastenbroek et
underpin anti-intersex selection are “essential” (Aurenque and Ehni 2013: 55). A bioethical analysis “is all the more necessary,” according to Diana Aurenque and Hans-Jörg Ehni, because “demand for it [PGD for anti-intersex selection] appears to be primarily cosmetic rather than medical” (2013: 55). Moreover, since PGD is promoted and/or under/unregulated in various countries (e.g. America [Nisker 2013; Deeney 2013]; Canada [O’Neill and Blackmer 2015: 10]; Australia [Carpenter 2016b; Government of Australia’s Ethical Guidelines 2017], UK [Handyside et al. 2013]), this bioethical concern may be more pressing than initially assumed.

**Eugenic Implications of PGD**

Curtis E. Hinkle, intersex activist and founder of OII, and Hida Viloria, intersex activist, Chairperson of OII, and founder and Executive Director of OII-USA, write, “surgical ‘normalization’ of intersex bodies is an attempt, like eugenics [emphasis added], to remove differences which some people have decided are undesirable” (2012: n.p.; also qtd. by G. Davis 2015a: 52). However, “eugenics” was not and is not just a simile. Karl Pearson, a leading figure of the modern eugenic movement in the early twentieth century, published data regarding assumed inheritable and undesirable characteristics including “hermaphroditism [emphasis added], hemophilia, cleft palate, harelip, tuberculosis, diabetes, deaf-mutism, polydactyly (more than five fingers) or brachydactyly (stub fingers), insanity, and mental deficiency” (qtd. by Kevles 1985: 39; also qtd. by L. Davis 2013a: 6; also see Dykerman 2015). “Hermaphroditism”

al. report a couple of cases where PGD detected cleft lip and palate (2007; also see Paterson et al. 2011). Disability scholars and activists critique the idea that autism is “a crippling disability” (Orsini 2009: 115) and the focus to cure and eliminate both autism and clefting. They worry about the ableism that fuels employing reproductive technologies to eliminate these variations as well as medical professionals “steering” (Bingham 2013: n.p.) parents to abort fetuses with these characteristics (see Chew 2013; Reuben 2015; Abraham 2010; Cox 2014; Paterson et al. 2011; P. Walsh et al. 2013; Botkin 2000; C. Williams, Alderson, and Farsides 2002). Recognizing the eugenic implications, Germany, Austria, Italy, and Switzerland banned using PGD for nonfatal variations (O’Neill and Blackmer 2015: 10; Hyder 2011). The National Ethics Committee in France proposed outlawing PGD because it may be used for non-medical, cosmetic reasons (O’Neill and Blackmer 2015: 10). PGD was not outlawed in France, but it is highly regulated under Article L2131-4-1 (Government of France 2011).
was deemed a degenerate state of being that could be eliminated by eugenic policies and practices. Intersex – “hermaphroditism” – has always been on the eugenic agenda.

Typically associated with the Nazis and the Holocaust, “old-style” eugenics (G. Allen 1989; Garton 2000; Baker 2002; Campbell 2000; S. Long 2015) were popularized in the United Kingdom in the early twentieth century (Sparkes 1999; Farrall 1985; Shakespeare 1998; Hansen and King 2001; McLaren [1990] 2014; Grekul, Krahn, and Odynak 2004; Beaud and Prevost 1996). Old-style eugenics “enjoy[ed] wide currency,” quickly spreading to Canada and America, and were promoted by numerous influential people (Hansen and King 2001: 240; also see L. Davis 2013: 6; Chesterton and Perry eds. 2000; Kevles 1985). Drawing from Charles Darwin’s theory of evolution, Darwin’s half-cousin (Saleeby 2000: 135; Fancher 2009), Sir Francis Galton, coined the term “eugenics” and defined it as “the study of agencies under social control that may improve or impair the racial qualities of future generations, either physically or mentally” (1908: 321). Positioning people with disabilities and other “unviable” individuals (e.g. hermaphrodites, perverts, criminals, racialized people) “along the wayside as evolutionary defectives” (L. Davis 2013b: 3), Galton and his advocates believed that the social body could and ought to be improved by ridding the population of these people. State-sanctioned interventions, such as strict immigration policies, sterilization practices, and strategic family planning, supported this aim to enhance the social body and control “problem populations” (Baker 2002: 672).

78 For example, after hearing Sir Francis Galton deliver a paper titled “Eugenics: its Definition, Scope and Aims,” George Bernard Shaw wrote, “I agree with the paper, and go so far as to say that there is now no reasonable excuse for refusing to face the fact that nothing but eugenic religion can save our civilisation from the fate that has overtaken all previous civilisations” (Shaw qtd. by Saleeby 2000: 136). Emma Goldman, seemingly contrary to her anarchist politics, expressed similar sentiments: “unless birth control was encouraged, the state would ‘legally encourage the increase of paupers, syphilitics, epileptics, dipsomaniacs, cripples, criminals, and degenerates’” (qtd. by L. Davis 2013b: 6; also see Kevles 1985: 90).
It is often assumed eugenic sentiments and policies were eradicated post-WWII (Shakespeare 1998; Kerr and Shakespeare 2002). However, approaching eugenics as “a complicated and heterogeneous series of discourses that have transmogrified into a variety of assumptions and practices” (Baker 2002: 664; also see Gould 1981; Campbell 2000), highlights the fact that eugenic ideologies and practices still enjoy wide currency. Old-style eugenics, characterized by state institutionalized racial and national “improvement,” shifted post-WWII. Post-WWII or “new” eugenics are narrated through seemingly apolitical and objective medical rhetoric and notions of health, welfare, and normality. To clarify, according to old eugenic discourses, people with unviable body-minds pollute the quality of the social body and ought not spread their inferior genes. According to new eugenic discourses, people ought to use reproductive technologies to select for “species-typical functioning” (Sparrow 2013: 32) for the baby’s welfare and against “aneuploidies” such as trisomy 21 (Down syndrome) and Klinefelter syndrome (an intersex variation) (“Genetic Testing [PGD]” 2013: n.p.). There is an identifiable shift from state welfare to individual welfare, from state responsibility to individual responsibility.

Who is responsible for ensuring supposed pollutants (or future spectral noncitizens) are not born shifted from the state to individual parents. Put differently, new eugenics is “operationalised by appeals to individual responsibility for the health of future offspring. The site of intervention in this case is [...] the management of fertility, of conception, such that ‘viable’ embryos of choice, will be implanted in a woman’s body” (Crowe 2000: 176) or other (potentially) pregnant people’s bodies. While there have been shifts from old to new eugenics, the focus on quality control remains the same (Campbell 2000; Crowe 2000). Just like old eugenics, new eugenics “seek to eliminate the birthing of bodies marked as ‘disabled’ or, in the
event of their/our post-natal ‘existence,’ to engage in ‘perfecting’ technologies that morph ableism and enshrine a particular understanding of ableist normativity and (real) human subjectivity” (Campbell 2000: 308). Examples of such “perfecting” or “curative” (Kim 2017) technologies include surgery and HRT that typically violently disabled and can even sterilize people with intersex variations (see Chapter 2).

Nevertheless, even though surgical procedures often result and have resulted in the sterilization of numerous of individuals with intersex traits (Greenberg 2012b: 33-34; Ford 2001: 480; seMbessakwini in Arana 2005: 34; Carpenter 2013c, 2013d; Chapter 2), claiming that sterilizing and altering intersex people’s body-minds or anti-intersex selection via PGD are eugenic may not be self-evident. Viewing eugenics as an ever-shifting discourse rather than a definitive political movement (Baker 2002; L. Davis 2013b; Campbell 2000; Shakespeare 1998; S. Long 2015), however, demonstrates that technologies (or in this case, “technologies of gender” [Preciado 2013: 387]) that have rendered intersex people infertile and have prevented intersex body-minds from being born because they are deemed defective are contemporary forms of eugenics. These procedures are new eugenic practices that apotheosize normative understandings of body-minds.

Using PGD to select against intersex variations is a new eugenic practice and will thus be named as such throughout the rest of this chapter to emphasize the political stakes. But, what sort of eugenic practice? Is it “Gender Eugenics,” as Sparrow inquires (2013: 29)? Yet, “which gender would be the target” (Couture et al. 2013: 59)? Avoiding the common conflation of sex and gender, Vincent Couture and colleagues (2013) note that PGD detects (inter)sex characteristics, not gender. Drawing the same distinction, G. Davis explains that using PGD for intersex eugenics safeguards,
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 [...]. Gender, on the other hand, is a stratification system with consequences at the individual, interactional, and institutional levels of society. (G. Davis 2013: 51).

Interestingly, rather than explicitly argue that the practice is intersex or interphobic eugenics, G. Davis proposes that, since the technology detects and can be used to select against traits typically deemed sex, this practice is sex eugenics. Taking liberties with this argument, one may posit further that this practice is sexist eugenics. Framing said practice as sexist could be productive in legal circumstances. Opposing sexism by prohibiting sex selection because XY “males” will be favoured is widely supported in mainstream culture and reflected in various national policies (e.g. Canada, UK) (Cattapan 2013; O’Neill and Blackmer 2015; Deckha 2007). If people are troubled by the idea of selecting against XX “females” (with “normal” sex characteristics) because it is sexist (Nisker 2013: 48), selecting against another embryo or fetus because of the (un)expected intersex formation of sexual anatomy could be similarly explained as sexist.

Using the discourse of sexism in the Canadian context points to contradictions in Canadian policy. In Canada, sex selection is prohibited because “it contravenes the dignity of human beings” and “may lead to gender discrimination and inequality” (O’Neill and Blackmer 2015: 10). However, there is a caveat in this policy: “selection for the purpose of preventing, diagnosing, or treating sex-linked disorders or diseases is permitted in Canada” (O’Neill and Blackmer 2015: 10). According to medico-scientific definitions of “sex-linked disorders or diseases,” these disorders or diseases include any “abnormality” inherited through sex

79 Chinyere Ezie (2011) similarly argues that the violence intersex people face is, or at least can be legally framed as, sex discrimination.
chromosomes (X or Y). For example, hemophilia, therefore, is a “sex-linked disorder or disease” and some intersex variations also fall under this umbrella. Positioning interphobic PGD employment as sex or sexist selection could enable one to argue that sex(ist) selection, as well as eugenics, is in fact legal in Canada. Ultimately, framing intersex eugenics as sexist could be useful in various circumstances. Nevertheless, there are dangers in linguistically conflating sexism and interphobia.

All that being said, in this chapter, I am primarily concerned with discerning and combating the queerphobia and ableism that underpin the interphobic practice (see Behrmann and Ravitsky 2013: 39; Holmes 2008b; Orr 2016b). Using the language of intersectionality or intersexionality, interphobic eugenics is situated at a complicated intersection where queerphobia, ableism, and interphobia meet and cannot be rendered distinct. Ultimately, intersex eugenic sentiments and practices are also queer and disability eugenics.

Arguments For and Against PGD Intersex Eugenics

Turning our attention to the few scholars engaged in the debate about PGD and intersex eugenics, I address The American Journal of Bioethics, volume 13, number 10 (2013). This volume is unique because it is the only entire collection devoted to, as the first article is titled, “Critically Appraising Prenatal Genetic Diagnosis to Prevent Disorders of Sexual Development: An Opportunity Missed” (McCullough 2013: 1). It is distinctive also because the contributing authors come from a variety of academic fields including, sociology and intersex studies (G. Davis 2013), medical ethics and health policy (McCullough 2013), philosophy (Sparrow 2013; Haramia 2013), gender, sexuality, and feminist studies (Behrmann and Ravitsky 2013; Gupta

80 See Chapter 2, Holmes (2000), Fausto-Sterling (2000b), Jordan-Young (2010), and Oudshoorn (1994) for information concerning the historically recent discovery of chromosomes and the subsequent sexing and gendering of chromosomes.
and Freeman 2013), bioethics and medicine (Behrmann and Ravitsky 2013; Miriam Bentwich 2013), reproductive genetics and science (Nisker 2013), neuroscience (Gupta and Freeman 2013), and psychology (Trafimow 2013).

The main concerns guiding the debate in this collection include: (1) whether or not PGD is an alternative to “normalizing” surgery. Sparrow (2013) believes PGD is a favourable alternative, but Nisker (2013) provides compelling opposing arguments. (2) Is using PGD for intersex eugenics an ethical means to prevent medical and social harms associated with intersex traits? Sparrow (2013) and Trafimow (2013) maintain PGD will prevent harms, not exacerbate them. G. Davis (2013), among others, demonstrate that medical issues attributed to intersex are overstated and discrimination will not be resolved by eliminating intersex body-minds. (3) Would this practice negatively impact societal diversity and the intersex community (or lack thereof)? Some (Sparrow 2013; Trafimow 2013) argue that there is no evident intersex community and so diversity would not be harmed. Other scholars point to transnational intersex communities. (4) Is this practice queerphobic? Behrmann and Ravitsky (2013) claim it is indeed. (5) The last primary point of concern, which is addressed in the conclusion to this chapter, is whether PGD provides people with reproductive freedom. I will discuss these arguments in greater detail and argue that PGD, like all reproductive technologies, is a technology of discipline, choice, and coercion.

**Arguments For and Against PGD Intersex Eugenics:**

**PGD > Surgery?**

The first concern, as noted above, is whether or not PGD is an auspicious alternative to “corrective” surgery or, in other words, disabling curative violence/mutilation. Sparrow posits,
“PGD for those [intersex] conditions that involve serious medical risks for those born with them is morally permissible,” “perhaps even morally required” (2013: 29, 34). “PGD for other ‘cosmetic’ variations in sexual anatomy,” Sparrow continues, “is more defensible than it might first appear” (2013: 29). According to Sparrow, intersex eugenics\textsuperscript{81} is morally permissible, perhaps required, because the harm caused by “corrective” surgery is avoided:

PGD has several advantages over “corrective” surgery if parents are concerned to raise a child with normal sexual anatomy. [...] Questions about the possibility of surgical and/or psychological harms to the individual being “treated,” which looms so large in the context of the debate about surgery for intersex conditions, do not arise in the context of genetic selection. (Sparrow 2013: 31).

For Sparrow, then, parents can avoid considering surgery and the anxiety associated with raising a child with “abnormal” sexual anatomy. No one need be harmed by irreversible, disabling, and mutilating procedures.

Sparrow’s position “worries” Nisker (2013: 48) because it privileges parents’ anxieties about sex differences. The assumed advantages of PGD, in this view, “are to the potential parents rather than the potential child” (Nisker 2013: 48). Nisker echoes many other intersex studies scholars and activists who critique medical intervention meant to abate parents’ anxieties about body-mind differences and diversity. Anxieties about differences, queerness, and pathology, many scholars point out, are also typically fanned by medical professionals (Roen 2005; Kessler 1998; Ford 2001; Greenberg 2012b; Preves 1999; Dreger 1999, 2004; G. Davis 2011, 2013, 2015a; Davis and Murphy 2013). Rather than attempt to avoid parents’ anxieties, the focus should be on the potential child’s welfare, “about the future well-being of their offspring” (Behrmann and Ravitsky 2013: 39). The focus should be on combating violent, curative, disabling procedures, medical malpractice, and providing parents “with information showing the

\textsuperscript{81} Sparrow does not use the phrase “intersex eugenics.” He primarily refers to the practice as “selecting against intersex traits.” However, as noted above, since I demonstrated that using PGD for this type of selection is eugenic, I refer to it as such to emphasize the political stakes.
reality of intersex people leading fulfilled lives, as well as the existence of clinical and social biases against diversity in sex, gender, and sexual orientation” (Nisker 2013: 39). Providing parents with this information “may influence [parents’] decisions” (2013: 39; also see Carpenter 2014b). Preventing socially “problematic,” “spectral,” or anxiety-inducing embryos from being implanted and possibly gestated and born does not solve the mutilation, disabling, discrimination, or curative violence problems. Doing so avoids performing the labour involved in combating compulsory ways of being.

*Arguments For and Against PGD Intersex Eugenics:*

*PGD and Preventing Medical and/or Social Harms*

Out of “concern for the well-being of the child,” Sparrow proposes, intersex eugenics protects potential intersex people from “serious medical harms” that stem from intersex anatomy (2013: 36) and the “hostile social environment” (2013: 34) people with intersex traits confront. Addressing Sparrow’s concern about medical harms, G. Davis (2013) notes that there is no unanimity about the medical issues that stem exclusively from intersex traits. Synthesizing literature regarding the medical concerns associated with intersex traits themselves (not medical responses to said traits), G. Davis observes that “the risks [...] vary substantially from study to study, leaving us to act on (what might be misguided) predictions about health factors” (2013: 52; also see Fausto-Sterling 2000b; Chapter 2). Arriving at a consensus regarding medical issues related to intersex traits is perhaps impossible because intersex, as a definitive category, is contested. Even so, people who experience medical issues throughout their lives – that is, all people to varying degrees – do not have wholly and fundamentally insufferable, unlivable lives (Clare [1999] 2009; Parens and Asch eds. 2000; L. Davis 2013b).
Refusing to work within the dichotomous medical-social framework, G. Davis emphasizes the interconnectedness of medical and social environments. “If one wishes to use the social and psychological harm argument to justify PGD to select against intersex traits,” G. Davis writes, “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’” (2013: 52). While some people with intersex characteristics may deal with health problems that extend from their intersex traits, the social stigma against intersex primarily extends from the medicalization of traits that do not reflect compulsory dyadism. To elaborate, “because the medical profession, not the intersex trait itself, is a major source of the social and psychological harm that perpetuates intersex stigmatization [...], justifying PGD by pointing to such negative outcomes is ill-advised and a circular logic” (G. Davis 2013: 52).

There is a cyclical, indistinct, or overlapping relationship between the institution of medicine and society; medicine is an aspect of culture. Rather than endorse intersex eugenics so potential people do not experience interphobia – rather than “perpetuat[e] social injustices” by promoting the notion that intersex is pathological and ought to be avoided – working towards creating a more inclusive and less dichotomous social climate truly privileges intersex people’s wellbeing (Haramia 2013: 42). And this anti-interphobia work is performed every day, for example, in classrooms, at conferences, meetings, and consultations (e.g. United Nations Human Rights 2017), through artistic, testimonial, and educational projects (e.g. The Interface Project n.d.; IntersexisBeautiful [Pagonis n.d.]; Intersexion [Lahood dir. 2012]; Intersex Day Project n.d.;

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82 Chase similarly argues, “[t]he primary source of harm described by former patients is not surgery per se, but the underlying attitude that intersexuality is so shameful that it must be erased before the child can have any say in what will be done to his or her body. Early surgery is one means by which that message is conveyed to parents and to intersexed children” (1999: 147). Endorsing PGD for intersex eugenics is another, more recent way in which this message is reproduced and conveyed to (potential) parents and intersex people.
Orchids [P. Hart dir. 2010]), and numerous organizations and initiatives (e.g. OII; InterACT; Accord Alliance; Intersex Initiative; Stop Intersex Genital Mutilation).

Arguments For and Against PGD Intersex Eugenics:

PGD, Societal Diversity, and Harming the Intersex Community

Failing to acknowledge the intersex community and the anti-interphobia work done by people engaged in the Intersex Rights Movement, Sparrow (2013) reasons that using PGD for intersex eugenics would not harm social diversity. For Sparrow, there are so few intersex people, the community is invisible or nonexistent. He posits, intersex people have no role models to look up to, and their life prospects are hindered for this reason (2013: 35). Sparrow begins his argument by comparing selecting against queer, racialized, and intersex embodiments:

the conclusion that it is immoral to select on the basis of race or same-sex attractedness out of concern for the future well-being of one’s child is less well-founded than might first appear. [...] [E]ach couple has only a limited power to combat the racism and homophobia that are likely to impact on [sic] their child’s welfare [...]. [T]he reproductive choice that parents face is whether their [emphasis in the original] child should suffer reduced welfare as a result of social injustices. It is far from clear that it would be morally blameworthy for parents to decide to prevent this. Indeed, arguing that parents should choose a child that is likely to suffer as a result of injustice, for the sake of the political project of combating such injustices, seems to demand that parents should sacrifice the interests of their children for the sake of the larger good [...]. Pending a convincing account of parental obligations in reproductive decisions in the context of injustice, [...] we might still hold that parents have good reasons to select against genes for intersex conditions. (Sparrow 2013: 34).

Characteristic of new eugenic discourses, Sparrow implies that it is benevolent to select against culturally devalued characteristics – queer, racialized, intersex – or, perhaps, not reproduce at all for the sake of the potential child. Ignoring the fact that parents need not engage with PGD and choose between one embryo or another at all (see Rapp 1999; van den Berg et al. 2005), Sparrow sets up a false dichotomy and creates a moral imperative to select against culturally devalued
characteristics. In the picture he paints, on the one hand, there are parents who select against devalued traits. He presents this selection as apolitical (or at least less political than selecting for said traits) by emphasizing that these (potential) parents are benevolently concerned for their future child’s welfare. On the other hand, according to Sparrow, there are parents who select for queerness, racialized characteristics, or intersex variations. These parents are explicitly politicized. Reproducing negative stereotypes of political activists (see G. Brown 2007; Bashir et al. 2013), Sparrow depicts these parents as militant, irrational, sanctimonious political advocates who view their potential children as sacrificial lambs. In doing so, Sparrow praises people who engage with new eugenic discourses and technologies and villainizes those who value stigmatized traits.

To be clear, both choices are political (see Rapp 1999: 3; C. Daniels 1993; Hershey 2000). Judgements about the un/viability or prospective suffering of a potential human being are necessarily politically fraught analyses with potentially eugenic ends. And of course, claiming that culturally devalued embodiments and ways of being are valuable and beautiful is indeed political (“Black is Beautiful” [Hraba and Grant 1970; Van DeBurg 1992; H. Edney 2006; Taylor 2016]; “we are intersexy” [“What It’s Like To Be Intersex” 2015; Pagonis n.d.; “#intersexy” n.d.]; “intersexy fat” [G. Davis 2016; Weeks 2017]; “gay is good” [Foreman 2008; Darsey 1991; T. Dunn 2016]). However, valuing such characteristics and having concern for a child’s welfare are obviously not mutually exclusive. Regardless, the parental binary Sparrow presents creates a moral imperative for people to select against stigmatized traits and collude.

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83 It is unclear when the term “intersexy” first surfaced or which intersex person coined the term to celebrate intersex(y) embodiments, express self-love, resist pathologization, and (re)narrate their body-minds. I first came across the term whilst watching the BuzzFeed video, “What It’s Like To Be Intersex” (2015). The video quickly went viral and currently has over 4 million views. Intersex activists, Sean Wall, Pidgeon Pagonis, Emily Quinn, and Alice Alvarez, proudly declare within the first few seconds of the video, “we are intersexy” (“What It’s Like To Be Intersex” 2015). The term has gained quite a bit of traction within the intersex community in the past couple of years. For example, use of the hashtag, #intersexy, grows and intersex activists, in addition to Wall, Pagonis, Quinn, and Alvarez, are claiming the expression for themselves (see G. Davis 2016; Keating n.d.; #intersexy n.d).
with systems of oppression. Focusing on potential individual children, rather than locating the problem in the systems, discourses, and ideologies that mandate normative ways of being and uphold discrimination masks the eugenic implications of PGD. Interestingly, in an article published before the piece in question, Sparrow articulates the same critique I am attempting to express. Critiquing Julian Savulescu’s position that parents have a moral obligation to select for the “best” child possible, Sparrow writes, “Savulescu’s argument [...] requires parents to become complicit with racism and homophobia (and other forms of oppression), which is yet another reason to reject it” (2007: 43). In his paper about intersex and PGD, Sparrow does not recognize that his position, just like Savulescu’s argument, also requires parents become complicit with various forms of oppression.

After comparing and endorsing racist, queerphobic, and interphobic eugenics, Sparrow notes a problem with his comparison. Racialized and queer individuals have a positive community, role models, and a distinct way of life whereas intersex people, apparently, do not. He therefore infers, intersex eugenics via PGD will not harm a distinctive intersex community or cultural diversity:

[T]he relative infrequency of intersex conditions differentiates them from race and sexual preference, and the ability of many intersex individuals to “pass” as one or the other of the conventional genders also differentiates intersex from race. For both these reasons, it is more plausible to divorce decisions about intersex conditions from the concerns about culture and identity that dominate discussions of these other cases. A child born with dark skin may suffer as a result of racism but also has the opportunity to gain strength from the identification as black, from the example of other black role models, and from participation in the black community. Being black opens some doors even if others are closed due to racism. Similarly, persons who are same-sex-attracted will usually have access to a community of other same-sex-attracted persons. These communities defined by race or sexual preference may then sustain and transmit a distinct set of cultural (or subcultural) ideas and values. Except in very large cities, persons born

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84 For a discussion of the urban/rural binary, spatiality, and the assumptions that (1) urban places are more tolerant to diversity, (2) diversity is always more visible in urban places, and (3) visibility is always desirable, see Emily Kazyack (2011, 2012), Dayna Prest (2016), Carly Thomsen (2015a, 2016b), and E. Cram (2016).
intersex are likely to be one of only very few individuals with their particular form of embodiment. Even in large cities, intersexed persons may be effectively invisible to each other as well as to the larger community. It is therefore much less plausible to object to a reduction in the number of children born intersex, as a result of PGD, on the grounds that this would jeopardize a distinctive “way of life” or “culture.” (Sparrow 2013: 34-35).

While conflating racialization, Blackness, dark skin, and Black identity and also assuming race is always evidently and unproblematically read off people’s bodies, Sparrow posits that selecting against intersex is different, perhaps less (obviously) eugenic, from selecting against Blackness and queerness. Black and queer people have access to supportive communities and role models. These communities and role models apparently outweigh the negativity of institutionalized racism and queerphobia. Intersex people supposedly cannot find each other and do not have a community or role models. As a result, the interphobia intersex people experience is not offset or balanced out by positive forces or life experiences. And, since there is apparently no community, intersex eugenics will not impact cultural diversity.

However, G. Davis caustically and succinctly observes, “[t]he intersex community is only ‘invisible’ (Sparrow 2013) to those who choose to ignore it” (G. Davis 2013: 51). While perhaps smaller than other marginalized communities (Haramia 2013: 42; Behrmann and Ravitsky 2013: 40), there are numerous transnational intersex organizations, communities, conferences, and meetings with remarkable contributing role models (Behrmann and Ravitsky 2013; Haramia 2013; G. Davis 2013, 2015a, 2015b, 2016, 2017; Hegarty and Chase 2000; Holmes 1994, 2009, 2008a, 2008b; Chase 1998a, 1998b, 1999, 2006; Viloria 2017; Carpenter 2013a, 2014a, 2016a; Pagonis n.d., 2017a, 2017b; Sean Wall 2015a, 2015b, 2016, 2017; Astorino 2013; Guillot, Bauer, and Truffer 2016; Truffer and Bauer 2017; InterACT and Human Rights Watch 2017; OII; InterACT; AIS-DSD Support Group; L. Long, Wall, and Pagonis 2016; L. Long 2015; Faker 1996). In fact, “a collective intersex movement is well underway,” and has been underway since
the early 1990s (Behrmann and Ravitsky 2013: 40). Moreover, with assistance from the Internet, intersex people form bonds with other intersex folks all over the world and perform on/offline activist work, community building, and healing/restorative labour. Increased mainstream media representation of intersex people and intersex experiences also increases intersex visibility. In addition to countless mainstream news articles about and authored by intersex people, we can look to award-winning television series featuring intersex characters and actors (e.g. *Faking It*, *Transparent*) (Anderson-Minshall 2016; Avery 2016; Whitney 2016). This increased mainstream representation of intersex people in television prompted the *Advocate* to ask, “Are We Witnessing the Birth of TV’s Intersex Liberation?” (Anderson-Minshall 2016: n.p.). There is much work to be done, but “Sparrow’s exclusively negative portrayal of intersex people as being inherently deficient in opportunities, isolated without role models, is misleading if not completely inaccurate” (Behrmann and Ravitsky 2013: 40).85 Sparrow’s assertion that intersex people and communities are invisible or nonexistent is simply untrue.

The size of a population ought to be irrelevant when considering whether we should acknowledge and respect a group of people. Unfortunately, the “minority” status and population of a given group is often deemed relevant and sometimes used to justify marginalizing a group of people, as Sparrow attempts to do. As Sharon A. Groch writes, “calling a particular group a minority justifies the subordination of that group” (1998: 106). The intersex activist community may be small. According to intersex activist and drug addiction counselor Sarah Graham, there are “only less than one hundred *out* [emphasis added] intersex activists in the whole world” (2017: n.p.). However, the intersex population is not nearly as small as Sparrow claims. Looking

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85 While considering this increased representation of intersex people in Western contexts, looking across time and space is important to remind ourselves that not all communities ignored or invalidated what the West calls “intersex” or “DSD” and created hostile social climates for people with said anatomical characteristics.
Fausto-Sterling estimates that 1.7 percent of people have intersex traits (2000b: 53). Melanie Blackless and colleagues (2000) calculate that 2 percent of live births have intersex anatomy. Intersex traits, therefore, are as common as twins and people with red hair (1-2 percent of population) and much more common than other well-known variations such as Down syndrome (1 in 800-1,000 births) and albinism (1 in 20,000 births) (Fausto-Sterling 2000b). Other scholars estimate that up to 4 percent of the population has intersex traits (Zeiler and Wickström 2009; Gough et al. 2008). Intersex characteristics are often assumed to be less common than they are because intersex people have been rendered invisible and shamed to keep silent. Intersex is also assumed to be uncommon because one misrepresentative statistic is often referenced. Viloria explains: “[s]ome groups use an old prevalence statistic that says we [intersex people] make up 1 in 2000, or .05% [...] of the population, but that statistic only refers to one specific intersex trait, ambiguous genitalia, which is but one of many variations which, combined (as they are in medical diagnostics and coding), constitute the 1.7%,” as estimated by Fausto-Sterling (2000b), the 2 percent, as estimated by Blackless et al. (2000), or the 4 percent as estimated by Kristin Zeiler and Anette Wickström (2009) and Brendan Gough et al. (2008) (Viloria 2015b: n.p.). These statistics help debunk the harmful myth that intersex is uncommon, a myth Sparrow perpetuates. That said, keeping in mind that drawing definitive lines between male, female, and intersex is impossible is important.

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86 The inability to conclusively define male, female, and intersex problematizes the project of gaining statistical knowledge about intersex. Statistics are contingent on the criteria the specific medical professional employs and whether intersex anatomy is consistently reported or diagnosed by medical professionals. It is probable that intersex births are reported more frequently in places where pregnancies are monitored by medical professionals closely, where people tend to give birth in hospitals rather than, for example, in the home, and in locations where the criteria of what constitutes male and female anatomy is very strict. The inconclusiveness of statistical reporting of intersex is evident in the varying statistical estimates. Nevertheless, the estimates show how large the intersex population may be.

87 These estimates also tell us that intersex anatomies are as common as people identifying as bisexual (1.3 percent of Canadian population; 1.8 percent of American population) or gay and lesbian (1.7 percent of Canadian and American population) (Black et al. 2000; Gates 2011; Statistics Canada 2015).
Entering this conversation, Trafimow counters Sparrow and his critics and suggests the negative medical issues and social stigma that intersex people experience outweigh any positive diversity and creativity intersex people bring to society. In writing that is peppered with ableist language, Trafimow asserts:

it seems like a fragile leg to stand on,\(^{88}\) to argue that society as a whole will have more creative ideas as a result of increasing the number of intersex children who are born. In addition, a defender of this conclusion would have to further argue that this gain in the totality of creative ideas in society would be so large as to make up for the negative consequences that [...] tend to happen to intersex individuals. (Trafimow 2013: 54).

Trafimow is unconvinced that the “expected value” of increased creativity and diversity “would be sufficiently impressive so as to outweigh the potential for harm to [intersex] individuals” (2013: 55). Put differently, according to Trafimow, when one weighs the potential benefits of intersex people’s contributions to society against their inevitable suffering, one discovers that the suffering intersex people endure is far too great to justify their contributions. One will not be adequately “impressed” (Trafimow 2013: 55). Since I addressed the concern for intersex people’s medical and social issues above, at this juncture, I am more troubled by the equations Trafimow and Sparrow employ. Their arguments hinge on pleasure-harm and positive-negative calculations to justify intersex eugenics. They take the liberty of judging intersex individuals’ qualities of life (and, as is the case with Sparrow, racialized people and queer individuals as well) to determine the social utility of intersex people. While there are many critical arguments made in the volume in question, there is no explicit discussion of this analytical tool. This mode of analysis, known as consequentialism or utilitarianism, problematically relies on dichotomous

\(^{88}\) See Amy Vidali (2010), Vivian M. May and Beth A. Ferri (2005), Ivor Armstrong Richards (1965: 118-119), Oliver Sacks (1984), and Jay Timothy Dolmage (2014) for disability studies analyses of ableist metaphors like “a fragile leg to stand on.”
thinking and fails to acknowledge that people’s lives, value, and becoming in the world cannot be reduced to such an unintersectional and reductive calculation.

Consequentialism and Justifying Intersex Eugenics

Sparrow and Trafimow’s arguments for intersex eugenics in the *American Journal of Bioethics* (vol. 13, no. 10) rely on consequentialist logic. This tool to evaluate ethical decisions and behaviours is problematically rooted in impartiality, binary thinking, and, consequently, misrepresents body-minds, embodied becoming, and people’s subjectivities. Since the nineteenth century, consequentialism has been a dominant method for unpacking ethical conundrums. With roots in traditional, Western, male-dominated philosophy, specifically utilitarian ethics (i.e. happiness must be maximized) and Kantian ethics (i.e. the Categorical Imperative, which insists that morality must be based on a rational, objective foundation) (Kant [1785] 1997; Korsgaard 2013; O’Neill 2013; Mulgan 2001; Railton 1984), consequentialism attempts to impartially identify and calculate possible good-bad, pleasure-suffering outcomes. When the outcomes are analyzed and identified, one apparently discovers the universal ethical standard, “the right thing,” or the course of action “with the best consequences” and least amount of harm (Mulgan 2001: 3). Many traditional bioethicists concerned with the ethics of reproductive technologies still appeal to this logic whilst trying to discern the quality of particular lives and what potential children are the “best” or “healthiest” (see Savulescu 2001, 2007; Sandel 2004, 2007; M. Parker 2007; Sparrow 2013; Trafimow 2013). In fact, the objection that an argument is “unconvincing in consequentialist terms” is taken quite seriously in certain bioethical and philosophical communities (Sandel 2007: 92).

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Critical disability studies scholar Margrit Shildrick posits that traditional, consequentialist bioethics, “with its confidence in a determinable calculus of harms and benefits” (3) is “out of touch” (2005: 1-2):

It is out of touch with bodies themselves, in the phenomenological sense in which the being, or rather the becoming, of the self is always intricately interwoven with the fabric of the body; it is out of touch with the developments in and impact of postmodernist theory as it problematizes the hitherto unchallenged certainty of binary thinking; and it is out of touch with the postmodern culture in which bioscience itself forces up to question what is meant by the notion of the human self. (Shildrick 2005: 1-2).

Bioethical concerns sieved through a consequentialist framework do not engage with the bodies of scholarship – postmodern, phenomenology, trans, intersex, crip, disability, feminist, queer,

89 In rejecting consequentialist methods, many of these feminist philosophers contributed to the development of standpoint theory. Standpoint theory takes into account people’s standpoints and various “situated knowledges” (Haraway 1988: 575; also see Hekman 1997), particularly marginalized people’s standpoints and knowledges. In addition, feminist scholars developed an “ethic of care” (Gilligan 1982; Noddings 1984). Critiquing Hume’s distaste for sentimentalism and his utilitarian ethic constructed to avoid sentimentalism and partiality, Nel Noddings (1984) demonstrated that care, affect, and emotions are integral to ethical decisions.

Returning to Sparrow and Trafimow’s arguments, Sparrow assumes authority over all intersex, racialized, and queer people’s experiences and weighs the positive/negative aspects of said experiences to determine if there is more or less happiness/suffering and diversity. Recall the quotation:

A child born with dark skin may suffer as a result of racism but also has the opportunity to gain strength from the identification as black, from the example of other black role models, and from participation in the black community. [...] Similarly, persons who are same-sex-attracted will usually have access to a community of other same-sex-attracted persons. [...] Even in large cities, intersexed persons may be effectively invisible to each other as well as to the larger community. (Sparrow 2013: 35).

Sparrow assumes an objective position and reasons there are not enough positive elements in intersex people’s lives to outweigh the negative. Hence, according to this logic, intersex people need not be born for their own good; their futures are “no good” (Kafer 2013: 3). Further, it is proposed, society will also not suffer a loss with less intersex people in the world because they are already invisible “to the larger community” (Sparrow 2013: 35). This consequentialist mode of analysis enables Sparrow to claim jurisdiction over countless people’s lives and reduces these lives to an equation that is a simplistic, unintersectional iteration of systemic oppression, compulsory ways of being, identity formation, subjectivity, and life experiences.

The facile nature of this equation is evident in the conflation of racialization, dark skin, Blackness, and Black community or identity (see Sparrow 2013: 35). The problematic,
unintersectional nature of Sparrow’s analysis is further pronounced by underlining the fact that there is no singular Black (or “dark”), queer, or intersex experience. Not only are these subjectivities, communities, identities, and the related forms of oppression experienced individually, they are not mutually exclusive. They have never been, nor will they ever be, discursively or literally mutually exclusive (see Chapter 3; Reis 2005, 2009; Magubane 2014; Munro 2010). They intersect for many people. As intersex activist, artist, advisor, and researcher, Sean Wall, notes: “I am not just intersex. I am Black and I am queer” (2016: n.p.; also see Sean Wall 2015 n.d.; Compton 2016; Pagonis 2016a). These identities and aspects of his embodiment intersect. As a result, Wall regards the violence enacted on Black, queer, and intersex communities as intertwined:

As a Black intersex man, I have witnessed the impact of state-sanctioned violence on my family and my community. I charge the police state and the medical community with state-sanctioned violence: Each targets non-normative bodies – the former through incarceration and execution, and the latter by means of surgical and hormonal intervention. As a Black intersex man, I stand at the intersection bearing witness to how this violence has incarcerated my friends and loved ones as well as being subjected to medically unnecessary surgical intervention. (Sean Wall 2016: 33).

Wall’s identities, what his body-mind characteristics signify, and his experiences cannot be separated, as Sparrow’s analysis incorrectly implies. It is not “plausible to divorce” (Sparrow 2013: 34-35) intersex, race, and queerness (see Chapter 3; Conclusion).

Employing the same unnuanced consequentialist logic, Trafimow assumes objective authority over intersex people’s life experiences. He determines all intersex individuals endure too much medical and social suffering to justify their creative, diverse contributions to society. Which is to say, intersex people should not exist for their own good and, possibly, for society’s good. Intersex people’s lives cannot be reduced to such a dichotomous equation. Furthermore, intersex people – or any devalued or supposedly unviable group of people – do not exist to meet
some neoliberal diversity, creativity, productivity, or utility quota. Lives “lived with and through difference” have “inherent value” (Holmes 2008b: 175).

Given that consequentialist arguments rely on dichotomous reasoning, the idea that there is an objective truth regarding ab/normal, un/healthy, dis/ordered, and dis/abled morphologies is privileged (see Jordan-Young; Daston and Galison 2007; Baglieri et al. 2011a, 2011b; Garland-Thomson 2009; van Dijck 2005; McRuer 2006). I discuss these binaries in more detail below, but I must briefly draw attention to Sparrow’s proposal that intersex people deviate from “species-typical functioning” and do not have “normal sexual anatomy” (2013: 32, 31). Recall Astorino’s analysis of the word typical. Typical “doesn’t have the same connotation as ‘normal’ [...] but I think that people would still say, ‘Oh, you’re sex-ATYPICAL....’ and not think of the distinction between a/typical as more/less frequent but less/more weird” (Astorino 2013: n.p). A/typical discourse is concerning, as Sparrow’s argument illustrates, because atypicality is often conflated with abnormality and, in turn, pathology.

Aurenque and Ehni observe, “[t]his is not the first time Sparrow has defended the normative significance for medicine of the ‘normal human body’ (Sparrow 2010)” (2013: 32). Notwithstanding Sparrow’s insistence that he, in his own words, is “not inclined to conservatism,” he “believe[s] that sexual dimorphism is a deep and valuable feature of the human condition” (2010: 10, 9). That is, characteristics that defy compulsory dyadism are pathologically abnormal; they violate and haunt the deified dyadic state of being. As Garland-Thomson writes, “normal” traits are “assumed to possess natural corporeal superiority” (1997: 279). Hence, by employing the ab/normal binary as an epistemological foundation, Sparrow can more easily justify intersex eugenics. Despite Sparrow’s efforts, “the normative meaning of ‘normal’ sexual anatomy remains keenly disputed” (Aurenque and Ehni 2013: 55).
Normal and abnormal are not objective, identifiable states; they are ideological constructs (Erevelles 2011a, 2011b; Garland-Thomson 1997, 2011; Fausto-Sterling 2000a, 2000b; G. Davis 2015a; L. Davis 1995, 2012, 2013b, 2013c; L. Davis ed. 2013a; K. Hall 2011; McRuer 2006; McRuer and Mollow eds. 2012; Durham and Kellner 2012; Butler 2005; Longmore 2003; Shildrick 2002; Kafer 2003, 2013). This fact is particularly clear when we examine Sparrow’s proposal that, unlike intersex, Black people and queer folks fall under the “normal range of human variation” (2013: 32). Since these types of people are deemed “normal” variants, selecting against Blackness or queerness, while Sparrow sympathizes with doing so, is more obviously eugenic. Aurenque and Ehni respond to this claim:

When Sparrow argues that “same-sex attractedness and dark skin color are part of the normal range of human variation” he is white-washing the long, frequently brutal historical struggle to establish the normality of those features of human phenotype and behavior. The normality of homosexuality in modern Western societies, like the unacceptability of treating individuals differently based on their skin tone, has only recently come to be a broadly accepted notion. Recall, for example, that homosexuality was considered a mental disorder, listed in the Diagnostic and Statistical Manual of Mental Disorders from 1952 (American Psychiatric Association, 1952), and that the last vestiges of formal legal discrimination were abolished no more than a single generation ago. Indeed, it is exactly because of the flexibility of the concept of “normal health” that the intersex community hopes for a society that someday will understand the condition as within the normal bounds of human sexual diversity” (Aurenque and Ehni 2013: 56).

The category “normal” has only recently expanded to sometimes, arguably rarely, include people of colour and queer individuals (see Garland-Thomson 1997: 8; Wilkerson 2012; Puar 2007, 2013a; Collins 2004). In fact, Sparrow, in part, acknowledges this in another article: “For much of the history of Western culture the ‘normal’ person was white” and people of colour “were thought to be inferior examples of the human form” (2005: 139). Furthermore, as many studies and analyses demonstrate, “the last vestiges of formal legal discrimination” (Aurenque and Ehni 2013: 56) against these people have not been abolished at the ideological or institutional level.
Since the boundaries of “the normal” expand and contract through time and space for political reasons, we cannot work under the assumption that there are objectively normal or “species-typical” states of being.

The above considerations demonstrate that consequentialism, with its investment in the notion of innate ab/normality, is a flawed, outdated analytical tool. Not only that, consequentialism appears integral to new eugenic discourses and practices. In order to justify new eugenics, an ethical analysis that supposedly can prove certain lives are not worth living is required. One could not claim that a group of people’s lives are so insufferable or abnormal they ought not exist for their own good without an ethical framework that enables one to assume impartiality, calculate pleasure and suffering, and identify ab/normal body-minds. If we started from an ethic that recognized “the inherent value in a life lived with and through difference” (Holmes 2008b: 175), the ethical imperative to determine whether a life is worth living or whether a body-mind or mode of becoming is ab/normal would not be a central debate or a necessary discussion.

Rather than addressing bioethical issues with consequentialism, these concerns “would be better addressed by a postconventional or postmodernist approach that specifically seeks to break down such binary categories as those of the normal and abnormal, of health and illness, of self and other” (Shildrick 2005: 4). Ann Kerr and Tom Shakespeare (2002) echo this sentiment: traditional bioethics is too “top down.” It is too invested in and focused on making normative prescriptions, both ideological and medical. Due to this top down approach, contemporary bioethics has not satisfactorily engaged with people’s ethical concerns about eugenics, old and
new (Kerr and Shakespeare 2002). Bioethics, therefore, ought to be more “bottom up” and reliant on marginalized people’s knowledges as well as the social sciences (Kerr and Shakespeare 2002). These debates ought to center the perspectives of the people in question: intersex people, people of colour, individuals with disabilities, and queer folks. And, these debates ought to rely on fields like queer, disability, crip, feminist, and intersex studies that do not take for granted normative prescriptions and ideologies – fields that are invested in social equity and combating compulsory heterosexuality, able-bodiedness, and dyadism. In addition to the problematic ethical method, consequentialism, and the dichotomous scaffolding it relies on, I must proceed to unpack the queerphobia and ableism that also serve to uphold intersex eugenic arguments.

*Interphobia and Queerphobia*

Queerphobia underpins interphobia and “curative” medical(izing) responses to people with intersex anatomies (Chase 1999; Roen 2005; Greenberg 2012b; Karkazis 2008; G. Davis 2015a; Amato 2016; Holmes 2000; Preves 2003; Coventry n.d.). Disabling medical interventions performed on intersex people (see Chapter 2) and technological interventions to prevent the implantation, gestation, and birth of people with intersex traits (e.g. PGD) are “regulatory practice[s] that can be identified as compulsory heterosexuality” (Butler [1990] 2006: 24) and, I add, compulsory dyadism. IGM, HRT, as well as other medical practices, are ways compulsory heterosexuality and dyadism are enforced, surveilled, and literally carved or integrated into body-minds. Intersex eugenics is another means compulsory heterosexuality and dyadism are expressed, enforced, and literally constructed and implanted into (potentially) pregnant body-
minds. Emphasizing that queaphobia contributes to new eugenic, interphobic discourses and practices is vital to understanding and combating intersex eugenics.

As Roen explains, unnecessary medical interventions are performed to “straighten out” the intersex child’s “deviant” body-mind, but also to ensure “straightness,” heterosexuality — “to set everything straight” (2005: 260). The desire for straightness is evident in surgeons’ assessments that “the ability to engage in penis-vagina intercourse is considered to be the mark of successful surgery” (Roen 2005: 266). As one doctor explains, “[a]dequate intercourse” and, by extension, “normal” sexuality and dyadic genitals, “is defined as successful vaginal penetration” (Gearhart qtd. by Baiez et al. 1992: 684; also see Chapter 2). Compulsory heterosexuality and dyadism is also illustrated in testimonies made by intersex people socio-medically assigned female. Many of these people explain that medical professionals ask, speak of, and encourage heterosexual engagement with (potential) boyfriends and husbands (Triea 1999: 143; Preves 2003: 77; Amato 2016: 84).

Some preoperative intersex patients have been told “corrective” surgery is vital so they can have “normal” heterosexual sex in the future. Laura Inter\(^90\) recalls: “one doctor explained that after the surgery I would have to use dilators and then I would be ready to ‘have sex normally, with your husband, when you get married.’ What the doctors didn’t know [...] was that since I was very young I had been attracted to women” (2015: 96). Pagoni recounts a similar experience: Doctors were coming into the room to tell me what was going to happen next. “We notice that your vagina is smaller than other girls”. While we’re in the operating room fixing your urethra, we can also make a small incision in your vagina to make it longer. This way, you’ll be able to have sex with your husband when you’re older – does that sound good?” I looked at my mom, who was in the prep room with me for this and wondered how to answer. I was only 11. I let out a shameful, “yes.” “Good

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\(^{90}\) Laura Inter is a pseudonym.
then, we’ll get that all taken care of for you as well during this procedure.”
(Pagonis 2015b: 104).

At the age of eleven, albeit already frightened and confused, waiting to go into surgery intended
to “fix” another intersex trait, Pagonis was coerced to agree to an additional “straightening out”
procedure they did not fully understand. Pagonis was shamed into feeling like an abnormal girl
because their anatomy would not be able to fulfil the cultural requirement of dyadism and,
therefore, heterosexuality. Likewise, Daniela Truffer reports:

> my endocrinologist always told me I couldn’t have a boyfriend without a proper
vagina. I wanted to be normal, and insurance wouldn’t pay after I turned twenty,
so at eighteen I decided to have a vaginoplasty. They cut a hole next to my
urethral opening, and lined it with a skin graft from my backside. After surgery, I
was bleeding and in pain, but I had to dilate my vaginal opening to prevent
stenosis. It was humiliating. The doctors said, I “best get a boyfriend soon.”
(Truffer 2015: 112).

These testimonies illustrate the coercion and shaming that often take place in medical contexts.
They also highlight that heterosexuality and dyadism are not merely assumed but enforced. And,
when intersex people challenge medical professionals’ insistence that surgery is/was the best
course of action, that dyadism and heterosexuality ought to be mandated, they are told you
“don’t know what you’re talking about” (Sean Wall in “What It’s Like To Be Intersex” 2015:
n.p.). When intersex people do not adhere to heterosexuality, some medical professionals deem
the treatment “a failure” (Karkazis 2008: 2) or maintain lesbian, gay, or queer intersex subjects
were assigned the wrong gender (Chase 1998b; G. Davis 2015: 78).

Parents of intersex children also express queerphobic and heteronormative ideologies,
ideas that may be further stoked by the clinical setting and medical professionals. Studies have
shown parents of intersex children typically prefer DSD terminology to intersex because the
latter negatively implies that their child is “between genders,” trans, queer, lesbian, bisexual, or
gay (Greenberg 2012b: 93; Karkazis 2008; G. Davis 2015a). Queerphobia fuels many parents’
attempts to distance themselves and their child from LGBTQ issues and identifiers (G. Davis 2015a: 24, 119). DSD discourse helps pacify parents’ queerphobic concerns because it opposes the idea that their intersex child is queer or “in between” male or female. DSD discourse emphasizes that the child has one, true, consistent sex and gender. The true sex simply needs to be uncovered and inscribed into the child’s body-mind. DSD nomenclature seemingly soothes parent’s anxieties surrounding queerness, but the narrative does not always aid parents in forging positive bonds with their intersex child (Karkazis 2008; Roen 2009: 35; Lahood dir. 2012). Parents fear that others will treat their intersex child differently because of the social stigma surrounding intersex and queerness. However, parents themselves may be the ones who treat their child differently. For instance, parents are often hyper-vigilant of their intersex child’s non/conforming gender performances and more lenient with their non-intersex siblings’ performances (Karkazis 2008). Strict gender policing can result in strained familial ties (Karkazis 2008; Lahood dir. 2012).91

Ironically, in the attempt to “straightening things out,” queer people are formed (Roen 2005: 670). “In carrying out these processes,” Roen contends, “clinicians (surgeons, endocrinologists, psychiatrists, and others) inevitably create newly queer beings” (2005: 270; also see Holmes 2000; Spurgas 2009; Morland 2009). To clarify,

Surgical and psychotherapeutic processes carried out in childhood are not forgotten. Even when carried out on newborns, the body remembers. No matter how much the technological procedures are perfected, the experience of treatment is not erased. Furthermore, for adults who are able to articulate their own understandings of identity, the surgical reconstruction of queer bodies does not ultimately determine what, or how, those bodies become. (Roen 2005: 270).

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91 Perhaps parents prefer DSD terminology to intersex because a medical condition, disorder, or disability may be easier to cope with than coming to terms with a queerly embodied child. Parents also may treat their child differently because medical professionals encourage parents to monitor their child’s gender performance and to view their child as abnormal and disordered (Karkazis 2008; G. Davis 2015a). Be that as it may, disability and queerness are not distinct issues here; disorder, disability, and queerness intersect.
Queer or strange body-minds and memories are created. Roen’s argument echoes Holmes’ (2000) claim that surgical interventions fashion queer sexes. Ultimately, body-minds are not normalized or rendered dyadic through medical intervention (Spurgas 2009).

Martha Coventry and Tiger Devore’s testimonies supplement this proposal. Coventry explains: “[t]he truth is that the very thing surgery claims to save us [intersex people] from – a sense of differentness and abnormality – it quite unequivocally creates” (n.d.: n.p.). Devore also notes: “the doctors insist that you can’t let a child go to school with ambiguous genitals, but the genitals they created were certainly strange looking” (Devore 1999: 80). Not only that, Devore “lost a tremendous amount of feeling tissue that I would like to have still. And that was taken from me” (in Harrison dir. 2011: n.p.). The surgeries intended to normalize Devore’s body-mind were “unnecessary failures” that did not produce dyadic genitals that “work” (in Harrison dir. 2011: n.p.). The interventions created queer, different beings, and/or, as is the case with Devore, “strange” genitals.92

Moreover, medical intervention does not prevent people from becoming or identifying as queer, as illustrated by Pagonis’ trajectory. Even though medical professionals attempted to construct Pagonis into a “normal” female, they identify as “a queer, gender nonconforming intersex person” (in “What It’s Like To Be Intersex” 2015: n.p.). In Roen’s words, “[s]uch becoming [emphasis in the original] is related to the subjectivity of the person who has undergone surgical reconstruction, not the technological sophistication of the surgery93 or the

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92 Devore’s “strange” or queer looking genitals were de/reconstructed through numerous surgeries. In 1999 Devore stated: “I’ve had 16 surgeries on my genitals, and they performed 10 operations by age 10, pretty regularly once a year” (1999: 79). Years later, Devore appends this account noting he has undergone 20 surgeries (in Harrison, dir. 2011). “I’ve hardly been in the world yet,” Devore explains, “and they [medical professionals] are already bringing out the steel to cut me up and make me into something they think I should be. [...] All the surgeries I’ve suffered, previous age 19, were unnecessary failures” (Devore in Harrison, dir. 2011: n.p.).

93 As noted in Chapter 2, medical professionals often argue that surgical techniques have improved over the decades. Nevertheless, improved techniques do not erase the fact that infants and children cannot consent; it also does not negate the fact that many people wish surgery never took place. Claiming “‘surgery is better now,’ is a strategy for
medical discourses through which the reconstruction may have been deemed ethically justifiable” (2005: 270). Or, alternatively explained by Sharon E. Sytsma, “neither chromosomes, nor gene sequences, nor gonads, nor hormones, nor rearing, nor genital appearance alone determined sexuality” or gender expression and identity (2006a: xx). Although compulsory, neither medical professionals nor intersex people can anticipate the ways in which heterosexuality and dyadism will not and cannot be internalized, embodied, and achieved.

Compulsory heterosexuality and dyadism underpin interphobic responses to intersex people. For that reason, it is imperative to acknowledge, Behrmann and Ravitsky insist, that parents may use PGD technologies to select against intersex because of queerphobic beliefs; “[p]arental choice against intersex may [...] conceal biases against same-sex attractedness and gender nonconformity” (2013: 39). I am disinclined to claim that they only “may influence” choices and recommendations. Researching women’s complex relationships with amniocentesis, Rayna Rapp (1999) learns that people “who choose to abort after a diagnosis of sex chromosome anomalies in their fetuses [...] believed those anomalies would lead to homosexuality. [...] The fear of a homosexual orientation was so profound that sex chromosome problems and sexual ‘problems’ were irrevocably conflated” (1999: 93). It is reasonable to suggest that some people confronting the same diagnoses detected by PGD could react in a similarly interphobic and queerphobic way. It is also reasonable to suggest that these discriminatory ideologies influence clinicians’ recommendations.

To combat queerphobia Behrmann and Ravitsky (2013) propose (potential) parents who think about selecting against intersex should be provided with resources about interphobia, intersex anatomies, support groups, and intersex people living fulfilling lives. “[P]arental silencing intersexed adults: it relieves surgeons indefinitely of the responsibility of listening to any former patients. If genital surgery is indeed ‘better now’ and getting better all the time, that is actually a strong argument for allowing intersex children to be free of nonconsensual early surgery” (Chase 1999: 151).
motivation to select against intersex may dissipate” with access to this sort of information (Behrmann and Ravitsky 2013: 40). Getting that information into fertility clinics and into (potential) parents’ possession will be difficult. Historically, medical professionals have largely failed to provide this type of information (there are rare, notable exceptions [see Quinn 2015: 109-110]) (Driver in Arana 2005: 31). Medical professionals have stifled the spread of this information and support by telling intersex people and their family members that they are on their own. Emily Quinn, an intersex activist with CAIS, explains that her doctor “did not direct me to any actual support” despite the fact that there is plenty of information about CAIS and there are support groups for people with CAIS (2015: 109). Like K. Walsh (2015), Zieselman (2015), Pagonis (2015a), among many others, Quinn was told, “there is nobody else like me” (in “What It’s Like To Be Intersex” 2015: n.p.). Accurate information and support have been historically withheld (G. Davis 2015a; Preves 2003; Garcia 2015; L. Long 2015; Peterson 2015; Truffer 2015; Sean Wall 2015b). I am therefore skeptical that this sort of information will be welcomed into fertility clinics and provided to (prospective) parents in the near future.

Another cumbersome barrier that would prevent this information from entering fertility clinics is the chasm between clinical terminology and the depathologizing nomenclature employed by intersex activists and intersex and feminist scholars (G. Davis 2015a; Karkazis and Feder 2008; Davies et al. 2011; Dreger and Herndon 2009; Feder 2009; Barthold 2011; Preves 2003). Medical professionals in fertility clinics, just like in other medical environments, do not even use the word “intersex.” Attempting to bridge this language gap via collaboration has been difficult and highly contested in medical, activist, and scholarly communities (G. Davis 2015a: 26-54; Greenberg 2012b).
One may expect, given that DSD nomenclature has become standard in medical settings (G. Davis 2015a; Greenberg 2012b), that fertility clinics and governmental documents that regulate reproductive technologies employ the same terminology. Yet, evaluating, for example, Canada’s PGD regulations and various fertility clinics, reveals that intersex is abstracted, misrepresented, and pathologized, but it is not explicitly pathologized through DSD terminology.

More broad, elusive language is used: “sex-linked disorders or diseases” (O’Neill and Blackmer 2015: 10). Ottawa Fertility Centre uses similarly elusive phrases: “sex-linked genetic disorders” and “chromosomal disorders” (“PGD and PGS” 2014: n.p.). And Ontario’s Maternal, Newborn and Early Child Development Resource Centre’s guide for Ontario fertility service providers refers to “sex-chromosome disorders” (“Reflecting on the Trend” 2007: 61) and “major congenital anomalies,” one of said anomalies being “Klinefelter Syndrome” (2007: 25). This sort of language is at odds with the fact that intersex traits themselves cause few, if any, medical problems. It is also misleading, fear-mongering (e.g. disease), incorrect, and esoteric which enables medical professionals to maintain jurisdiction over intersex (G. Davis 2015a). The discourses also cultivate the best conditions for eugenic choices. Ultimately, it seems unlikely that positive and accurate information about intersex would enter fertility clinics anytime soon.

94 The report’s glossary defines Klinefelter syndrome as “an abnormal condition in a male characterized by two X chromosomes and one Y chromosome, leading to infertility, smallness of the testes, sparse facial and body hair” (2007: 78). The word “major” and “anomaly,” as well as the definition, is misleading, if not false. It is estimated that between 1 in 500-1000 males have this variation (Bojesen, Juul, and Gravholt 2003; Fullerton, Hamilton, and Maheshwari 2010). Klinefelter is hardly anomalous; G. Fullerton, M. Hamilton, and A. Maheshwari, refer to Klinefelter as “common” (2010: 588). Further, people with Klinefelter syndrome are not necessarily infertile (Damani, Mittal, and Oates 2001; Paduch et al. 2008; Ramasamy et al 2009; Schiff et al. 2005; Wikström et al. 2006; Gianpiero et al. 1998; Fullerton, Hamilton, and Maheshwari 2010). People with Klinefelter mosaic cell lines may have reproductive sperm and can fertilize an egg without reproductive technologies. Further, since the development of microsurgical techniques and reproductive technologies, many people with Klinefelter can and do have biological children (Damani, Mittal, and Oates 2001; Paduch et al. 2008; Ramasamy et al 2009; Schiff et al. 2005; Wikström et al. 2006; Gianpiero et al. 1998; Fullerton, Hamilton, and Maheshwari 2010). Given these findings and developments, “the label of infertile should be reevaluated” (Fullerton, Hamilton, and Maheshwari 2010: 595). At any rate, a person is not innately disordered or diseased if they cannot or do not reproduce.
given the evident gap between discourses. More difficult and painful linguistic collaboration would need to occur for resources to be made available in fertility clinics.

In addition to queerphobia underpinning medical professionals’ recommendations and (potential) parents’ motivations to avoid intersex, queerphobia is evident in Sparrow’s argument for intersex eugenics. Sparrow maintains selecting against intersex is permissible because of potential social harms. Intersex “children are at risk of psychological harms from being teased or persecuted for having ‘different’ genitals, this is clearly a social problem” (Sparrow 2013: 33). However, his notion of social harms quickly becomes queerphobic, interphobic, and medicalized when he begins sympathizing with a very narrow definition of “properly functioning genitals.” His concern for intersex people’s welfare also becomes questionable when he voices concern for intersex people’s potential sex partners. Sparrow writes:

[W]hile the empirical claim that children born with ambiguous genitalia suffer consequent social and psychological harms may be controversial, it is also plausible (Elliot 1998; Warne and Bhatia 2006) and – if true – might justify PGD out of concern for the welfare of the future child. Importantly, there is a sense in which three of the key “biological functions” of the genitals are already social. If we think of “healthy” genitalia as granting the capacity for intercourse leading to reproduction, eliciting sexual attraction in mates, and providing pleasure, then relations with other people are essential to the first two of these and will often be central to the third. Genitals that don’t “fit” with the genitals of other people, that fail to elicit desire in one’s sexual partners, and/or that render pleasure difficult to achieve in the prevailing social circumstances (which include access – or lack of access – to vibrators and/or other sex toys) are arguably functionally deficient [emphasis added]. Establishing that the difficulties associated with being born intersex are a function of social context would not therefore itself rule out their being the appropriate objects [emphasis added] of medical intervention. (Sparrow 2013: 33-34).

The claim that people (rather than objects) born with variant genitals and other intersex traits confront social and psychological harm is not actually particularly controversial.\(^95\) However, the three key “biological functions” that indicate “health” are contentious. To

\(^{95}\) I add “other intersex traits” because Sparrow problematically conflates variant genitals with intersex. Not all people with intersex anatomy have variant genitals.
unpack this quotation, I interrogate each noted biological function and the idea of genital “fit.” I then close this section and lead into the next section on ableism by problematizing Sparrow’s use of the term “healthy.”

The suggestion that healthy genitals lead to reproduction (unless otherwise impeded by, for example, contraception) via, it is implied, penis-in-vagina sex, is often assumed to be the natural order of things. Lee Edelman refers to this belief as the “absolute logic of reproduction” and the cultural investment in “reproductive futurism” (2004: 11, 2). The cultural investment in, or demand for, dyadic sex and therefore heterosexual sex (i.e. compulsory heterosexuality [Rich 1980]) and reproduction (i.e. compulsory reproduction [Butler (1990) 2006: 125-126]) is not “natural,” but an “unquestioned value” (Edelman 2004: 4). The undisputed logic of reproduction creates “a hierarchical system of sexual value” in which able-bodied “[m]arital, reproductive heterosexuals are alone at the top of the erotic pyramid” (Rubin 1984: 151; also see Rubin 1975). The pronatal hierarchy is so naturalized that having children is, for example, represented and reasoned to be “the natural destiny of all women and marriage the only legitimate means for its fulfillment” (Carroll 2012: 27). Rather than being the natural order of things, the logic of reproduction is a cultural construct that is institutionalized through and propagated by, for instance, secular and religious institutions of marriage, medical professionals, and certain scholars like Sparrow (2013).

People who do not or cannot fulfil compulsory dyadism, able-bodiedness, heterosexuality, and reproduction are often pathologized and demonized. Edelman writes, “[w]hatever refuses this [reproductive] mandate by which our political institutions compel the collective reproduction of the Child must appear as a threat not only to the organization of a given social order but also, and far more ominously, to social order as such” (2004: 11). The
“whatever,” in this context, is the queer: “the queer comes to figure the bar to every realization of futurity” (Edelman 2004: 4). Also, people, primarily women, “whose desires or social roles escape this [reproductive] function [e.g. spinsters] confound the ideological construction” that women’s biological destiny is to reproduce (Carroll 2012: 27). Or, considering Sparrow’s claim, intersex people with variant genitals or intersex people who cannot reproduce are deemed unhealthy precisely because they confound the “absolute logic of reproduction” (Edelman 2004: 11); they are near or at the bottom of the “erotic pyramid” (Rubin 1984: 151) and threaten “social order as such” (Edelman 2004: 11). Variant genitals are not innately unhealthy or pathological if they cannot or do not lead to reproduction. They are only pathologized because they do not conform to the apparent natural, pronatal order of things. Claiming that intersex eugenics is in the interest of potential intersex people because they may not be able to reproduce becomes difficult to defend when one questions the logic of compulsory reproduction, dyadism, and heterosexuality. The potential intersex child is not being protected by the logic of compulsory reproduction, but rather pronatal, discriminatory ideologies are being safeguarded.

Seemingly rooted in evolutionary theory or objectivist aesthetic theory, another supposed function of healthy genitals is that they elicit attraction and desire in one’s sexual partners (Sparrow 2013). Variant genitals – queer, disordered/disabled, crip genitals – apparently do not elicit such desire; they are, Sparrow suggests, innately unattractive. The idea of an objective genital aesthetic standard, while untenable, reinforces compulsory dyadism and queerphobia, and justifies intersex eugenics under the guise of protecting the potential intersex person from teasing, bullying, and rejection for ostensibly having innately ugly characteristics. There is no objective genital aesthetic standard, even though Western philosophers, primarily before the eighteenth century, have attempted to provide objectivist aesthetic theories (see Aristotle [4th
Attractiveness is also not merely subjective, as many subjectivist philosophers claim in opposition to objectivists (Kant [1790] 1951; Hume [1740] 1988, 1757] 1894). What characteristics are deemed attractive or unattractive, beautiful or grotesque, is an ideological assessment and political value judgement (Collins 2004; Wolf 1990; Tate 2007; Robinson-Moore 2008; Satayana [1896] 1955). Standards of genital beauty, attraction, and health have shifted through time and space. And these shifts demonstrate the political nature of what genital characteristics are deemed un/healthy and un/attractive.

Historically, fueled by anti-Semitism, the circumcised penis was construed as a mark of pathological sexual difference, disease, impairment, and incompleteness (Gilman 1991). This understanding has shifted considerably. Currently, influenced by (inconclusive) medical and scientific studies and aesthetic claims, uncircumcised penises are regarded as ugly, unhygienic, vectors of disease in countries where circumcision is common practice (e.g. America, Canada) (Hellsten 2004). Or, consider the current increase in female genital cosmetic surgeries performed on non-intersex, cis women who want to attain the more “desirable,” “normal,” “tucked-in look” (woman qtd. by Braun 2009: 242), as seen in mainstream pornography (Braun 2009; Liao and Creighton 2007; F. Green 2005). Our cultural assumptions and representations of genitals reproduce and inform our understandings of genital attraction. Genitals are not inherently un/desirable. Specific socio-political ideas and cultural contexts influence people’s aesthetic evaluations.

In Kessler’s terms, “How hard one ‘looks’ at genitals and what one ‘sees’ [i.e. beauty, ambiguity, ugliness] is not constrained by the optic nerve but by ideology” (1998: 44-5). Variant

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96 Also see the discussion in Chapter 3 about South African women’s genitals. They were assumed to be ambiguous and excessive and, therefore, perverse, degenerate, and illustrative of insatiable sexuality. This was an aesthetic assessment of genitals which was fueled by biological racism, colonialism, and compulsory dyadism.
genitals are not inherently unattractive. They challenge the assumed normality of heterosexuality and dyadic sex; they challenge people’s (hetero)sexual imagination. Even though Sparrow insists that he is concerned for (potential) intersex people’s welfare and health, voicing a concern for potential lovers’ aesthetic stance on variant genitals indicates otherwise. Beauty is not a marker of health; beauty is a political, ideological assessment.

Another function of healthy genitals, Sparrow purports, is that they provide pleasure. I was initially confounded by the notion that variant genitals may not provide pleasure or may render it “difficult to achieve” (Sparrow 2013: 33). If an intersex person escapes curative violence or disabling medical interventions, genital sensation and orgasm is not hindered. Be that as it may, Sparrow mentions “one’s sexual partners” (2013: 34) whilst discussing the functions of health genitals; he appears to be concerned with intersex people’s partners’ pleasure (or assumed lack thereof). An intersex person’s partner will apparently struggle to be pleasured by variant genitals and/or the partner will struggle to pleasure the intersex person with variant genitals because they are apparently illegible. The former suggestion, receiving pleasure will be “difficult” (Sparrow 2013: 34), is only logically consistent if one takes for granted the belief that dyadic, heterosexual, penis-in-vagina sex is the most pleasurable or, in Sparrow’s words, if we assume “the prevailing social circumstances” are dyadic and heterosexual (2013: 34). Assuming that these circumstances are optimal for sexual pleasure reproduces queerphobia and compulsory heterosexuality. This assumption also, for example, neglects the fact that heterosexual, penis-in-vagina sex is frequently not optimal for non-intersex, cis women with vaginas because there is no, or not enough, clitoral stimulation (see Laumann et al. [1994] 2000; Harvey, Wenzel, and Sprecher eds. 2008; Wade, Kremer, and Brown 2005; Armstrong, England, and Fogarty 2012). This type of sex is optimal for heterosexual, non-intersex, cis men with penises. Despite
Sparrow’s claim that he is concerned for (potential) intersex people’s welfare, voicing a concern for potential lovers’ inability to be easily sexually pleased indicates otherwise. It is hard not to question Sparrow’s legitimate concern for intersex people when he refers to them as “functionally deficient [...] appropriate objects [emphasis added] of medical intervention” because their genitals may “render pleasure difficult” (2013: 34).

The latter suggestion, providing pleasure to people with variant genitals will be difficult, reminds me of sexist stereotypes about women with vaginas: vaginas are impossible to decode; women take longer than men to orgasm; reaching orgasm is challenging for women (see Laumann et al. [1994] 2000; Harvey, Wenzel, and Sprecher eds. 2008; Wade, Kremer, and Brown 2005; Armstrong, England, and Fogarty 2012). These false stereotypes have material consequences. In addition to women being shamed and pathologized, there is remarkable orgasm inequity between non-intersex, cis, heterosexual men and women. Like the assumption that women are difficult to please because of a biological deficit, Sparrow suggests that intersex people are difficult to please because of an innate biological problem or hindrance. As the literature about these sexist stereotypes and the orgasm gap show, there is no inherent, pathological problem with vaginas and clitorises. There is a sexist, social, and education problem (Laumann et al. [1994] 2000; Harvey, Wenzel, and Sprecher eds. 2008; Wade, Kremer, and Brown 2005; Armstrong, England, and Fogarty 2012). Similarly, variant genitals are not intrinsically difficult to please; there is a interphobic, queerphobic, social, and education problem.

Crosscutting all of these claims about “healthy” genitals is the premise that variant genitals do not naturally “fit” (Sparrow 2013: 33), I presume, with ostensibly dyadic genitals or perhaps even with other variant genitals. This anxiety regarding fit is also evident in the
preoccupation with normalizing or “straightening” (Roen 2005: 670) out variant genitals (Amato 2016: 84). To the homophobic proposal that men with penises who have sex with men with penises is unnatural because “the parts [penises] don’t fit,” Duane Simolke cheekily responds, “[y]ou obviously lack imagination” (2005: 23). He also suggests proponents of this claim read some publications, “whether erotic or clinical” (Simolke 2005: 23). Lending from Simolke, to the notion that variant genitals do not fit with supposed dyadic people’s genitals, I recommend thinking more creatively, queerly. Thinking queerly reminds one that people’s genitals can and do fit in and are placed in, around, and on numerous places, subjects, and objects to experience pleasure. Thinking queerly challenges the queerphobic, pronatal notion that genitals have an essential purpose or natural place to fit.

Historically framed by religious discourses, the accusation that certain genital formations do not fit together has long been used to pathologize queer people, primarily gay men (Dynes 2014). Wayne R. Dynes summarizes and historicizes this rationalization:

Simple observation shows that the sexual organs of the male body protrude, while the female genitalia are concave. The organs fit together like an electrical plug in its socket. For this reason heterosexual couplings are simple, direct, and inviting, while homosexual ones are awkward, contrived, and unsatisfactory. [...] This claim represents a subset of the argument from design. Popular in the seventeenth and eighteenth century, the argument has been revived in recent years by Creationists, who hold that God’s imprint is found everywhere in the world in the form of “intelligent design.” (Dynes 2014: 81).

Employing the same sort of reasoning as the often-referenced human eyeball argument – the human eyeball is so complex, God must have designed it (see McRoberts and Sandefur 2005) – the queerphobic idea that penises and vaginas were constructed by God to fit together is espoused. More recently the idea of “fit” has been transformed and taken up in medico-

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97 Sparrow invites us to think about some obvious options, “access – or lack of access – to vibrators and/or other sex toys” (2013: 34). Nevertheless, he still proposes that variant genitals do not naturally “fit” in “prevailing circumstances” and are “arguably functionally deficient” (2013: 33, 34).
biological, evolutionary, and secular discourses to pathologize queer sex/uality (Dynes 2014; McRoberts and Sandefur 2005) and intersex people with variant genitals (Sparrow 2013). In any case,

Modern sex research has pointed to crucial biological discrepancies that have weakened the old notion of the perfect suitability of male and female sexual organs. For one thing, the “fit” of the penis to the vagina is not notably better than its fit to the anus. [...] In addition, the male and female biorhythms summoned by sexual excitation show notable difference, and much negotiation and adjustment is required to achieve mutual satisfaction. [...] If this argument were conclusive, everyone would experience more pleasure and satisfaction from opposite-sex couplings than same-sex ones. Yet many do not. (Dynes 2014: 82).

In addition to the research Dynes draws from, post-structuralist, queer, trans, feminist, crip, disability, and intersex studies scholars have discredited the essentialist claim that anatomical parts have natural purposes and ought to perform certain (sex) acts and (gendered) labour. Thinking imaginatively and queerly about what to do with and where to put genitals and other erogenous zones, as queer, intersex, disabled, and crip people do, is not simply about exploring sexuality and sexual stimulation. Doing so contributes to anti-queerphobic and anti-interphobic projects like the systemic disabling of intersex people and intersex eugenics. So, as Simolke (2005) suggests, let us stimulate our imaginations, read some literature, and think queerly.

*Interphobia and Ableism*

Sparrow’s suggestion that variant genitals are “unhealthy” is one of the various characterizations of intersex traits that leads me to consider intersex eugenics, and the treatment of intersex people in general, as a disability issue. Hence, queerness cannot be separated from disability when considering (the prospect of) an intersex child. Disorder, health, disability, and queerness overlap; they “[fold] into each other” (McRuer 2006: 71). A disability lens is requisite when analyzing intersex eugenics and PGD technologies in order to fully understand why intersex
eugenics is said to be benevolent, “perhaps even morally required” (Sparrow 2013: 29; Trafimow 2013). A disability studies approach reveals that intersex anatomies are presumed to be and represented as fundamentally disordered, disabled, diseased, and “functionally deficient” (Sparrow 2013: 34). Intersex is being successfully assimilated into conventional notions of disability. And, since disabilities are imagined to be insufferable, intersex people are presumed to live intolerable, pitiable lives. Put simply, a disability approach reveals that intersex eugenics is justified by explicitly ableist discourses.

While queerphobia undeniably figures in arguments for intersex eugenics, queerphobic sentiments are more implicit when compared to ableist discourses. In fact, queerphobic ideologies are justified via ableist discourses of, for example, un/healthy and species a/typicality. Yet, the bioethical literature concerning intersex eugenics does not really unpack the ableism present in arguments for intersex eugenics. I propose that ableist rhetoric, rather than queerphobic rhetoric, is more explicitly employed not because there was an apolitical nomenclature shift from intersex to DSD which, by happenstance, resulted in the further pathologization of intersex. Intersex is strategically discursively constructed as a disability precisely so ableist narratives can prominently figure in conversations about PGD and intersex “treatment” in general because doing so is a means, in G. Davis’ terms, “for medical professionals to reassert their authority and maintain their exclusive jurisdiction over intersex” (2015a: 70). That is, I suggest, harnessing ableist logics is, at present, easier – more culturally admissible – than explicitly employing queerphobic rhetoric. Homonormative expressions and representations of queerness are increasingly common and accepted. Further, many nations actively position themselves as accepting of queer people. Homonationalist narratives are widely circulated and celebrated (Puar 2007, 2013a; Dryden and Lenon eds. 2015). Hence, queerphobia
cannot be as readily or explicitly mobilized in policies or debates concerning PGD, intersex eugenics, or intersex treatment. Doing so would be interpreted as discriminatory. Unlike queerphobic discrimination, ableism is rarely construed as discrimination. Ableism remains generally undetected because ableist logics are perceived to be natural and common-sense. Ableist narratives, therefore, are liberally mobilized. Ultimately, in order to combat intersex eugenics, we must combat ableism and crip our analyses.

Drawing on disability studies scholars to complicate the seemingly straightforward and objective descriptors “healthy” and “unhealthy,” I further unpack Sparrow’s suggestion that variant genitals are unhealthy. I also critique the ways in which intersex is conflated with “paradigmatic” disabilities (McRuer and Mollow: 2012: 12; Sparrow 2013). And, I identify and examine the ways medical professionals and fertility clinics misrepresent intersex by conflating intersex traits with life-threatening diseases (e.g. cancer). Representing intersex as a disability or disease in these medical(izing) contexts is a means to exploit ableist sentiments for intersex eugenic projects. Presenting intersex as a disability or disease in circumstances that devalue disability is a discursive maneuver to ensure medical professionals retain jurisdiction over intersex (see G. Davis 2015a) and reify compulsory able-bodiedness, dyadism, and heterosexuality.

Interphobia and Ableism:

It’s a...baby: Unhealthy, Sexless Intersex Infants

Reading Sparrow’s proposition that variant genitals are unhealthy, alongside Danielle Peers’ disability studies analysis of “healthy” births, highlights the necessity of a disability approach. Peers writes:
Judith Butler (1988) argues that one of the first constituting acts of subjectivity is the sexing of newborns. The movement from it to girl in the declaration “It’s a girl!” is the first of many sexing technologies that secure an essential part of our subjectivity. Yet, before the celebratory announcement of the sex of a newborn (or fetus), there is almost always and equally critical qualifier, namely, healthy. Indeed, my strong breath and normative number of digits marked my movement from thing to human just as much as my vagina did. Borrowing from Butler, I contend that discrete health and ability statuses – not unlike “discrete genders” – “are part of what ‘humanizes’ individuals within contemporary culture” (522). Objectified knowledges of gender and health, along with their corresponding technologies of division and normalization, have each fundamentally constituted me not only as a person, but also as a particular sort of person to be recognized, treated, and acted upon in corresponding ways [emphases in the original]. (Peers 2015: 339).

Intersex and feminist studies scholars identify the fact that a problem arises when the constituting act of sexing and gendering a newborn baby cannot instantly take place because of identifiable, “queer” intersex traits (Fausto-Sterling 2000b; Kessler 1998; Preves 1999, 2003). Considering Peers’ apt observation that being legibly healthy constitutes one as human together with (1) the pathologization of intersex and (2) Sparrow’s suggestion that variant genitals are unhealthy complicates the idea that the “problem” with intersex is solely a sex or queer issue. Upon confronting an intersex newborn with variant genitals, a gender qualifier is not immediately applied and the equally critical, humanizing qualifier “healthy” is also not applied. Rather than the declaration, “it’s a healthy baby girl/boy,” a parent may be met with the alarming declaration, “it’s a baby.” Or, perhaps, as Baseema was, a parent may be met with unnerving silence: “I said, ‘is it a girl or a boy?’, and they didn’t, they just didn’t say anything. They did not have a word” (qtd. by Gough 2008: 500; also see Zeiler and Wickström 2009). When discursive “sexing technologies” (Peers 2015: 339) fail to apply to an infant with variant genitals, that infant is then discursively constructed as unhealthy, disordered, disabled. That is, health is often defined in
terms of normalcy (Roen 2005: 259; also see Sparrow 2013). The variant genital “problem” is an intersecting queer and disability issue – a crip issue. Intersex newborns with variant genitals are not rendered fully human because they are “sexless” (Preves 1999: 52) and, therefore, “unhealthy” (Sparrow 2013). In order to prevent this situation from occurring, reproductive health and “sexing technologies” (Peers 2015: 339) (e.g. PGD, DEX) are made available. Or, to ostensibly remedy the unhealthy situation “sexing technologies” (Peers 2015: 339), “biodrag” (2013: 191), and surveilling technologies (Spurgas 2009) (e.g. IGM, HRT, genital examinations) are made available.

The assumption that atypical characteristics are innately unhealthy and inferior remains intuitively correct to bioethicists concerned with people having the “healthiest” children, or in Savulescu’s terms, having the “best children” who will be able to lead “the best [lives]” (2001: 413; also see Savulescu 2007; Sparrow 2007, 2011). Yet, health is not an objectively inherent or apolitical quality or state of being; it is an ideology (Claire [1999] 2009, 2017; Goodley 2011, 2014; Garland-Thomson 2002; M. Chen 2011; L. Davis 1995; Samuels 2012; Murphy et al. 1988; Cahill and Eggleston 1995; Wendell 1996, 2013). To quote Goodley, “health and illness are aspects of larger systems and are not located entirely within the single person” (2011: 82; also see Garland-Thomson 2002: 1560; M. Chen 2011; Clare [1999] 2009; Peers 2012). Un/healthy states of being are not wholly rooted in the body-mind; health is discursively constructed and, in turn, creates unhealthy or disabled subjects (Peers 2012, 2015).

Intersex infants born with variant genitals are not fundamentally unhealthy; their visible sex traits queer or crip sex and gender systems. Drawing from Julia Kristeva, “it is not lack of cleanliness or health that causes abjection but what disturbs identity, system, order. What does

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98 In other words, “[m]edical claims are couched in terms that attempt to conceptualize deviance” or abnormality “as a medical problem” that requires treatment, cure, and/or alteration (Conrad and Schneider [1980] 1992: 266) rather than an ideological shift.
not respect borders, positions, rules. The in-between, the ambiguous, the composite” (1982: 4),
the intersex, crip, queer, disabled body-mind. Innate unhealthiness is not what renders intersex
shocking, spectral (Sparrow 2013: 29), or abject – capable of literally silencing medical
professionals and striking fear in parents (Baseema qtd. by Gough 2008: 500; Zeiler and
Wickström 2009). Intersex variations are abject because they disturb boundaries and compulsory
ways of being. Locating the problem with intersex in the intersex trait itself, as Sparrow does
when he refers to variant genitals as unhealthy, opens up a space to restore “identity, system,
order” (Kristeva 1982: 4). And, medical professionals fill that space with various “technologies
of gender” (Preciado 2013: 387) and technologies of “health” such as IGM, HRT, and
reproductive technologies. The taken-for-granted premise that intersex variations are unhealthy
portrays these technologies – tools apparently capable of exorcising the spectre – as necessary
and benevolent.

Interphobia and Ableism:

Intersex, Leglessness, and Deafness: Conflating Intersex with Paradigmatic Disabilities
According to Sparrow, like “deafness and leglessness,” intersex variations are unhealthy,
species-atypical, medical problems (2013: 34). Conflating intersex with these sorts of
paradigmatic disabilities integrates intersex into conventional notions of disability, exploits
ableist sentiments, and works to depoliticize intersex eugenics. Interestingly, Sparrow attempts to
illustrate that intersex is primarily a medical problem by appealing to disability studies scholars.
He states, disability scholars maintain that “medical problems [e.g. deafness, leglessness] have a
social component” (2013: 32). This delineation of disability scholars is misrepresented and
unnuanced. Disability studies scholars critique the social model of disability (i.e. all disabilities

However, Sparrow incorrectly implies that disability scholars therefore support the idea that all disabilities are principally “medical problems” and only have one, “a [emphasis added] social component” (2013: 32). In doing so, Sparrow incorrectly insinuates that disability studies scholars see medicine and society as distinct entities. Rather, “disability studies place the problems of disability in society,” not always or principally in the body-mind (Goodley 2011: xi).

Working with this misrepresentative iteration of disability theories, Sparrow proceeds to claim there is “a rough consensus” that “a failure to develop legs,” “leglessness,” and “deafness” are medical issues because they “are deviations from species-typical functioning which will raise barriers and reduce opportunities” (2013: 32). As a result, “[s]election against these traits looks to be justified by concern for the life prospects of the future child” (2013: 32). After naming and reviewing the key biological functions of healthy genitalia, Sparrow concludes,

It seems likely that some intersex conditions should properly be thought of as analogous to leglessness or deafness – that is, as medical conditions [...]. In such cases PGD to avoid the condition is morally permissible – and perhaps even morally required (Harris 2011). Some may be tempted to argue, as per the “disability critique” of prenatal testing (Asch 1988; 2000; Kaplan 1993; Saxton 1997; Wendell 1996), that selection is morally problematic even in these cases. However, [...] the claim that such intersex conditions should be thought of as “mere variations” rather than harmful deviations from species-typical functioning [is] [...] implausible. (Sparrow 2013: 34).

That is, Sparrow argues, like people who do not have legs and deaf individuals, people with intersex anatomies are fundamentally and harmfully species-atypical because their body-minds
are not readily accommodated by the current infrastructures and gender, sex, and linguistic systems: there are “barriers and reduce[d] opportunities” (2013: 32) and their quality of life is low. Therefore, selecting against these (potential) body-minds is, for Sparrow, benevolent not ableist. Sparrow’s logic is backwards. These folks are not innate deviations because they do not reflect compulsory modes of being, fit neatly into dominant ideological structures, or move freely in ableist infrastructures. Rather, instituted culturally mandated ways of being create discursive and literal environments that exclude and fail to value the full diversity of body-minds.

To explain further, Sparrow’s focus on individuals’ assumed welfare masks the ableism that unpins his argument. This “individual discourse,” Goodley describes, “creates a number of ‘fault lines’: disability is cast as an essentialist condition (with organic aetiologies)” (2011: 8). Moreover, “disabled people are treated as objects rather than as authors of their own lives” (2011: 8). Recall Sparrow referring to intersex people as “objects” opportune for medical intervention (2013: 34), not subjects who become through time and space (Holmes 2000; Roen 2005). “[P]erson fixing’ rather than ‘context changing’ interventions are circulated” (Goodley 2011: 8); or, where PGD is concerned, preventative technologies are promoted. “[T]he power of health and social care professionals intensifies” (2011: 8); and, as is the case with medical and reproductive interventions, medical professionals retain jurisdiction over intersex (G. Davis 2015a). Ultimately, “presenting the disadvantage of disability as [a] [...] ‘biological flaw’ lets exclusionary society off the hook” (Goodley 2011: 8; also see Linton 1998; McRuer and Wilkerson 2003; Abberley 1987). Presenting intersex traits and/or (other) disabilities as species-atypical defects – exploiting taken-for-granted ableist logic – enables one to more readily evade the charge that selecting against these variations is discriminatory and eugenic.
The assumption that intersex is like a disability or is a disability is also reflected in the language employed by fertility clinics. For example, Rainbow Fertility provides PGD to “detect anomalies” and “abnormal chromosomes,” like “Turner Syndrome,” an intersex variation, to prevent the “adverse outcomes” of “the birth of a child with physical and/or mental disabilities” (“Additional Options with IVF” 2016: n.d.; also see “Rainbow Fertility” 2016; Carpenter 2016c). Reproducing the rhetoric of tragedy – employing pathologizing, ableist, and culturally disconcerting terms like “adverse,” “abnormal,” and “disabilities” – frames intersex as an innate disability that ought to be avoided. Similarly, City Fertility Centre endorses PGD, a tool used to screen out “genetic abnormalities” “that may prevent implantation to the uterine lining, lead to pregnancy loss, or result in the birth of a child with physical and/or mental disabilities. PGD may help prevent these adverse outcomes” (“Genetic Testing [PGD]” 2013: n.p.; Carpenter 2016b). Such abnormalities, according to City Fertility Centre, include “Down syndrome or Trisomy 21” and “Klinefelter syndrome (XXY)” which may result in “physical differences and mental retardation” (“Genetic Testing [PGD]” 2013: n.p.). When presented “as physiological failures or flaws, as medical crises that demand normalization” (Garland-Thomson 2005: 1567), Klinefelter syndrome and Down syndrome must be prevented via PGD.

Sparrow’s position and the discourses used by fertility clinics are not unique (Trafimow 2013; Savulescu 2001, 2007; Harris 2011). Yet, Sparrow’s (2013) essentializing comparison/conflation of intersex with deaf people is noteworthy because it thoroughly contradicts his 2005 article, “Defending Deaf Culture: The Case of Cochlear Implants.” Echoing many disability scholars, Sparrow argues that the disadvantages deaf people confront are produced by ableist “social and institutional causes and could be rectified by changes in the way
society is organized” (2005: 137). He challenges the idea that disability is an innate defect and works to expand the confines of normal human variation or species-typical functioning:

Deafness is a disability because hearing is one of the six senses that humans characteristically possess [...]. But a moment’s thought reveals [...] the limits of normal human capacities will be the result of who we consider to be part of the range of normal human variation amongst persons. If we include the deaf, then hearing will not be something that all normal people have. It will instead become a less important mark of difference, like hair or eye color [...]. It is also timely here to emphasize how far the boundaries of the ‘normal’ have already shifted. For much of the history of Western culture the ‘normal’ person was white, male and propertied. Women, non-whites and working class people were thought to be inferior examples of the human form. (Sparrow 2005: 138-139).

Recognizing how ideologies concerning normality and disability shift, as Sparrow previously did (2005), the fact that intersex variations are not innately deviant or species-atypical is clear, as Sparrow more recently suggests (2013). The interphobic, ableist, and queerphobic oppression intersex people experience, to quote Sparrow, “could be rectified by changes in the way society is organized” (2005: 137). “[R]eductive biological understandings” (K. Hall 2011: 5) of sex, gender, health, and disability do not rectify these injustices but exacerbate them and cultivate the best conditions for new eugenics. In other words, “a moment’s thought” (Sparrow 2005: 138) demonstrates that dispelling the myth of normality, innate disability, sex dyadism, and “[t]he myth of the normal child” is vital to remedying social injustices (Baglieri et al. 2011b: 2124; also see M. Chen 2011; Stockton 2009).

Interphobia and Ableism:

Conflating Intersex with Diseases

Intersex traits are also compared to and regarded as if they were life-threatening diseases (Holmes 2000: 85, 97; Mitra 2014a: 389; G. Davis 2015a; Chapter 2). Rather than being diseased or “sick,” Holmes notes, “it is the culture around the child which is dis-eased [emphasis in the
original], as it were, made uneasy by the child’s intersex characteristics” (2000: 97). Regarding intersex variations as diseases/diseased, (potentially) cancerous, or comparing intersex to diseases enables medical professionals to more readily justify “curative,” disabling, violence (Chapter 2). This discourse also enables state regulators to support access to PGD and fertility clinicians to rationalize promoting and employing PGD for intersex eugenics.

G. Davis’ study verifies: some medical professionals “compare intersex traits to dangerous diseases, despite the fact that most intersex traits have minimal, if any, health risks. Dr. C., for instance, viewed DSD terminology as ‘an analogy. It’s like talking about skin cancer and brain cancer’” (2015a: 69).99 The analogy is distinctly misrepresentative when one takes into account that the five-year survival rate of children diagnosed with brain cancer varies from 40-80 percent and, if they survive, they will deal with an array of long-term consequences (e.g. cardiac problems, depression, and post-traumatic stress disorder) (Woodgate et al. 2016; M. Smith et al. 2010; Reimers et al. 2009; Iuvone et al. 2011).100 Children with intersex traits cannot potentially die from their intersex traits themselves. And, as discussed in Chapter 2, claims that intersex people are at a greater risk of developing cancer, and therefore require early surgery, are inflated and contested (Carpenter 2013d). Regarding intersex as (the same as) a type of cancer creates a

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99 Given that intersex is represented as being akin to cancer, it is unsurprising that a tool was developed to assess the psychological states of parents of intersex children. The tool is essentially the same tool used to assess the psychological states of parents whose children were recently diagnosed with cancer. Sandberg and Mazer describe the tool: “The Psychosocial Assessment Tool [...], a tool originally designed for families of newly diagnosed children with cancer, is among the earliest instruments to be administered in the DSD-TRN [Disordered of Sex Development-Translational Research Network] to screen for psychosocial risk [i.e. stress, coping mechanisms] in families. The Psychosocial Assessment Tool (PAT), developed out of the Pediatric Psychosocial Preventative Health Model framework (Pai et al., 2008), was designed to screen for psychosocial risk in families of children newly diagnosed with cancer (Nielsen-Bohlman, 2004). With minor [emphasis added] modifications, it has been modified for use in DSD” (Sandberg and Mazur 2014: 109-101). Rather than supply parents with accurate resources about sex variations, intersex people, and support groups, parents are encouraged to understand their child as diseased, cancerous. It is not shocking that parents of intersex children “reported overall levels of PTSS [post-traumatic stress symptoms] that were comparable to those reported by parents of children diagnosed with other disorders, in this case cancer” (Pasterski et al. 2014: 373). See Pagonis (2017a) for their open letter to Sandberg’s pro-surgery stance.

100 I present statistics about children with brain cancer rather than adults because when discussing the treatment of intersex, the focus is typically intersex infants and children.
“state of exception” which then “lay[s] the groundwork for justifying medically unnecessary interventions” (G. Davis 2015a: 23). This state cultivated by medical professionals, exploits parents’ anxieties about chronic ill health, disabilities, and death to justify unnecessary medical interventions or preemptive screening reproductive technologies. Parents’ are understandably profoundly distressed and believe they are acting in the best interests of the (potential) child or fetus when they agree to various procedures.

Intersex is also misrepresented as a disease in Canada’s PGD regulations. Recall that sex selection is prohibited in Canada but, “[s]ex selection for the purpose of preventing, diagnosing, or treating sex-linked disorders or diseases [emphasis added] is permitted in Canada” (O’Neill and Blackmer 2015: 10). Without explicit definitions and distinctions between disease and disorder, intersex variations are misrepresented and can be misconstrued to be life-threatening diseases. Disease, then, as it relates to intersex in this context, is a metaphor. And, as Phil Smith explains, “the disease metaphor” is useful means to create body-mind differences and justify “exclud[ing]” or eliminating what is culturally disruptive or perceived to be “repulsive and revolting” (2004: n.p.)

**Conclusion: “Choosing” PGD and Intersex Eugenics**

Reflecting on the fact that reproductive technologies are deployed to prevent the implantation of embryos or gestation and birth of fetuses with (perceived) disabilities, defects, and atypical traits, Bill Hughes states:

> The ghosts of imperfection and impairment haunt modern medicines’ art of iatromechanics. Prenatal genetic diagnosis is the exorcist. [...] Disabled people

\[101\] Iatromechanics, a theory held by medical practitioners in the late seventeenth century, suggests the body is comprised of a “set of mechanical tubes, engines, and implements” and each part of the body has a distinct and specific function that can go awry or is innately dys/functional (T. Brown 1970: 12). Viewing the body as a machine with innate functions, these practitioners sought to develop a consistent theory of pathology and therapy. Theodore
have, in the past, been singled out by “genetic inquisitions” and identified as “suspect sires” [i.e. old-eugenics]. [...] The new genetics disavows this disreputable ancestry but disabled people have good reason not only, to remain unconvinced by such assurances, but also to affirm the import of Tom Shakespeare’s (1995, p. 22) suggestion that the new genetics is a case of “back to the future”. [...] The new genetics establishes a framework for distinguishing people – not to mention cellular entities in utero and in vitro [emphases in the original] – on the basis of the amount of “genetic capital” that can be identified in a given sample of DNA. An embryonic system of biological and aesthetic stratification is inherent in the framework. (B. Hughes 2000: 564).

The spectre of intersex and/as disability haunts contemporary reproductive technologies, prenatal diagnosis and preimplantation genetic diagnosis. Hence, eugenic practices and ideologies have not been eradicated; they have transformed. And, as this chapter underlines, disabled, intersex, and/or queer individuals have good reason to remain unconvinced by medical assurances and legal narratives that allege eugenics are over.

In addition to remaining unconvinced that eugenics are over, the active promotion of PGD, particularly the ironic promotion to LGBTQI communities (Carpenter 2016b), provides us with the opportunity to question liberal, homonational discourses of LGBTQI acceptance and inclusion (see W. Brown 2006; Puar 2007, 2013a). Narratives of queer diversity or tolerance cannot be taken seriously when PGD is used to prevent the implantation of queerly disabled, crip, intersex embryos and their possible subsequent gestation and birth. Technologies employed to detect and prevent the gestation and birth of fetuses with intersex variations tells us that intersex, crip, disabled, and/or queer people are not and should not be wanted in the future (see Kafer 2013). As a result, when PGD is promoted to LGBTQI groups, we need to be self-

M. Brown contextualizes this theory: “[i]natromechanism (sometimes also called ‘iatrophysics’ or ‘iatromathematics’) is generally considered a byproduct of the Scientific Revolution, representing the attempt, foolish at worst and premature at best, to achieve in the medical domain what had already been achieved in the physical by the ‘mechanization of the world picture’” (1970: 12). The approach was “foolish,” as T. Brown states, because this theory lead medical practitioners to endorse and practice dangerous, but often traditional therapies such as bloodletting and inducing vomiting. The idea that the body-mind is a machine and has innate dys/functions remains. While, of course, this approach to bodies has advanced medicine, it has also marginalized and harmed people with (perceived) disabilities like intersex people. People with disabilities and/or intersex people are perceived to have dysfunctional body-mind parts that must be fixed or avoided at all costs.
reflexive and interrogate the ways in which we are called to be complicit in intersecting forms of discrimination. In doing so, we recognize the relationship between intersex, queerness, and disability and the constitutive relationship between compulsory dyadism, heterosexuality, able-bodiedness, and reproduction. Given this relationship, there is good reason for intersex, queer, disability, crip, and feminist pro-choice activists to align with and learn from each other.

Many disability activists and scholars note that pro-choice advocates must engage with disability activists because they often appeal to ableist narratives to justify access to reproductive technologies (Clare 2017; Knight 2017; Stapleford 2014; Sheible 2014; Henry 2013; Hershey 2000; M.C. Hall 2013; Rohrer 2011; Sharp and Earle 2002). For instance, some pro-choice activists argue that people should have access to later term abortions if they discover that the fetus has a disability. “This strategy,” according to queer, disability activist, Lenzi Sheible, attempts to justify later abortions to anti-choicers by trading on the rhetoric that some abortions – of fetuses with “abnormalities” – are inarguably necessary. Rather than reasoning that all abortions should be equally accessible no matter what, many pro-choice advocates lean on the argument that of course [emphasis in the original] people, including anti-choicers, would opt out of having a disabled child if they had the means. (Sheible 2014: n.p.).

Likewise, pro-choice stances need to be mindful of the ways in which, in addition to ableism, interphobia and queerphobia underpin arguments that seek to justify people’s access to reproductive technologies. People’s right to reproductive technologies need not implicitly or explicitly be made at the expense of people with disabilities, people with intersex characteristics, or queer people. Ensuring such discriminatory discourses are not employed resists dehumanizing and (re)marginalizing these communities.

The idea and legislation of reproductive “choice” is complicated when taken alongside the discriminatory, new eugenic discourses used to justify access to reproductive technologies. Indeed, returning to the language of haunting, (potentially) pregnant people confront the
narrative that they could, but ought not, implant, house, and gestate an unviable, monstrous (Shildrick 2002), “gender-disabled” (K. Morgan 2005: 301), “sideways” growing phantasm (Stockton 2009: 1). Furthermore, people who give birth to “spectral” babies with disabilities, differences, or diseases are often blamed and shamed (Rapp 1999; Rabin 2006; Payne 2006; Parens and Asch eds. 2000; L. Davis 2013b; Waggoner 2015; E. Armstrong 2003; C. Daniels 1993). These narratives and shaming practices create a cultural, moral imperative to “choose” the “viable” embryo or fetus.

To emphasize my point, consider Sparrow’s ghostly language: “confronted with the spectre of intersex, modern medicine makes choices available to parents and physicians” (2013: 29). PGD is one of these choices. The ghostly rhetoric unequivocally communicates that the prospect of implanting an intersex embryo, gestating an intersex fetus, and giving birth to an intersex baby is a frightening possibility. Sparrow presents choosing for intersex, or not choosing against intersex, as a prima facie poor choice, perhaps even an immoral choice. Choosing for or not choosing against the phantasm, according to Sparrow’s narrative, suggests that the parent does not have the future child’s welfare in mind. He creates a moral imperative to select against intersex, to “choose” new eugenics. As Nisker explains, “[o]nce a difference [e.g. intersex] becomes a medical disorder to which the medical profession is dedicating time and resources to prevent, procedures to this end become endowed with appropriateness and thus threaten a woman’s ability to reject” (2013: 47; also see Kaposy 2014, 2015).

(Potentially) pregnant people’s engagement, or lack thereof, with preventative, eliminative, and exorcising reproductive technologies is not simply about freely making a choice. Choice and coercion, freedom and cultural imperatives, are coextensive. Shakespeare observes: “the medical profession and the context in which reproductive decisions are made, undermines
the capacity for free choice, and promotes eugenic outcomes” (1998: 666). Eugenic sentiments are promoted, but masked as personal choices. Reflecting on the ways parents of intersex children are coerced to agree to early surgical interventions, G. Davis explains that “medical professionals […] place the responsibility for medical decisions entirely on parents, thereby avoiding responsibility for questionable interventions” (2015a: 23). Similarly, placing responsibility on (potential) parents to avoid implanting certain “unviable” embryos and gestating ghostly fetuses, whilst narrating that responsibility as a choice, enables medical professionals, reproductive technology researchers, and governments to avoid responsibility for eugenic interventions.

Considering who benefits from more reproductive “choices” is illuminating. As this chapter illustrates, these sorts of reproductive technologies do not benefit people with culturally devalued characteristics, characteristics these technologies seek to eliminate (see Kaposy 2013, 2014, 2015; Kaposy and Downie 2008). Rather, they further exacerbate stigma. Moreover, many (potentially) pregnant people do not necessarily feel liberated when more choices and diagnostic technologies are made available to them (Rapp 1999). Legalizing, under/unregulating, and making these technologies easily accessible benefit nation states invested in reproducing a (hetero)normative, normate, “productive” workforce whilst avoiding explicitly endorsing discriminatory logics and eugenics (see C. Thompson 2005). These technologies also primarily benefit capitalistic corporate bodies, clinics, and researchers who economically profit from developing, providing, and promoting reproductive technologies with eugenic implications (Kaposy 2014, 2015).

102 Considering reproductive technologies used to test for Down syndrome,

Chris Kaposy explains: “the arms race to develop these tests is not being driven by the needs of people with Down syndrome or the needs of their families. [...] Devotion to create a test that helps parents to avoid the birth of people who tend to enjoy their lives seems somehow [...] off the mark” (2015: n.p.; also see Kaposy 2013, 2014; Meredith et al. 2016). Similarly, Carpenter acknowledges that “conflicts of interest [...] arise when clinicians making decisions on what constitute ‘serious genetic disorders’ financially benefit from conducting those tests” (2016b: n.p.). The fact that people profit from coercive new eugenic discourses and tests that “prevent specific groups from accessing and exercising full rights as human subjects” (Holmes 2008b: 175) is extraordinarily troubling.

I do not propose that anyone’s access to reproductive technologies should be limited; access to reproductive technologies, such as contraception, abortion, and prenatal care, desperately need to be expanded so all people can access them, not just the most privileged. Holmes “[insists] on the right of women to terminate pregnancies, even in cases where I might prefer they decide otherwise” (2008b: 178). Likewise, I defend, insist on, and celebrate (see Thomsen 2013) the rights of all people who can become pregnant or are pregnant to terminate pregnancies or choose one embryo over another embryo, even in cases where I am troubled by the ideological underpinnings of said decision. That said, we must critically question why eugenic choices seem ethical, magnanimous, even required. We need to evaluate what dominant ideological, literal, and financial systems make these eugenic decisions desirable.

Equally important, we must be diligent in celebrating and supporting all people with diverse body-mind variations and culturally devalued modes of becoming. That means, we need to continue to demand medical professionals rethink the systemic pathologization and active erasure and elimination of intersex variations, disabilities, differences, and queer and crip ways
of being. It is imperative we “recognize the inherent value in a life lived with and through
difference,” and ensure all people can “exercise their own level of qualified autonomy within the
networks of social support that enables the qualified autonomy of all persons” (Holmes 2008b:
175, 179).
Conclusion
“The Future is Intersex:” Combating Compulsory Dyadism and the Eradication of Intersex

Intersex is, Morgan Holmes confirms, “a perpetually shifting phantasm in the collective psyche of medicine and culture” (2002: 175; also see Reis 2005, 2009; Fausto-Sterling 1993, 2000a, 2000b; Kessler 1998) and it is a relatively new celebrated identity category (see G. Davis 2014, 2015a; Viloria 2017; Preves 2003). And yet, intersex is typically represented and violently treated as innate disorder, disability, or disease by medical professionals (Holmes 2008b, 2011; G. Davis 2015a; Spurgas 2009; Mitra 2014a). This dominant representation and treatment of intersex prompted me to think through how intersex intersects with and is haunted by disability. Building on important feminist research in the fields of intersex, queer, disability, crip, and hauntology, I asked, how do we understand and reconcile the contested meanings, responses to, and (haunting) effects of intersex? Using hauntology (Gordon 2008, 2011; Derrida [1993] 1994; Fisher 2013; Buse and Stott eds. 1999) as a linchpin, I explored the contested meanings of intersex, particularly the undertheorized, and sometimes resisted (see Wilkerson 2012; Colligan 2004; Koyama 2006; Cornwall 2009), connection between intersex and disability. In doing so, this dissertation illustrated that ableist conceptions of disability and compulsory able-bodiedness are at the heart of contemporary and emerging medicalized discourses about, and the subsequent maltreatment of, people with intersex characteristics.

Even though I identified some, arguably inadvertent, “stigmaphobic distancing” from disability (McRuer 2006: 85) as well as a lack of engagement with disability studies by most intersex studies scholars and activists, by engaging intersex studies’ theories of inter/sex (Karkazis 2008; Chase 1998a 1998b, 2002, 2006; G. Davis 2015a; Magubane 2014; Morland
2009; Roen 2005) and bridging this field with feminist disability and crip theories of
an intersex politic and intersex studies rooted in a disability politic and disability studies
(Koyama 2006; Holmes 2008b, 2011; Cornwall 2013). Drawing attention to the “intersexion”
(Preciado 2005; “Intersex-ionality” 2016; #intersextionality n.d.; Lahood dir. 2012) of intersex
and disability, refines our theoretical understanding of the relationship between inter/sex,
sexuality, gender, and disability, expands our comprehension of how interphobia and ableism
circulate and are maintained, and, in turn, helps intersex studies scholars and activists combat
interphobia in new, more effective ways.

Expanding the ways in which scholars theorize culturally mandated ways of being (i.e.
compulsory heterosexuality, able-bodiedness, reproduction, motherhood) (Rich 1980, 2003;
Puar 2009; Maroney 1985; Edelman 2004; Deifelt 2005; Butler [1990] 2006) and drawing
inspiration from many intersex activists’ adoption of dyad terminology (Costello 2009a, 2009b,
AIS-DSD Support Group; Actually Intersex), I conceived of the phrase “compulsory dyadism”
to help us understand and analyze institutionalized anti-intersex violence. Compulsory dyadism
is a useful theoretical and methodological tool to name and deconstruct the instituted societal
dictate that people cannot have intersex traits, house the “spectre of intersex” (Sparrow 2013:
29), or identify as intersex. Using this tool, I critically analyzed three cases of compulsory
dyadism that extend beyond national borders through a feminist disability and crip lens:
nonconsensual medical interventions, sport sex testing, and employing the reproductive
technology PGD to select against intersex characteristics. Examining these case studies revealed that intersex is presently and quite successfully being integrated into conventional notions of disability. Or, in other words, intersex is often presented as or conflated with “paradigmatic” disabilities (Mollow and McRuer 2012: 12). Intersex traits that breach compulsory dyadism are understood as simultaneously violating compulsory heterosexuality as well as compulsory able-bodiedness. And, therefore, so the discriminatory logic goes, intersex must be detected, exorcised, and surveilled. Compulsory dyadism is wrapped around, or is an iteration of, compulsory able-bodiedness. Discursively integrating intersex into conventional notions of disability has adverse, indeed disabling, consequences for apparently disabled intersex people and undermines the various human rights projects of the Intersex Rights Movement (see G. Davis 2015a). Recognizing the interconnection of intersex and disability and theorizing intersex and disability together is not merely theoretically interesting, it is necessary.

In more specific terms, in Chapter 1, I elaborated on the fact that nonconsensual and unnecessary medical interventions are usually deemed essential because intersex variations, according to medical professionals, are disorders, disabilities, or diseases. Disabled embodiments supposedly must be “fixed.” Yet, ironically, these procedures often result in a variety of disabilities. Typically, discourses of mutilation, queering, torture, human rights violations, and sexual assault are employed to explain and theorize the occurrences and short-/long-term outcomes of medically managing intersex (Chase 1998a, 1998b, 2006; Roen 2005; Holmes 2000; Khan qtd. in Karkazis 2008: 1; May et al. qtd. by Jordan-Young 2010). I do not suggest that these discourses are inaccurate or should be done away with; they are invaluable for a number of reasons. As I argued above, however, integrating the notion of “curative violence” (Kim 2017) and conceptualizing the lingering, haunting consequences of said violence as body-mind
disabilities can benefit intersex rights claims to body-mind autonomy and full citizenship status (see Grabham 2007; G. Davis 2015a; Snyder and Mitchell 2010). Claims of, for example, mutilation, torture, and sexual assault are easier for authoritative doctors and people in positions of power to dispute; they seem, and are discredited as, sensationalized, misrepresentative, and hyperbolic.

Asserting that the consequences of violent “curative” medical procedures constitute body-mind disabilities in strategic circumstances not only underscores the intersection of intersex and disability, but doing so also holds medical professionals and institutions accountable in new ways. The discourse of violently disabling highlights a troubling paradox in a more explicit manner: in an effort to “enable” or “cure” apparently disabled, diseased, or disordered intersex people – in an effort to expel traits that supposedly bedevil and pollute people’s body-mind – medical professionals create newly disabled, crip subjects and ghosts. The very institutions that claim to cure, heal, and safeguard individuals contribute to creating gratuitous disabilities such as, chronic pain, depression, anxiety, loss of genital sensation or ability to orgasm, incontinence, inability to urinate without assistive devices or discomfort, and/or infection. The “spectre of intersex” (Sparrow 2013: 29) and “the spectre of disability” (Belser and Betcher 2013: 344) are, in the case of nonconsensual, “curative,” medical interventions, often indistinguishable. And, these phantasms are “ways in which abusive systems of power make themselves known and their impacts felt in everyday life, especially when they are supposedly over and done with” (Gordon 2011: 2). The narratives of curative violence and disabling intersex people bolsters well-supported, evidence-based claims to medical malpractice and violations of the Hippocratic Oath (see Pagonis 2017b; Grabham 2007; Ford 2001).
The disabling results of medical malpractice and outright violations of the Hippocratic Oath are ways in which intersex and disability haunts the intersex subject, even if the spectre has supposedly been removed or deferred and surveilled (see Roen 2009; Spurgas 2009). Intersex, as explained by Michael O’Rourke and Noreen Giffney in Holmes’ edited collection *Critical Intersex* (2009), “is not ontological, but rather hauntological” (2009: x) in that intersex can never be fully extracted from people’s body-minds. Intersex always threatens to resurface and reveal itself, for example, through one’s queer sexuality, gender presentation, memories, or during one’s experience of puberty and growth. Consequently, intersex people are routinely surveilled and become life-long patients (Spurgas 2009) so they do not (continue to) “grow sideways” (Stockton 2008). In Chapter 3, extending this argument and reworking a disability adage – enabled people are only ever “temporarily [emphasis in the original] able-bodied” (Clare [1999] 2009: 82; also see M. Chen 2011) given that “the spectre of disability” (Belser and Betcher 2013: 344) “haunt[s] us all” (Garland-Thomson 1997: 9) – I ascertained that the “disabled” intersex spectre haunts all people, not just pre-/post-medically altered intersex individuals. Intersex is “a perpetually shifting phantasm” (Holmes 2002: 175) and is always in the process of being discursively (and literally) re/constructed. Intersex-as-disability, therefore, could be attached to or “read off of” (Kessler 1998) any person’s body-mind. All people are always and already contested (Butler [1990] 2006). To explain, people can and do discover they have (or have had) intersex traits at various points in their lives and are subsequently subjected to the violent process of pathologization or, in Lena Eckert’s terms, “intersexualization” (2009: 64). Even though anyone could learn they have characteristics deemed intersex, intersex is not and has never been represented as indiscriminate, unsystematic. As my investigation into past and present sport sex testing practices show, intersex and intersexualization is a political multi-tool.
By underscoring the fact that women athletes have historically been and currently are targeted and rendered (suspect) intersex and given that there is no evidence to suggest athletes’ abilities extend exclusively from sex (however sex is defined) (see Dworkin and Cooky 2012; Zaccone 2010), it is clear that sex testing works to re/stabilize the sex and gender binaries and justify sport sex segregation. Sex testing serves as a reminder that we need to continue to undermine binary thinking that enacts violence on and excludes (suspect) intersex people and women. This practice also calls us to reimagine how sport is organized. Sport sex segregation does not represent people’s body-minds or abilities. In fact, sex segregation was established when women began entering “masculine” athletic arenas and were outperforming men (Dworkin and Cooky 2012). Sport sex segregation was not instituted to reflect “innate” gendered physical capacities, but rather to construct and preserve “images of male superiority” (McDonagh and Pappano 2008: 17; also see Cahn 1994; M. Cohen 2009; Kane 1995; Milner and Braddock 2016).

Looking even closer at which groups of women are and have been targeted for testing, and reading this alongside the particular broader cultural climate, tells us that sport sex testing functions to delegitimize and shame certain races, nations, cultural identities and expressions of femininity, political alignments, and even assist in projects of war. For example, during the Cold War women athletes from the Soviet Union were targeted for testing as a means to disparage communism and Soviet conceptions of femininity that did not align with America’s investment in capitalism or American notions of femininity, namely, the idea that women are quiet and weaker, smaller, and less muscular than men (Pieper 2014, 2016). Currently, women athletes of colour from colonized nations in the Global South are targeted for testing (Mitra 2014b: n.p.; also see G. Davis 2015a: 152; Karkazis 2016b). Targeting these women, delegitimizing their
identities and athletic achievements, shaming their nations and cultures, and imposing Western notions of sex, DSD, femininity, and beauty, I demonstrate, continues the colonial, racist, orientalist, imperial work that began centuries ago.

Approaching sex testing and sport sex segregation with a feminist disability lens enabled me to remain cognizant that intersex is regarded as a disorder, disability, or disease. In doing so, I identified another paradox: intersex is construed in this way by medical professionals in and outside of sport contexts, but in the context of sport, intersex traits are represented as an advantage whereas outside of sport they are represented as inferior, disordered lack. This contradiction reveals the logical shortcomings of Western dichotomous thinking about sex, gender, dis/order, and dis/ability. Claiming that a (supposed) intersex person is both better and worse in the context of sport, draws attention to the il/logic powerful institutions rely on in order to justify, uphold, and institutionalize discriminatory ideologies. Not only that, this discrepancy calls us to question sport dis/ability segregation as well as sex segregation.

Sport is not and cannot be completely segregated by sex, gender, or dis/ability. And such segregation ought not be a goal. Sex testing and sport sex and dis/ability segregation does not make sport fair, but rather re/marginalizes and enacts violence on already marginalized and devalued athletes, namely, athletes from colonized nations, athletes with intersex traits, trans athletes, athletes with (perceived) disabilities, and women athletes, particularly racialized women athletes. My project calls for removing sport policies that violently police, exclude, impose, invade, and mandate certain embodiments; it calls for fundamentally reimagining and decolonizing sport.

Considering the practice of employing the reproductive technology PGD to ensure an intersex embryo is not implanted into a potentially pregnant person, as I did in Chapter 4, draws
attention to another group of people who are believed to hide, and in this case, potentially
gestate, the intersex spectre: (potentially) pregnant people. These people, their embryos, and their
potential fetuses are surveilled and, when deemed necessary, require a sort of preemptive
medical exorcism. This practice has primarily been referred to as anti-intersex selection or
selecting against intersex. By engaging feminist disability scholarship concerning reproductive
technologies, reproductive freedom/choice, and eugenics (Magnet 2013; G. Allen 1989; Garton
2000; Baker 2002; Campbell 2000; S. Long 2015; Sparkes 1999; Farrall 1985; Shakespeare
1998; Hansen and King 2001; McLaren [1990] 2014; Grekul, Krahn, and Odynak 2004; Beaud
and Prevost 1996; L. Davis 2013a; Chesterton and Perry eds. 2000; Kevles 1985; Kerr and
Shakespeare 2002; Gould 1981; Thomsen 2013), I illustrated that this practice is not simply
about selecting against apolitical traits. It is about eradicating culturally devalued characteristics
and ensuring (potential) people will more readily conform to and embody compulsory dyadism,
heterosexuality, able-bodiedness, and reproduction. This use of PGD is a form of “new
eugenics.” New eugenic discourses rely on ableist logics of health, normality, and “species-
typical functioning” (Sparrow 2013: 32) to responsibilize and coerce (potentially) pregnant
people to “choose” to select against species-atypical functioning. And this eugenic “choice” is
commended; it is regarded as ethical, prudent, and “perhaps even morally required” (Sparrow
2013: 34) because said choice is ostensibly “for the baby’s welfare.” New eugenic discourses
frame technologies like PGD as mere tools to advance reproductive freedoms (see Trafimow
2013). Yet, the technologies and discourses surrounding them cultivate the perfect environment
for eugenic choices. They put pressure on (potentially) pregnant people to “freely chose” to
literally embody and gestate compulsory dyadism, able-bodiedness, and heterosexuality.
Various feminist intersex studies scholars critique new eugenic PGD practices by drawing attention to the fact that queerphobia intersects with interphobia and, therefore, underpins the new eugenic practices (G. Davis 2013; Behrmann and Ravitsky 2013). My own analyses of various governmental, fertility clinic, and scholarly documents (re)confirmed these claims. However, since intersex is discursively constructed as a disability, ableist narratives figure particularly prominently in conversations about PGD and intersex. I suggest, harnessing ableist logics is, at present, easier – more culturally admissible – than explicitly employing queerphobic rhetoric. Homonormative expressions and representations of queerness are increasingly common and accepted. Further, many nations actively position themselves as accepting of queer people. Homonationalist narratives are widely circulated and celebrated (Puar 2007, 2013a; Dryden and Lenon eds. 2015). Hence, like sexism, queerphobia cannot be as readily or explicitly mobilized in policies or debates concerning PGD and intersex. Doing so would be interpreted as discriminatory. Unlike sexist and queerphobic discrimination, ableism is rarely construed as discrimination. Ableism remains generally undetected because ableist logics are perceived to be natural and common-sense. Ableist narratives, therefore, are liberally mobilized in conversations and policies pertaining to reproductive technologies, freedoms, and choices. Claims that intersex traits are inherently unhealthy, diseased, disabled, disordered, unnatural, and deformed saturate bioethics articles that endorse anti-intersex eugenics, fertility clinic documents and guidelines, and Canadian governmental policies concerning access to and regulation of PGD and reproductive technologies more generally. In this case, intersex is effectively integrated into ableist, conventional notions of disability in order to justify intersex eradication and to distance from and deflect accusations of queerphobia and sexism. Since ableism is so central to promoting this new eugenic application of PGD, yet remains absent from
scholastic and activist assessments, anti-ableist discourses and disability analyses of reproduction and eugenics are vital as intersex studies scholars and activists continue to critique and combat this new eugenic practice.

Ultimately, by analyzing the intersection of intersex and disability – crippling intersex studies – and identifying the benefits that accrue when compulsory dyadism and able-bodiedness are placed on the same continuum, whilst simultaneously attending to haunting body-mind effects of curative violence, this dissertation extends the academic fields of feminist intersex, disability, queer, crip, and hauntology studies. My project unpacked the complex ways compulsory dyadism, able-bodiedness, heterosexuality, reproduction as well as colonialism and racism are “imbricated systems” (McRuer 2013: 370).

Alliances and Identity Politics

I began my dissertation with a lofty request. I asked possible discontented readers to forbear in order to see what benefits emerge from theorizing intersex and interphobia through a feminist disability and crip lens. I am deeply grateful for my readers’ attention and engagement with my work as I explored and demonstrated that such theorizing accrues many benefits and is, in fact, necessary. Doing so nuances our understanding of inter/sex and disability, how compulsory dyadism is instituted and maintained, and strengthens intersex human rights claims.

That being said, I remain cognizant that a material activist alignment or alliance between intersex and disability groups may not always be constructive. There are possible drawbacks and limitations to proposing this alliance, particularly when topics of identity, awareness, education, and activist funding are broached. The (contested) alliance between intersex and LGBTQ(I) communities serves as an example (see Pagonis 2016b; Koyama 2006; Cornwall 2009; Astorino
Some intersex people align and/or identify with queer identities, communities, and activist organizations. For some intersex people, queer identities reflect their subjectivities and experiences in the world as lesbian, gay, trans, bi, queer, and/or intersex subjects. Queer organizations, groups, and gatherings provide these folks with spaces to reflect on and share their experiences and take part in activist labour and community building projects. Intersex individuals’ engagement in LGBTQ(I) spaces have enriched these spaces and the conversations and initiatives that take place (see Viloria 2017; Pagonis 2016b; Astorino 2013). However, other intersex people reject this association because it leads many people to believe that all intersex people are, or identify as, queer. Other individuals rightly note that, adding the “I” to the LGBTQ acronym is often an empty gesture. Interphobia is frequently an afterthought or not actively integrated into or taught to LGBTQ(I) activists groups. That lack of education results in many people (in and outside of queer communities) conflating intersex with trans embodiments and subjectivities (see “Basic differences” 2011). Or, when specific LGBTQ organizations add the I, intersex issues are often not given ample space or funding.

Similar to how LGBTQ(I) environments function for certain intersex people, according to Cornwall (2009), forging an alliance with disability groups may provide non-queer-identifying intersex people with locations and forums to share their experiences of pathologization and medical violence. Cornwall’s proposition is compelling. Similar to Cornwall, even though I am not comfortable policing how people identify (see Viloria 2017), many intersex people could claim disability and crip as identities and enter these spaces to build bonds, take part in activist work, and provide unique perspectives. Many intersex people, however, do not identify with disability or crip. While some intersex individuals may distance from disability for a variety of reasons, some intersex people, and I am merely hypothesizing, may feel like they cannot claim
disability or crip. They may think that they are infringing on disability and crip boundaries and spaces.

Despite the fact that “[w]hat is interpretable as disability” – or a disability issue – “need not be tethered to a disability identity” (McRuer and Mollow 2012: 13; also see L. Davis 2013c) and what is interpretable as intersex – or an intersex issue – also need not be tethered to an intersex identity, when intersex and disability groups align and work together, difficult (yet familiar) conversations about identity – who is “in” and who is “out” – will occur in activist and academic circles. Difficult (yet familiar) discussions about organizational funding re/distribution and educational logistics will also take place. I say “when intersex and disability groups align” because I am optimistic, and also because I want to emphasize that intersex, crip, queer, and disabled embodiments are not going anywhere; they are in the future.

**Intersex in the Future**

In spite of all the institutionalized forces that attempt to defer, surveil, and eradicate the spectre of intersex, intersex will always haunt. I am hopeful, however, that intersex will not always haunt through curative violence, medical examinations, surveillance, and created body-mind disabilities. The tireless labour performed by intersex activists, advocates, and scholars – the remarkable progress of the Intersex Rights Movement and intersex studies that is ostensibly taking intersex “out of the shadows” (Caplan-Bricker 2017: n.p.) – is steadily ensuring that intersex will haunt in a better, more just world. My dissertation contributes to this incredible intersex justice project. It works to imagine and ensure that there is a world in which intersex and/as disability is celebrated, that intersex and/as disability is in the future. In witnessing and experiencing the violence intersex people face, Sean Wall asserts: “We are here. We exist. And
we are moving forward” (2015a: n.p.). Against all the forces that seek to shame and eradicate people with intersex traits, Pagonis declares through their art: “The future is Intersex” (n.d.: n.p.).

These proclamations that intersex is in the now and in the future remind me of multidisciplinary visual artist and educator, Alisha B. Wormsley. In line with Afrofuturist philosophies and theories that “[imagine] possible futures through a black cultural lens” (LaFleur qtd. by Womack 2013: 9), Wormsley developed the mantra, “There are black people in the future” (“There are black people:” n.p.). “I was working in this neighbourhood [Homewood] where young men are shot and killed and incarcerated,” Wormsley describes,

There was this idea of being able to see myself in the future, including my students. […] I feel that it’s a mantra, that if I say it, then it will happen … there are Black people in the future. […] For me it became important to say it and phrase it. If I print this, it has some merit with people who are trying to kill us. […] We will always exist because we exist right now. […] Those things that are trying to attack us will never be successful. (Wormsley qtd. by Conley 2016: n.p.).

In addition to developing the mantra, Wormsley produced an art project of the same name to explore and illustrate “Homewood’s existence and survival. And mine [Wormsley’s]…” (“There are black people:” n.p.). In spite of the myriad cultural forces that seek to eradicate, or seek the “extinction” (Wormsley “Extinction [w/Mantras]”: n.p.) and “execution” (Sean Wall 2015b: 33), of Black people, Afrofuturists, critical race and de/anti-colonial theorists, activists, and artists,

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103 Wormsley’s video installation “Extinction (w/Mantras)” also explores the cultural forces that aim to eradicate black people and the mantra, “there are Black people in the future.” As described on the artist’s website, “Extinction (w/Mantras) is a video installation about different perspectives of extinction. I was in Whole Foods in an affluent neighborhood in Pittsburgh. While there I had three separate conversations about the extinction of: redheads, bananas and bees. I left that neighborhood to go to teach at a high school in a neighborhood called Homewood. This neighborhood has an amazing legacy of American art, music and culture innovated by this working to middle class African American population, like many similar areas, through racist city planning and institutional neglect, the Reagan era, this neighborhood now suffers from abandoned [sic] and an increase in violence as a means of survival. When I arrived at school I learned that one of my students brother’s had been murdered. And I thought that there is even privilege in extinction. That redheads, bananas and bees will probably not become extinct but is the concern of the affluent, not the extinction of young black men. This installation is on three screens. [T]he extinction video is in the middle and goes through two cycles and then on it’s third the two screens left and right show a man and woman of african american descent saying mantras in full circles. The idea is the mantras exist to elevate and protect the african american race from extinction” (Wormsley “Extinction [w/Mantras]”: n.p.).
like Wormsley, know that there are Black people in the future; there is a “trajectory of black futurity [emphasis in the original]” (“Black Futurity Month” 2015: n.p.; also see Womack 2013; T. Dean and Andrews 2016; R. Anderson 2016; Yaszek 2006; Nelson ed. 2002; Eshun 2003; Fisher 2013; Okoye 2016; David 2007; T. Dean 2016; Lindsey 2016).

I am also reminded of Alison Kafer’s observation that “disabled people are continually being written out of the future, rendered as the sign of the future no one wants” (2013: 46).

“Disability is disavowed” in the future, Kafer explains, in two main ways:

first, the value of a future that included disabled people goes unrecognized, while the value of a disability-free future is seen as self-evident; and second, the political nature of disability, namely its position as a category to be contested and debated, goes unacknowledged. The second failure of recognition makes possible the first; casting disability as a monolithic fact of the body, as beyond the realm of the political and therefore beyond the realm of debate or dissent, makes it impossible to imagine disability and disability futures differently. [...] Rather than assume that a “good” future naturally and obviously depends upon the eradication of disability, we must recognize this perspective as colored by histories of ableism and disability oppression. Thus, in tracing these two failures of recognition – the disavowal of disability from “our” futures – I imagine futures otherwise, arguing for a crippled politics of access and engagement based on the work of disability activists and theorists. [...] I am yearning for an elsewhere – and, perhaps, an elsewhen – in which disability is understood otherwise: as political, as valuable, as integral. (Kafer 2013: 3).

And, lastly, I am reminded of the queer rallying cry, “we’re here, we’re queer, get used to it,” which insists on a current presence and a future existence of queerness; people need to “get used to it” because we are not going anywhere. Queer Nation, a New York City LGBTQ organization founded in 1990 by AIDS activists from ACT UP, popularized the now ubiquitous motto during demonstrations opposing the various forms of violence against LGBTQ people (“Queer Nation” 2016; Berlant and Freeman 1992; Gray 2009). Often, representations of queer futures are depicted as diminished, violent, diseased, and nonexistent because they do not follow “straight time,” time that “links heteronormativity, including heteronormative conceptions of reproduction, with deeply linear, apocalyptic temporalities that cannot conceive of copresence” (Boellstorff in Latour et al. 2015: n.p.; also see Halberstam 2005, 2011; Boellstorff 2007).

Combatting these representations, queer activists and scholars have and continue to imagine and theorize “queer futures,” “anti-futures,” and even “no futures” in which queer temporalities and lives are not invested in the notion of futurity itself (see Gamson 1995; Boellstorff and Dave 2015; Mereish, Katz-Wise, and Woulfe 2017; K. Hart 2004; Brown and Knopp 2003; Edelman 2004; Valentine 2015; Halberstam 2005; B. Adam 2009). “Queer subcultures,” Jack Halberstam explains, “produce alternative temporalities by allowing their participants to believe that their futures can be imagined according to logics that lie outside of those paradigmatic markers of life experience – namely, birth, marriage, reproduction, and death” (2005: 2). Mary L. Gray “labour[s] to imagine different futures” for queer folks “that do not claim moral imperatives” and do “not look like the idealized middle-class, forty-hour work week” (Gray in Latour et al. 2015: n.p.). Queer people ideate, insist on, and live outside of the constraints of straight temporality and develop new futures.
Dominant, discriminatory discourses of futurity render intersex, disabled, queer, crip, and/or racialized embodiments as sites of “no good future[s]” (Kafer 2013: 3). In rejecting this narrative and resisting discursive and literal erasure and eradication, these marginalized groups assert they are in the future. And, as this project illustrates, all of these embodiments, and subsequent forms of institutionalized oppression, are not distinct, but wrap around and fold into each other to form a complex “maze” (Clare [1999] 2009: 143; also see Crenshaw 1989, 1991; Nash 2008; Cho, Crenshaw, and McCall 2013; Carbado et al. 2013; Puar 2007; Stienstra and Nyerere 2016). “Gender reaches into disability; disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of race” (Clare [1999] 2009: 143); race envelops intersex (Reis 2005, 2009; Sean Wall 2015b; Somerville 2000; Magubane 2014; Willis ed. 2010); intersex extends out to disability (Holmes 2008b, 2011; Koyama 2006; Colligan 2004), “… everything finally piling into a single human body” (Clare [1999] 2009: 143).

By continually venturing back to the largely untrodden thoroughfares where intersex and disability and compulsory dyadism and able-bodiedness meet in this complex maze, I identified “multiple, often unexpected, locations” (McRuer and Mollow 2012: 13) where intersex and/as disability manifest and interconnect. In untangling this intersextion, I reimagined and theorized possible futures. I envisioned futures in which the diverse, valuable, and political ways intersex and/as disability become (visible) and haunt together in unobstructed and celebrated ways. And, as this future takes shape, we will encounter intersex and/as disability in even more unexpected, multiple, phantasmal, welcomed, and #intersexy ways.
Works Cited


Adam, Barry D. “How Might We Create a Collectivity That We Would Want to Belong To?”

Adam, Mohammed. “Olympic medals are good, but let’s remember where the true heroism is.”


Adayener, C., and I. Akyol. “Distal Hypospadias Repair in Adults: The Results of 97 Cases.”

“Additional Options With IVF.” Rainbow Fertility, 1 Feb. 2016,


Anderson, Paul, and Rob Kitchin. “Disability, space and sexuality: access to family planning
services.” Social Science and Medicine, vol. 51, no. 8, 2000, pp. 1163-1173.


“Anonymous Asked.” Actually Intersex, 6 Jun. 2015,


“Anonymous Asked.” Actually Intersex, 16 Jun. 2016,


Atbreucht, Katie. “Disability Studies and the Language of Mental Illness.” *Review of Disability*


Baril, Alexandre. “N[eeding to acquire a physical impairment/disability: (re)thinking the connections between trans and disability studies through transability.” *Hypatia*, vol. 30, no. 1, 2015a, pp. 30-48.


Bazerman, Charles, and Paul Prior, editors. What Writing Does and How It Does It. Lawrence


Bennett, Catherine. “Cheating in sport is becoming even harder to judge.” *The Guardian*, 12 Jun.


Bermon, Stéphane, and Pierre-Yves Garnier. “Serum androgen levels and their relation to


Billings, Andrew, and Brittany D. Young. “Comparing Flagship News Programs: Women’s Sport Coverage in ESPN’s *SportsCenter* and FOX Sports 1’s *Fox Sports Live*.” *Electronic News*, vol. 9, no. 1, 2015, pp. 3-16.


---------. “Critically Queer.” *GLQ*, vol. 1, no. 1, 1993, pp. 17-32.


Canadian Association of Genetic Counsellors. “Reproductive genetic testing and screening


---------. “Intersex: Current issues and approaches.” Health in Difference 2013: Our
Bodies. Our Minds. 8th National LGBTI Health Conference, 18 Apr. 2013c, Melbourne, Australia.


---------. Shadow Report Submission to the Committee on the Rights of Persons with Disabilities on the situation of intersex people in Australia, in consultation with the board of OII Australia, OII Australia, Jun. 2017b.


---------. “We celebrate Maltese protections for intersex people.” 2 Apr. 2015b,


Chandler, Eliza. Review of Feminist, Queer, Crip, by Alison Kafer. Canadian Journal of


--------. “Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism.” GLQ, vol. 4, no. 2, 1998b, pp. 189-211.


--------. “Surgical Progress Is Not the Answer.” Intersex in the Age of Ethics, edited by Alice Domurat Dreger, University Publishing Group, 1999, pp. 147-160.


Clark, David L., and Catherine Myser. “Being Humaned: Medical Documentaries and the


Connolly, William. Identity\Difference: Democratic Negotiations of Political Paradox.


---------. “Cis Gender, Ipso Gender.” *Trans Fusion*, 30 Jun. 2015,


--------, interview with Casey Morell. “UNVL Professor Explores the ‘Dubious Diagnosis’ In


Deafstudent. “I’m deaf, I’m not disabled! Why should I do this?” *Being Deaf and in education in*


Del Cura, Mercedes. “The Future We Want: Demanding Rights for People with Disabilities


Devore, Tiger. “Growing up in the Surgical Maelstrom.” Intersex in the Age of Ethics, edited by Alice Domurat Dreger, University Publishing Group, 1999, pp. 79-82.


---------, interview with Rachel Christiansen. “Understanding Intersex: The Call For Leaving


Donaldson, Elizabeth J. “The Corpus of the Madwoman: Toward a Feminist Disability Studies


Dunbar, Norah E. “Theory in Progress Dyadic Power Theory: Constructing a Communication-


--------. “The Color of Violence: Reflecting on Gender, Race, and Disability in Wartime.”


Eveleth, Rose. “Does Double-Amputee Oscar Pistorius Have an Unfair Advantage at the 2012 Olympic Games?” *Smithsonian*, 22 Jul. 2012a,

--------. “Should Oscar Pistorius’s Prosthetic Legs Disqualify Him from the Olympics?”


Fraser, Sylvan. “Constructing the female body: using female genital mutilation law to address


-------. “Should Doctors Operate On Intersex Babies.” *Buzzfeed*, 15 Aug. 2015,


---------, “Intersexuality and the Endocrine Aspect of Sex.” *Endocrinology*, vol. 1, no. 4, 1917, pp. 433-56.


Gough, Brendan, et al. “‘They did not have a word’: The parental quest to locate a ‘true sex’ for


Government of Ontario, Canada. *Toby’s Act (Right to be Free from Discriminatory and Harassment Because of Gender Identity or Gender Expression).* 2012, c. 7 - Bill 33.


Green, Fiona J. “From clitoridectomies to ‘designer vaginas’: The medical construction of


---------. “Should Surgeons Perform Irreversible Genital Surgery on Children?” Newsweek, 26


Hall, Kim Q. “Reimagining Disability and Gender Through Feminist Studies.” *Feminist


Hansen, Randall, and Desmond King. “Eugenic Ideas, Political Interests, and Policy Variance.” 


---------. “The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical


Hennessy, Rosemary. *Profit and Pleasure: Sexual Identities in Late Capitalism*. Routledge,


Hoad, Neville. “‘Run, Caster Semenya, Run!’ Nativism and the Translations of Gender Variance.” Safundi, vol. 11, no. 4, 2010, pp. 397-405.


--------. “Queer Cut Bodies.” Queer Frontiers: Millennial Geographies, Gender, and


Reel to Real: Race, Sex, and Class at the Movies. Routledge, 1996.


Hubbard, Ruth. “Abortion and Disability: Who Should and Should Not Inhabit the World?” The


Ignagni, Esther, et al. “‘Some people are not allowed to love’: intimate citizenship in the lives of people labelled with intellectual disabilities.” *Disability and Society*, vol. 31, no. 1, 2016, pp. 131-135.


2015 (Appendix 6 and Appendix 7 amended), 2015,


---------. IAAF Regulations Governing Eligibility of Females With Hyperandrogenism To Compete In Women’s Competition, 2011.

International Paralympic Committee. “History of the Paralympic Movement,” pp. 1-3,


“Intersex Health.” Rainbow Health Ontario, Aug. 2011,


“Intersex-ionality: Why Confronting Racism Matters.” OII-USA, 4 Jun. 2016,


“Intersex Links.” Organization Intersex International: United States,


“Intersex Surgeries - Vaginoplasty and Clitorectomy.” YouTube, uploaded by Emilord [Emily


“IW Gregorio.” InterACT Advocates for Intersex Youth,


Johnson, Julia R. “Cisgender Privilege, Intersectionality, and the Criminalization of CeCe
McDonald: Why Intercultural Communication Needs Transgender Studies.” *Journal of International and Intercultural Communication*, vol. 6, no. 2, 2013, pp. 135-144.


---------. “Compulsory Bodies: Reflections on Heterosexuality and Able-bodiedness.” *Journal of


---------. “Do We Really Need an Even Better Prenatal Rest for Down Syndrome?” Impact


Klein, Alyssa. “South Africans on Twitter Defend Caster Semenya Against U.S. Media.” *Okay*


Lavers, Michael K. “Chilean officials oppose intersex children ‘normalization’ surgery.”


Layden, Tim. “Is it fair for Caster Semenya to compete against women at the Rio Olympics?”


Lindsey, Treva B. “The #BlackFeministFiyah Re-Up.” *The Black Scholar*, vol. 46, no. 2, 2016,

Löfgren-Mårtenson, Lotta. “‘Hip to be Crip?’ About Crip Theory, Sexuality and People with Intellectual Disabilities.” *Sexuality and Disability*, vol. 31, no. 4, 2013, pp. 413-424.


Maccartney, Jane, and Hattie Garlick. “Girls will be girls at Olympics – sex tests will prove it.”


“Metasoma-deactivated20160727 Asked.” *Actually Intersex*, 16 Jun. 2016,


Mod H. “An Alternative to ‘Dyadic.’” *Fuck Yeah Sex Education*, 5 Nov. 2014,


“Ontario Government to Fund IVF.” Lisa Feldstein, 15 Apr. 2014,


Orr, Celeste, and Amanda Watson. “‘We changed her nappies. We saw that she was a girl.’ Caster Semenya’s Femininity and the Power of Maternal Testimony.” Mothering, Mothers, and Sport: Experiences, Representations, Resistances, edited by Judy Battaglia, Rebecca Bromwich, and Pamela Redela, Demeter Press, forthcoming.


Pace, Yannick. “Malta introduces ‘X’ marker on passports, ID cards and work permits.” *Malta Today*, 5 Sept. 2017,


Pagonis, Pidgeon. “6 Things Intersex Folks Need to Know About How We Perpetuate Anti-Black Racism.” *Everyday Feminism*, 3 Jun. 2016a,


--------. “A Doctor Asked Me for a Dialogue on Why They Shouldn’t Cut Up Intersex Babies –
Here’s My Response.” *Pidgeon Pagonis*, 20 Oct. 2017a,


--------. “IntersexisBeautiful.” *Etsy*,

--------. “Intersexy! Educate and Chill.” *Pidgeon Pagonis*, 2016c,

--------, interview with Lana McDonagh. “‘Female Genital Mutilation and Intersex Genital Mutilation are Similar Procedures’: Pidgeon Pagonis on Their Journey of Discovering They Were Born Intersex.” *Ditch the Label*, 26 Oct. 2016d,


Paltrow, Lynn M. “Roe v Wade and the New Jane Crow: Reproductive Rights in the Age of


with a Disorder of Sex Development.” *Archives of Sexual Behavior*, vol. 43, no. 2, 2014, pp. 369-375.


Phala, Mbali. “South Africa: Who is Caster Semenya and Why Does She Matter?” *All Africa*, 26


“Program.” *4S/Easst Conference BCN-2016*, 2016,


“Rainbow Fertility: Who We Are.” *Rainbow Fertility*, 1 Feb. 2016,


Ross, Ronald K., et al. “Effects of Hormone Replacement Therapy on Breast Cancer Risk:


Siebers, Tobin. “A Sexual Culture for Disabled People.” *Sex and Disability*, edited by Robert


Silvers, Anita. “‘Defective’ Agents: Equality, Difference and the Tyranny of the Normal.”


---------. “Women’s Perspective as a Radical Critique of Sociology.” *Feminism and Methodology,* edited by Sandra Harding, Indiana University Press, 1987b, pp. 84-96.


Spital, Aaron, Clive O. Callender, and Patrice V. Miles. “Ethical Issues in Dialysis:
Institutionalized Racism and End-Stage Renal Disease: Is Its Impact Real or Illusionary?”


Stienstra, Deborah, and Leon Nyerere. “Race, Ethnicity and Disability: Charting Complex and


Sullivan, Claire F. “Gender Verification and Gender Policies in Elite Sport: Eligibility and ‘Fair Play.’” *Sport and Social Issues*, vol. 35, no. 4, 2011, pp. 400-419.


Swaab, D.F. “Sexual differentiation of the human brain: relevance for gender, identity,
transsexualism and sexual orientation.” *Gynecological Endocrinology*, vol. 19, no. 6, 2009, pp. 301-312.


Tosh, Jemma. “The (In)Visibility of Childhood Sexual Abuse: Psychiatric Theorizing of


Truth, Sojourner. “Ain’t I a Woman?” Women’s Convention, Akron, Ohio. 28-29 May 1851.


Reach of Prenatal Hormones? Brain Organization Theory, Digit Ratio (2D/4D), and Sex Difference in Preferences and Cognition.” *Perspectives on Psychological Science*, vol. 6, no. 2, 2011, pp. 134-146.


Velpeau, Alfred A.L.M. *An Elementary Treatise on Midwifery; or, Principles of Tokology and Embryology*. Translated by Charles D. Meigs, Lindsay and Blakiston, 1845.

Vidali, Amy. “Seeing what we know: disability and theories of metaphor.” *Journal of Literacy*


--------. “OII’s message of ‘Intersex’ pride reflected in great video! :).” OII-USA, 31 Mar. 2015c,


“What is Intersex?” OII Australia, 2010,


“What It’s Like To Be Intersex.” Buzzfeed Videos, 28 Mar. 2015,


Whelan, Joan. “Joan Whelan address to Robert Wood Johnson.” ISNA, 2002,


Williams, Clare, Priscilla Alderson, and Bobbie Farsides. “‘Drawing the line’ in prenatal screening and testing: health practitioners’ discussions.” *Health, Risk and Society*, vol. 4, no. 1, 2002, pp. 61-75.


Yaeger, Lynn. “Model Hanne Gaby Odiele on What It Means to Be Intersex – And Why She’s


Zaccone, Laura A. “Policing the Policing of Intersex Bodies: Softening the Lines in Title IX


