2018

Systems of Expression: Counter-Discourse in Online Intersex Communities

Jasmine Shirey

Recommended Citation
http://scholarship.claremont.edu/cmc_theses/1964

This Open Access Senior Thesis is brought to you by Scholarship@Claremont. It has been accepted for inclusion in this collection by an authorized administrator. For more information, please contact scholarship@cuc.claremont.edu.
Systems of Expression: Counter-Discourse in Online Intersex Communities

A Thesis Presented
by
Jasmine Shirey

To the Keck Science Department
Of Claremont McKenna, Pitzer, and Scripps Colleges
In partial fulfillment of
The degree of Bachelors of Arts
Senior Thesis in Literature and Neuroscience

April 23rd, 2018
Table of Contents

ABSTRACT ............................................................................................................................... 5
INTRODUCTION .......................................................................................................................... 7
1. HE SAID, SHE SAID: HOW MEDICINE, POP CULTURE, AND LAW TALK ABOUT INTERSEXUALITY .................................................................................................................. 13
   1.1 ‘MEDICS’ AND WORDS: THE STATE OF IS IN MEDICINE ............................................. 14
   1.2 FICTION AND ENTERTAINMENT: THE STATE OF IS IN POPULAR CULTURE .......... 21
   1.3 CASE LAW AND INVISIBILITY: THE STATE OF IS IN LAW ................................... 32
2. ‘I REMAIN A MEMBER OF SOCIETY’: HOW OICS HAVE RESPONDED TO MEDICAL DISCOURSE ......................................................................................................................... 39
   2.1 REIMAGINING THE THEORIST’S ROLE IN COUNTER-DISCOURSE .......................... 40
   2.2 COUNTERING THE MEDICAL COMMUNITY ............................................................... 42
   2.3 THE PUSHBACK TO ‘CHROMOSOMAL PRIMACY’ IN DETERMINING SEX AND ‘DSD’ NOMENCLATURE .................................................................................................................. 43
   2.4 (FILL IN THE BLANK) SURGERY ................................................................................ 53
   2.5 TALKING BACK: QUESTIONING DOCTOR/PATIENT INTERACTIONS ..................... 64
3. CAL’S PLATFORM: HOW OICS ENGAGE MIDDLESEX AND OTHER REPRESENTATIONS OF INTERSEXUALITY IN POPULAR CULTURE ......................................................... 73
   3.1 INTERSEX IN MIDDLESEX ............................................................................................ 74
   3.2 (MIS)REPRESENTATIONS OF INTERSEX ON TELEVISION ...................................... 82
   3.3 THE POWER OF WIKIPEDIA ......................................................................................... 89
4. I’S OF LAW: HOW INTERSEX ACTIVISM AND COUNTER-DISCOURSE WORK WITH(IN) THE LEGAL SYSTEM .................................................................................................................. 93
   4.1 INTERACT AND ONLINE LEGAL INTERSEX ACTIVISM ............................................ 95
   4.2 INTERSEX DISCRIMINATION: WILMA WOOD V. C.G. STUDIO ................................ 96
   4.3 COLUMBIA AND THE LEGALITY OF CONSENT ....................................................... 98
   4.4 THE MC CASE .............................................................................................................. 101
CONCLUSION ............................................................................................................................ 105
ACKNOWLEDGMENTS ............................................................................................................. 111
GLOSSARY ............................................................................................................................... 113
WORKS CITED ......................................................................................................................... 115
Abstract

Individuals who do not fit neatly into the expected genetic and phenotypic XX/XY binary have been misrepresented, ignored, operated on without consent, denied legal rights, and gaslighted by multiple spheres of dominant society including, but not limited to: medicine, popular culture, and the justice system. Using Michael Foucault’s conception of ‘counter-discourse’ in conversation with the work of Gayatri Spivak, I ask how online intersex communities (OICs) have participated in counter-discourse by examining forums, blogs, comments, organization websites, memoirs and social media pages. Major examples of phenomena OICs respond to, engage with, and critique include: surgery on intersex infants; the introduction of the term ‘DSD’; intersexuality in popular television shows; chromosomal primacy; and legal standings of intersex individuals in different countries. I found that ‘counter-discourse’ within OICs include efforts to: redefine the ‘truth’ against common problematic appeals to medicine, morals, or nature; advocate acceptance of all bodies; and create a sense of belonging where there is space for people to heal and organize on a foundation of affinity.
Introduction:

What Happens When Words and Bodies Meet

This project is at the crossroads of literature and identity, medicine and power, discourse and experience. Originally, as someone who studies both neuroscience and literature, I thought I was researching and critiquing the existing medical literature on ‘male’ and ‘female’ brains, and analyzing how creative writers have complicated these ‘scientific’ accounts. But the more I read studies about how different behavior in children indicates innately different brain structures and how differences in MRI images indicate x, y, and z the more I wondered: who comes up with these research questions? How much of our own biases affect the research questions and the conclusions that get drawn? Is our society so wedded to the idea of a sexual binary that researchers aren’t willing to consider the possibility that a different categorization structure might work better? I’m not the first person to ask these questions. Intersex (IS) individuals and especially intersex activists have been pushing them for years. At best, intersex individuals are forced into choosing one of two sexes when their bodies have markings of both ‘male’ and ‘female’ anatomies, at worst, they aren’t given the choice and are operated on as infants as an effort to fit them into one of the two ‘M/F’ boxes. So I turned to a different research question: what are the people who are most hurt — psychologically and physically — by the imposed sexual binary saying?

Organisation Intersex International (OII) writes on their homepage, “Intersex people are born with sex characteristics that do not fit typical binary notions of male or female bodies” (OII). There are many living definitions of ‘intersex’ but I share OII’s definition
since I find it to be the most flexible. Since, at its root, intersex activism, like many forms of activism, advocates letting people speak for themselves and their own bodies, I utilize flexible definitions and the phrase ‘individuals who identify as intersex’ in order to avoid unnecessary imposed sorting. However an individual decides to define ‘sex characteristics’, ‘typical binary notions’, and ‘male/female bodies’ when it comes to their own identity labels, is up to them. Intersex individuals are excluded from most discourses on sex because the current binary system is an oversimplification caused by the institutional production of definitions. To undue this erasure we must privilege the voices of those who have been ignored when they speak through different texts and sources, and embrace it when they create more flexible and inclusive definitions.

Chromosomes, genitals, gonads, genes, hormones, brains, gender, sexual preferences, bone structure = sex?

The current dominant discourse around intersexuality is the result of the intersections between a presumed sexual binary, medical language, and other interlocking power dynamics and sociopolitical factors of our time. This interdisciplinary study seeks to document our Dominant Culture’s discourse around intersex bodies and the counter-discourse that occurs when individuals who identify as intersex speak for themselves. Dominant Culture, as a concept, is understood throughout this work as the force that is able, through economic, political, or social power to impose values, language, and ‘truths’ on those who live with and within it (Dominant Culture). In the United States, and much of the world, ‘the’ Dominant Culture is White, Christian, Straight, upper class, and able bodied — and these are often the factors that influence the discourse that Dominant Culture produces.
the most. Brian Still writes, “Truth is shaped by discourses, which are shaped by the schools, the books, the media, the doctors, and the greater mass of people in general” (Still, 8). In what follows I highlight examples of discourse produced by our Dominant Culture and how intersex individuals and activists have created and utilized specifically online communities and neighborhoods to produce counter-discourse. I critique forms of discourse institutionally produced from medicine, ‘popular’ culture, and the legal system and analyze how online intersex communities (OICs) engage with the rhetoric particular to these realms.

OICs include any online platform where multiple people come together to write: sharing ideas, stories, and resources, around the topic of IS (which can, and does, take many forms). For the purpose of this project it is useful to think of OICs in light of Arjun Appadurai’s ‘technoscape.’ Appadurai defines ‘technoscape’ as “the global configuration, also ever fluid, of technology, and of the fact that technology, both high and low, both mechanical and informational, now moves at high speeds across various kinds of previously impervious boundaries” (Appadurai, 297). The Internet, as part of the technoscape, is fluid, it moves too fast and it is mechanical and informational and messy. How often are students told not to use Wikipedia as a source, to ‘not believe what you read on the Internet’, or to pick up a ‘real’ book? It is true: online sources are not peer reviewed and legitimated the way books, scholarly articles, and research papers are — but this is why they are of upmost importance to this study and where Appadurai’s ‘previously impervious boundaries’ can come in. To publish a memoir, get an article peer reviewed, or take a case to court takes time, money, and/or connections that are extremely limited. Intersex communities are engaging in counter-discourse but it isn’t just Hida Viloria or Thea Hillman in these conversations, it is Pidgeon Pagonis, ‘Jessie’, and ‘Sam’, ‘Carlos’, and
‘AnonymousUser051’. OICs are where discourse can be published without insurmountable obstacles, and where I turned to in order to document direct intersex voices that are not produced or mediated by institutions.

I make efforts throughout my work to quote from individuals who suffer the most stigmatization and marginalization, such as people of color who identify as intersex. In addition, I ask that readers, especially those who are White, work not to assume an individual who posts is also White. Many of the people most affected by ‘intersexphobia’\(^1\), who have been most ill treated by the medical community, and who have produced the most influential counter-discourse, are People of Color.

By attending to counter-discourse and amplifying existing intersex voices into the academic realm I hope to counteract methods of erasure that render intersex individuals, their voices, and their lives invisible. Questioning institutional definitions and modes of producing discourse, and concentrating on the voices of people in marginalized positions are practices I believe academia needs to cater to. With this work I hope to provide an example of what such practices can look like.

The thread of this project follows four chapters. The first deals intimately with hegemonic discourse around sexuality, providing examples of institutional representations of IS and familiarizing the reader with key terms and trends in the way our Dominant Culture talks about the sexual binary. Each of the other chapters goes into depth on one sphere of dominant society — medicine, popular culture, and the legal system respectively — and how intersex individuals have utilized OICs to produce counter-discourse engaging each of these spheres. I aim to avoid oversimplification and as such I attempt to analyze

\(^1\) A prejudice or dislike of intersex people or the concept of intersexuality. Often gets lumped in with homophobia and transphobia, especially when people do not know that IS exists or what it is.
each story and post on its own terms. However, trends and patterns of counter-discourse will emerge — such as efforts to ‘redefine presupposed truths’ such as the sexual binary itself — and I will mark these as we go along.

Where possible I include full quotations and postings. This project is built through individual stories and dialogue, so I have tried to avoid editing those voices. Where applicable, I have changed names to protect the identities of the individuals who have been brave enough to publish their stories and thoughts online.
1

He Said, She Said: How Medicine, Pop Culture, and Law Talk about Intersexuality

*Its just discouraging how some persons ignore that intersexuality exist. And its even worse when even some "medics" tell you so.*

*Im tired of being mislabeled, or not being believed and getting my medical needs attanded. Or just simply that my body its what it is.* (Susan’s Place)

The primary focus of this work is the counter-discourse and counter-narratives that have developed in intersex communities, which challenge the narratives of our Dominant Culture. Critiquing the narratives of our Dominant Culture and looking closely at counter-narratives will involve explaining both. The explanation of dominant discourse — or foundation setting — is the aim of this chapter.

I begin every chapter with a quote from an individual publically posting to an OIC. I do not edit, abridge, or include “[sic]” in these quotes. I am less interested in hegemonic grammar rules than the emotions and experiences people in marginalized positions are trying to communicate in making these posts. Throughout, the voices of the intersex community will come predominantly through OIC posts rather than more typical journal articles and books to take advantage of the elements of the technoscape that allow us to move across previously impervious barriers. Chat rooms, blogs, and forums do not require anywhere near the level of resources one must have to publish a book or credited article. My own discipline of literature is often guilty of creating insurmountable obstacles for
writers to overcome to be published, or receive an award, all in the effort to be read².

Memoirs such as *Born Both: An Intersex Life* by Hida Viloria and *Intersex (For Lack of a Better Word)* by Thea Hillman are beautiful works of art illustrating the authors’ respective experiences. However, I will be focusing on digitally self-published work to provide a more representative portrayal of individuals who are participating in these conversations.

The quote at the beginning of this chapter is an excellent example of someone opting into a conversation that intimately concerns them. The author emphasizes a feeling of ‘discouragement’ in the face of feeling invisible, and calls out the medical community as part of this problem. They point specifically to the issue of oversimplification when they complain about being ‘tired of being mislabeled.’ A lack of conversation, conversation describing the realness and presence of intersexuality, is what this individual finds discouraging. I argue in this chapter that this epistemology — the view that intersexuality doesn’t exist — amounts to the process of what this individual calls ‘mislabeled’ (what I think of as oversimplification to the point of erasure) and is deeply prevalent in medical language, popular cultural productions, and legal documents.

1.1 ‘Medics’ and Words: The State of IS in Medicine

Sexual morphology is — in an evolutionary sense — necessarily tied to reproduction; if a species’s reproduction is at least in part sexual (as opposed to solely asexual) the species will have some morphological distinction between parts that we describe as ‘male’ and ‘female’. However, just because a species reproduces sexually does not mean all individual organisms in that species are necessarily either ‘male’ or ‘female’; it

---

² For more on this see Chris Jackson’s Literary Hub article “Diversity in publishing doesn’t exist but here’s how it can.”
does not mean there is one determining sex factor; and it does not mean reproduction is simply the ‘coming together’ of these ‘male’ and ‘female’ ‘parts’. In short, the fertility and reproduction of a species, obviously vital to its survival, can easily be superficially imposed onto every individual member of a species in a reductive way. Some intersex individuals are fertile, others are not, just like non-intersex individuals, and sex variation does not undermine the continuation of sexual reproduction. While a species must reproduce to survive, and may have distinct gametes assigned ‘male’ and ‘female’, there is no ‘biological truth’ that says individuals members must therefore be so categorized\(^3\). The traditional description of homosexuality as ‘unnatural’ and the associations that superimpose femininity onto gay men and masculinity onto lesbians rely on similar arguments about ‘biological truths’ that link back to reproduction. The invisibility of IS is an effect of this discourse. It’s not just that our society doesn’t see or identify intersex individuals: it is that our categories of differentiation make it ‘impossible’ for them to exist since the labeling system is flawed and labels are what render people visible or readable. It should be noted that visibility and nuanced understanding are two very different things; this distinction will be brought back up in chapter three.

I provide this brief background on the relationship between reproduction and sexuality to indicate that there is no simple scientific or medical law that indicates that animals must be divided into two and only two sexes just because different types of fertile gametes must come together for the continuation of the species. To suggest this conflation of species reproduction and individual sexuality is to propose compulsory heterosexuality

---

\(^3\) For more on the conversation of evolution, sex, gender, and diversity, see Joan Roughgarden’s *Evolution’s Rainbow*
and impose unnecessary and harmful binaries. In life’s early forms, mutations, or variations in replication were necessary for evolution. In asexual reproduction, if a parent cell replicated perfectly every time, the offspring would always be exactly identical to the parent and no evolution could occur. Thus, human beings would not exist if it weren’t for mutations or variation: no complex life would. The nonexistence of a sexual binary and the centrality of mutation and variance to the characteristics of a species are important to remember anytime there is an appeal to a scientifically ‘natural’ or ‘normal’ human body or sex, or an appeal to normalization and centralization of fertility in individuals.

The way intersex bodies are talked about in medicine today is the result of a shift that happened around 1900. Through the middle half of the nineteenth century medical professionals studied intersex individuals (though ‘hermaphrodite’ was a more common term back then) and published case studies that by and large did not make appeals to ‘correcting’ ‘unnatural’ bodies. But in a few short years — most likely due to ‘advancements’ in science and the church — the reports stopped coming and new ideas of ‘normality’ and ‘abnormality’, what it means to be ‘male’ and ‘female’, and how to talk about (or not talk about) bodies that didn’t fit this binary, came about (Still, 25).

From the 1980s through early 2000s, Anne Fausto-Sterling advanced the conversation of intersex through her books, “Myths of Gender” and “Sexing the Body”.

---

4 Note the difference between ‘genetic mutation’ and ‘anatomical deformation’. A genetic mutation is a natural phenomenon in which genes gets transcribed differently leading to variation in a species: necessary for evolution. Anatomical deformation is a term used to describe animal body parts that either developed or were injured in such a way that someone has decided they are undesirable, whether because they cause harm and/or inconvenience, etc. As we can see, the latter term is a slippery one, and easily (mis)used for harm.

5 The word ‘hermaphrodite’ comes from an Ancient Greek myth in which Hermaphroditus fuses with a nymph and thereafter possesses traits of ‘male and female sexes’. The word is used to describe species today that produce multiple types of gametes but is stigmatizing and scientifically inaccurate to use when talking about people due to the mythic origins and conflation with non-human animal biology. Some intersex individuals use the term affectionately, similar to ‘queer’ in LGBT+ communities, but for the purposes of this paper the word will not be utilized.
Fausto-Sterling provides us with a quick overview of the medical conversation revolving around intersexuality starting in the 1950s. Subsequently, I will describe the medical language used today, in 2018, and my own findings from collecting publications from the last few years.

In the 1950s the John Hopkins psychologist John Money — infamous among intersex activists for the role he played in popularizing medically unnecessary surgery on infants — along with his colleagues ‘treated’ intersex patients. The group agreed with Albert Ellis who studied eighty-four cases of intersex individuals and concluded that, in the development of masculinity, femininity, and sexuality, nurture matters a great deal more than nature. Ellis thought environment had a more determinant role than DNA for determining someone’s masculinity and sexuality, still a controversial opinion, but Money and his colleagues agreed. Money and his group conducted their own studies, which Fausto-Sterling remarks on in the following way:

[They] state in the extreme what these days seems extraordinary for its complete denial of the notion of natural inclination. They concluded that gonads, hormones, and chromosomes did not automatically determine a child’s gender role: ‘From the sum total of hermaphroditic evidence, the conclusion that emerges is that sexual behavior and orientation as male or female does not have an innate, instinctive basis.’ Did they then conclude that the categories ‘male’ and ‘female’ had no biological basis or necessity? Absolutely not. These scientists studied hermaphrodites to prove that nature mattered hardly at all. But they never questioned the fundamental assumption that there are only two sexes, because their goal in studying intersexuals was to find out more about ‘normal’ development. Their patients required medical treatment because they ought to have become either a male or a female. The goal of treatment was to assure proper psychosexual development by assigning the young mixed-sex child to the proper gender and then doing whatever was necessary to assure that the child and h/er parents believed in the sex assignment. (Fausto-Sterling, 22)

John Money and his colleagues never questioned the naturalness of a heterosexual (non-intersex) binary, but did question the naturalness of deviations from these categories.
Fausto-Sterling recounts a history of doctors and scientific professionals/academics claiming that as far as gendered behavior and orientation go, there is no innate basis, all are produced by environment. Fausto-Sterling then makes the insightful observation that despite these claims, the medical community did not publically question the validity of the very categories ‘male’ and ‘female’.

Today, the medical community does not consider mutations that result in diverse hair color, ‘mistakes’. There is no practice (as far as I know) among doctors of telling parents their child really has brown hair not red and there was just a mistake they can fix. We just accept multiple colors of hair. Unfortunately sex is much ‘higher stakes’ than hair color. Due to the value placed on the performance of gender in Western society, medical professions opt for ‘corrective surgery’, which facilitates a more ‘intelligible’ and convincing performance of gender. Fausto-Sterling continues her discussion of the history of intersexuality within the medical community by saying the following (note this work was published in 2000):

Today, despite the general consensus that intersexual children must be corrected immediately, medical practice in these cases varies enormously. No national or international standards govern the types of intervention that may be used. […] Whatever treatment they choose, [physicians] who decide how to manage intersexuality act out of, and perpetuate, deeply held beliefs about male and female sexuality, gender roles, and the (im)proper place of homosexuality in normal development (Fausto-Sterling, 48).

In 2018 there is still no consistent medical protocol (though intersex activists have made great strides in decreasing the amount of infant surgeries).

So far we have looked at how intersex individuals have been thought about, studied, and treated by medical professionals since the 1950s. We will now turn to more specific
words the medical community is using today in order to get an idea of how intersex bodies are talked about.

In 2005, the Chicago Consensus recommended new terminology to describe bodies that don’t fit into the male/female binary: disorders of sexual development (DSDs). The statement was then adopted by the American Academy of Pediatrics (Hughes). Members of the medical community were hoping ‘individuals with DSDs’ would replace terms like ‘hermaphrodites’ — and their lay and potentially derogative connotations. Needless to say, many individuals who identify as intersex found, and continue to find, the widespread use of the term ‘disorder’ derogative. While many intersex folks do require medical care in conjunction with their body’s sexual expression, many do not, and the medical community is faced with the task of addressing individual medical concerns, without contributing to the continued stigma surrounding neither solely ‘male’ nor solely ‘female’ bodies.

With an eye toward complicating and combating rhetoric and terminology that comes out of the non-intersex medical community, I conducted quantitative research to determine some of the most frequent words and phrases that appear in published medical work regarding intersex bodies. This will give us a framework moving forward to understand the type of language, and even exact words, to which individuals and groups within intersex communities are responding.
Figure 1.1 shows a graphic representation of the frequency of various words in recent medical publications regarding intersexuality. The highest frequency represented is 201 incidents, while the lowest is 32.

Using the PubMed database I took a cross section of scientific papers, ranging from case studies to review articles. I limited my search to publications released within the last twenty years, identified relevant articles on bodies with various intersex ‘classifications’ that came from ‘reputable’ journals, and took the fifty most cited. Some articles were identified through DSD nomenclature or by specific names: congenital adrenal hyperplasia, Androgen Insensitivity Syndrome (AIS), 5-α reductase deficiency, and Klinefelter’s Syndrome being the most common. I ran the report abstracts through word-cloud counting software. Within the fifty publications the words ‘disorders’, ‘management’, and ‘ambiguous’ were all used over forty times each (Figure 1.1). These words are demonstrative of an episteme that encourages body ‘normalization’. Genitals can only be ‘ambiguous’ if you have a ‘standard’ category to compare them too, only that which should not be left on its own must be ‘managed’, and what do you do with a ‘disorder’ but fix it?
With a beginning understanding of the ways intersex individuals have been treated over the past decades, as well as some of the most common words found in medical papers on IS, we turn away from medical activity and rhetoric and towards another sphere of our Dominant Culture: pop culture.

1.2 Fiction and Entertainment: The State of IS in Popular Culture

Describing a universal popular, or mass media, ‘representation of intersexuality’ would be an impossible task, and, if attempted, would undoubtedly lead to gross oversimplifications. Instead, to discuss the role pop culture has played in shaping intersex narratives, and to highlight the work that has been done by intersex communities to complicate these narratives, I am choosing three ‘case studies’. These case studies are forms of popular cultural production, which Intersex communities have responded to and engaged with. They are Jeffery Eugenides’s novel *Middlesex*, television shows — specifically the popular shows *Friends* and *House* — and the Wikipedia page on ‘Intersex.’

But what is ‘popular culture’? After all, cultural productions — such as movies, books, music, and artwork more generally — are most often produced for specific audiences, contingent upon factors such as education level, race, class and gender. This chapter will focus on American ‘popular culture,’ but this is a broad category. For the purposes of this study I utilize a flexible understanding of ‘popular culture’, focusing on accessibility and reach. The novel, television shows, and Wikipedia page I analyze are all widely accessible and have already reached millions of people, whether on the internet or through the public library.
Accessibility and reach are intentionally not concrete parameters. Existing ‘popular culture’ affects every author, filmmaker, artist, and thinker’s beliefs, concerns, and biases due to the prevalence of certain images and ideologies. It is difficult to measure how the popular ideologies woven into a work affect a work’s accessibility and reach. Accessibility and reach end up saying more about the effect a product will have on popular culture itself. This research is interested in both these things: what representations are getting most consumed, and how these representations might influence public perception. For these reasons I will not place too tight a leash on the phrase ‘popular culture’ but instead will look at the novel, television shows, and article brought up earlier to see how applying the phrase to each of them can be helpful.

Jeffry Eugenides published *Middlesex* in 2002, and since then it has been a bestseller and won a Pulitzer Prize. For many outside the intersex community, *Middlesex* was an introduction to the very idea that humans are born outside of the imposed male/female binary. It is the most famous book with an intersex main character and has brought a lot of publicity to the concept of IS, if not actual intersex activists. Public reviews attempt to explain 5-α reductase deficiency syndrome, revel in the ‘complexity’ of Cal’s gender, and use the term ‘hermaphrodite’ liberally, unfortunately they rarely use the word ‘intersex’ and almost never point to real world intersex activism. The novel tracks ‘Cal’ Stephanides, starting with his grandparent’s story as Greek refugees and progressing to his immediate family life. Cal’s paternal grandparents were brother and sister and fled Greece together and their cousin’s daughter is Cal’s mother; the story of Cal’s genes is steeped in stories of incestuous sexual relationships. When Cal is born he is sexed as female and raised as ‘Callie’. He falls in love with his female best friend, struggling with his identification as
a lesbian and when he is fourteen a doctor says he is intersex. Cal (at this point still ‘Callie’) undergoes a series of tests. He finds out he is being recommended for sex reassignment surgery because based on the tests the doctor determined Cal ‘should be’ a woman even though he has somewhat ‘masculine’ genitalia. But after learning he has a Y chromosome, Cal determines it is all a lie and he has been a man, with a “male brain” all along (Eugenides, 19). He runs away to San Francisco, adopting the alteration of ‘Calliope’, ‘Cal’, and masculine pronouns. The following passages from Middlesex, and my brief critical commentary, highlight the type of language the novel employs (and to which OICs respond).

From the beginning, Middlesex is an unusual intersex story because it glosses over the fact that its main character escaped ‘corrective’ surgery. The first lines of Middlesex read: “I was born twice: first, as a baby girl, on a remarkably smogless Detroit day in January of 1960; and then again, as a teenage boy, in an emergency room near Petoskey, Michigan, in August of 1974” (Eugenides, 3). As Viola Amato notes in Intersex Narratives: Shifts in the Representation of Intersex Lives in North-American Literature and Popular Culture these lines, given the reality for many intersex individuals, imply that Cal underwent surgery to enact this gender transition, when in fact this is misleading since all that happened was an emergency room doctor said his genitals looked ‘abnormal’ (Amato, 168). Middlesex enables Cal to physically run away from surgery as an adolescent: something many real life intersex people wish they had had the opportunity to do.

Cal also expresses an unusual fondness of being examined by the medical community. At one point Cal talks about his doctor, Dr. Luce, putting his hand on the small of his back. “Luce’s hand was now proclaiming: Here she is. My star attraction. The terrible
thing was that I responded to it; I liked the feel of Luce’s hand on my back. I liked the attention. Here were all these people who wanted to meet me” (Eugenides, 420). While it is not impossible that an intersex individual has had a similar experience, and however they react to their medical treatment would be completely valid, I have not come across any narratives that fit anything close to this description. While some individuals have a neutral opinion, or are even grateful for the way they were operated on as babies, there are only a few, if any, accounts of people enjoying having their genitals and bodies repeatedly examined and even photographed. Despite this, Eugenides chose to depict his character as, at least in part, liking the attention of having his body inspected by doctors, when there are hundreds, if not thousands, of accounts online describing how traumatic an experience this can be. This authorial choice was presumably based on a couple of factors that we should keep in mind: Eugenides is not intersex and he did not research the experiences of intersex individuals for the novel (Mullan). The choices he made in depicting an intersex story, as well as Eugenides’s positionality, are taken up extensively on OICs and will be discussed at length in chapter three.

There are many ways to be sex-variant and to identify as intersex. A lot of intersex activism has attempted to make clear that genitals don’t make sex and they certainly don’t make a human being, even if they are given a lot of attention due to surgery on infants. In Middlesex, however, genitals are given the spotlight; they are the subject of many descriptions, and at one point Cal reflects that: “my genitals have been the most significant thing that ever happened to me” (Eugenides, 401). While many can undoubtedly identify with this sentiment, it doesn’t loan much credence to the idea that intersex is about more than phallae.
The relationship between normative ideas of sex, gender, and sexuality, has an interesting role in the novel. Cal falls in love with his best (female) friend growing up but is never able to identify as lesbian; instead the text describes these sexual feelings as “inklings of her true biological nature” (Eugenides, 327). While ‘inklings that something else is going on’ is a sense that many queer people, myself included, can identify with, this is importantly different from the ‘true biological nature’ being foreshadowed in Middlesex; Eugenides doesn’t mean inklings of queerness, but that Cal’s sexual attraction to women is a result and sign of his ‘true’ male biology. In addition to the homophobia woven into such sentiments — that who someone is attracted to determines their sex or vice versa — this quote is also reminiscent of the chromosomal primacy the novel takes when determining sex. Once Cal learns his chromosomes are 46XY he ‘realizes’ he has been ‘male all along’, referencing his ‘male brain’ as the reason he needs to run away to ‘live up to his biology’ (Eugenides, 19 & 437). While some individuals with 5-α reductase deficiency syndrome are raised female and transition to male later in life, this is by no means the only ‘true’ way to be, as the novel depicts, and in fact are in the minority: most individuals with 5-α reductase deficiency syndrome are women. Additionally, while many individuals with 5-α reductase deficiency syndrome in real life identify as intersex, Cal identifies only as male after discovering ‘the truth’.

Even with problematic language, it is important to remember that Middlesex’s position as a mainstream and influential work of fiction, and Eugenides’ frequent broadcasted interviews after publication, brought a lot of attention to intersex movements and depicted a three-dimensional, nuanced, intersex character (something Friends and House cannot claim as we will soon see). Fallout is something I want to consider when
looking at productions of popular culture. Unfortunately, it is the fallout of the publication of *Middlesex* that many intersex activists take the most issue with. Eugenides was, and still is, invited to many interviews to speak about IS extensively, often using the term ‘hermaphrodite’ in place of ‘intersex’ and rarely, if ever, referencing intersex activists in his talks. The analyses of the passages above give an indication of what is at stake with the topics in *Middlesex* — gender, surgery, sexuality, among others — and show how IS visibility without amplification of intersex voices could put individuals who identify as intersex in very vulnerable positions.

Since 2000, a number of popular television shows have also incorporated intersexuality into the plots of episodes. I look at *Friends* and *House* because they are two of the most widely watched shows that have represented intersexuality. I quote the relevant scenes in these two shows as examples of the pervasiveness of damaging portrayals and misrepresentations of individuals who identify as intersex. Chapter three will examine how individuals have engaged in counter-discourse around these two popular television shows’ episodes.

In 2001, *Friends* aired “The One With the Rumor”. My transcript of the scenes that reference IS are quoted below:

Rachel: So you guys would just like get together and just like say mean things about me?
Will: Well we did a little more than that.
Ross: No no, no no.
Phoebe: What? What else did you do?
Will: We started a rumor.
Rachel: What rumor?
Phoebe: Oh come on Will, just take off your shirt and tell us.
Rachel: Ross!
Ross: It was no big deal. We, we said that the rumor was that um you had both male… and female… reproductive parts.
(Laughing)
Will: Ha!
Rachel: What?!?
Will: That’s right. We said your parents flipped a coin decided to raise you as a girl but you still had a hint of a penis.
Rachel: (Opens mouth) Oh my god! (Hands on face)
Monica: You started that?
Rachel: What? You heard that?!
Monica: Everyone at our school heard it!
Chandler: Everyone at my school heard it! You were the hermaphrodite cheerleader from long island??
Rachel: Oh no!!
(Laughing)
Rachel: Oh my god this is all making so much sense to me now. This is why Adam Gardner wouldn’t go out with me, that’s why Billy Trat would just stay in this (motioning to breasts) region.
Ross: Actually Bill Trat is gay now so that one’s not really our fault.
(Laughing)
Rachel: Monica how come you never told me this?
Monica: I thought it might be true. I was afraid that you were gonna cry and then show it to me.
(Laughing)
(Joey stares at Rachel’s crotch)
Rachel: Joey stop staring! There’s nothing there! It’s not true!
Joey: I’m afraid I’m gonna need proof.
(Laughing)
[Different scene]
Rachel: Ok, ok, listen to what Sean McMan wrote in my yearbook senior year: ‘Dear Rach, you’re such a great person,’ not girl… person!
Ross: Rach I think you’re reading a little too much into it.
Rachel: ‘Dear Rach, you’re a great person, sorry about your teeny weeny.’
(Laughing)
Will: (Laughs loudly)
Ross: Look, what do you want me to do? Do you want me to call everyone in the entire school and tell them it wasn’t true?
Rachel: Yes.
Will: Would you also tell them I’m skinny now?
Monica: Oh! Me too.
Ross: Look look I’m not calling anybody, it was like a million years ago.
Rachel: I don’t care how long ago it was. You told people that I was half and half!
[…]
Rachel: Ok fine you guys can have your stupid little club but I would just like to say that what you did to me is way worse than what I did to you. You gave me a teeny weeny.
Will: Yeah ha ha yeah yeah (nodding).
Monica: Alright, listen. You’re just being silly. Rachel even with that rumor you were one of the most popular girls in school. Everyone wanted to be like you. One girl wanted to be like you so much she stuffed her pants with a tootsie roll.

(Laughing)

Rachel: Wow (touched).

From making a humorous plot point out of IS, to depicting horror at the concept of someone starting a rumor that a non-intersex character is intersex, this scene does not have a promising start. It is obvious that humor was the writers’ aim given the extremely offensive sound bites employed: ‘hermaphrodite cheerleader from long island’, ‘half and half’, and ‘teeny weeny.’ The suggestion that a character must show everyone their genitals to prove they are not intersex is tragically reminiscent of the violence intersex and trans individuals face, not to mention the popular misogynist call for women to take off their clothes for the benefit of men in the room. The episode not only mocks the experiences that individuals and their families have to go through in terms of making decisions about gender rearing and difficulty with sexual relationships, it also fails to even recognize IS as a fairly common identity: leaving viewers with the potential to walk away assuming the show was making fun of an impossible anatomical phenomenon and contributing to the erasure of IS even in its representation of it.

The other television episode I look at is from a medical drama: a more common place to encounter representations of IS. In the episode “Skin Deep”, released in 2006, the show House also uses intersexuality as a way for the main character (named ‘House’) to make his characteristic inappropriate remarks — once again centering IS as comic relief. House is a doctor charged with solving seemingly unsolvable and problematic cases. The inclusion of IS on the show immediately centers the identity as a ‘strange’ disorder. My transcript of the relevant scene is as follows:
House: We found a tumor.
Austin: She has cancer?
House: Technically no.
Austin: So it’s not cancer?
House: No it’s cancer but ‘he’ has cancer. On ‘his’ left testicle.
Alex: I don’t have testicles.
Austin: She’s not a guy.
House: His DNA says you’re wrong. Frogs and snails and puppy dog tails. You’ve got male pseudo-hermaphroditism.
See we all start out as girls and then we’re differentiated based on our genes. The ovaries develop into testis and drop. But in about 1 in 150,000 pregnancies the fetus with an XY chromosome, a boy, develops into something else, like you. Your testis never descended because you’re immune to testosterone. You’re pure estrogen, which is why you get heightened female characteristics: clear skin, great breasts. The ultimate woman is a man. Nature’s cruel huh?
Austin: This is obviously a joke huh? This is impossible.
House: No a joke would be me calling you a homo. See the difference? [It came out earlier that Alex’s dad had slept with her.]
I’ll schedule ‘him’ for surgery.
Alex: No! You’re wrong! I’m a girl! (Reveals self under dressing gown). See? How could you say I’m not a girl? See? They’re all looking at me. I’m beautiful!
House: The anger, it’s just the cancer talking. Put your clothes back on. I’m gonna cut your balls off. Then you’ll be fine (shrug).

Unlike the Friends episode, “Skin Deep” has an intersex character. However, inappropriate language, incorrect scientific references, comical mis-gendering, and chromosomal primacy create a representation of IS that perpetuates discourse that encourages infantile surgery, the assumption that there is an underlying ‘true’ sex, and the idea that intersex individuals are appropriate targets of ridicule and mockery. In this scene a medical professional speaks to a patient in absolutist language about their gender (on top of telling her she had cancer) and mocks the emotional reaction it causes. This is not unlike experiences countless trans and intersex individuals have been subjected to, but instead of engaging that experience, the show used it as comic relief.

This last product of popular culture is a bit more complicated in its relationship to our Dominant Culture, and is a good segue into looking at how intersex communities use
the Internet as a platform to speak for themselves. The Wikipedia page on ‘Intersex’, like any Wikipedia page, can be edited by anyone as long as the edits pass a minimal screening process done by Wikipedia staff. Given that intersex individuals are the experts on intersexuality and that public perceptions on intersexuality will impact them the most, I would not be surprised if a disproportionate number of the people who write and edit the Wikipedia page on ‘Intersex’ are intersex.6 The bibliography for the page includes sources outside the medical community, including human rights organizations’ publications, Fausto-Sterling’s works, statements from intersex organizations, and legal statements from multiple countries (“Intersex,” Wikipedia). Wikipedia pages have more vetting, input, and traffic, than many other online platforms so we can think of this page as a fairly direct product of popular culture while simultaneously a segue into how OICs publish literature that complicates popular discourse on IS.

Using the same word-cloud counting software I used to evaluate medical publications I ran the entire Wikipedia page on ‘Intersex’ (12,209 words). Within the article, the words ‘sex’, ‘people’, ‘rights’, and ‘medical’ were all used over thirty five times each (Figure 1.2). Unlike the medical literature, the Wikipedia page heavily features human-centric words: ‘people’, ‘rights’, ‘human’, ‘support’ etc. The page also includes heavy usage of ‘sex’ — centering the conversation of intersexual experience on an issue of boundary disruption or at least in conversation with the concept of only two sexual categories — and ‘medical’ — illustrating how central the topic of medical engagement is in intersex communities and activism.

---

6 This is not possible to check because Wikipedia does not require contributors to publish personal information, for good reason.
Figure 1.2 shows a graphic representation of the frequency of various words in the Wikipedia article on ‘intersex’. The highest frequency represented is 66 incidents (omitting ‘intersex’ itself), while the lowest is 15.

So far we have looked at medical tactics of engaging with IS, words that are commonly used to describe IS in medical publications, descriptions of IS from the most famous novel with an intersex protagonist, representations of IS in television, and the most common words in the Wikipedia page for ‘intersex’. This is a lot of raw material to grapple with but it should not be difficult to see that intersex individuals are marginalized by medicine and multiple manifestations popular culture (the Wikipedia page being a possible exception). Common themes we see throughout include: the idea that intersex bodies should be fixed, that genders can and should be imposed upon intersex individuals, that IS is humorous, that intersex voices matter little to medical professionals and entertainment producers who are publishing representations of IS, and that when there is more space for individuals to contribute to representations, the resulting text shifts the focus from medicine and humor to humanity.
1.3 Case Law and Invisibility: The State of IS in Law

The legal system produces hegemonic discourse about intersex issues differently than medicine or popular culture. Part of this is because law acts so slowly. New books, television shows, articles, and even medical statements/publications — or at least doctor/patient interactions — can occur daily, but the passing of laws, or rulings on cases take months if not years. There are many representations of IS in medicine, quite a few examples in popular culture, and hardly any in legal literature.

Legal frameworks set certain precedents for the way we perceive human beings as legal subjects; how difficult it is to find mention of intersexuality in legal documentation speaks to the invisibility of intersex individuals as legal subjects. Counter-discourse in OICs focuses most heavily on the rhetoric of medicine and popular culture, but OICs have also been instrumental in helping intersex individuals navigate the legal landscape on issues such as the legality of surgery and intersex discrimination. Many of the legal issues OICs engage with also have to do with complicating existing legal debates to include intersex people: marriage equality for instance, or bathroom bills. The patchiness of legal information around IS available online indicates the way the law has, in many ways, rendered intersex individuals invisible. As the law continues to affect intersex people, intersex individuals are forced to grab bits and pieces to patch together a picture of themselves as legal subjects. To evaluate the counter-discourse produced in OICs around legal issues it is important to understand the backgrounds of a few of the most talked about cases and policies.

In Pennsylvania in 1987, Wilma Wood was fired from her job at C.G. Studio after her employer found out she was intersex and had undergone genital surgery and she
brought them to court. This is the only example of a case I have been able to find that was based the charge of intersex discrimination. She brought suit against her employer claiming her intersexuality was the cause of her termination, but the U.S. District Court in Pennsylvania found that, while it is illegal for employers to discriminate against women or men due to their status as females and males respectively, under the Pennsylvania Human Relations Act (PHRA), employers are not legally prohibited from terminating employees based on their status of being intersex (“Employment Discrimination”).

This decision was based on the interpretation of PHRA and case law arising under Title VII. The court claimed, “The Title VII cases unanimously hold that Title VII does not extend to transsexuals nor to those undergoing sexual conversion surgery, and that the term "sex" should be given its traditional meaning” (“Employment Discrimination”) and that Wood’s case was one of ‘gender corrective surgery’ and so fell under this case law. The court linked Title VII case law and PHRA, saying “The Commonwealth Court recognizes Title VII cases as persuasive authority on the subject of sex discrimination due to the substantial similarity between Section 2000e-2(a)(1) of Title VII and Section 5(a) of the PHRA” (“Employment Discrimination”).

Finally, the court made appeal to Pennsylvania Supreme Court saying, Pennsylvania Supreme Court would probably find that discrimination on basis of gender-corrective surgery did not constitute discrimination on basis of sex under the Pennsylvania Human Relations Act, so that employer would not be liable for allegedly failing to promote and terminating employee solely because employee had undergone surgery to correct her hermaphroditic condition prior to working for employer. (“Employment Discrimination”)

The Wood case set a precedent for seeing IS as a disorder rather than a recognizable sexual category in a number of ways that should be parsed out.
First, the court did not see ‘intersex’ as a sexual category, appealing instead to the ‘traditional meaning’: implying only ‘male’ and ‘female’ are legitimate sexual categories to be recognized. This of course begs the question: where are intersex people to be positioned? Presumably, the court felt intersex individuals do have a ‘true sex’ that is either male or female and that Wood’s case was not tied to discrimination based on that ‘true sex’. Of course, this overlooks the fact that intersex individuals have different experiences and undergo additional forms of discrimination based on sex than non-intersex individuals. The fact that this binary is written into the law perpetuates the invisibility of intersex sexual identity and the discrimination that accompanies it.

The court leaned heavily on the status of trans sexual identity and discrimination in Pennsylvania for this ruling, conflating trans and intersex identities. This marks a fundamental misunderstanding of IS: while some intersex individuals are trans, and many intersex and trans issues do overlap due to our heteronormative Dominant Culture, some intersex individuals are not trans and a simple conflation of the two is oversimplifying different complex life experiences.

Lastly, the court used the phrase ‘solely because employee had undergone surgery to correct her hermaphroditic condition’. ‘Solely,’ of course, minimizes the status of surgery on intersex individuals based on their sexual phenotypes. ‘To correct her hermaphroditic condition’ marks Wood’s IS identity as her own fault — a disorder she chose to engage and ‘correct’, an aberration that she has to deal with alone. In addition, the couching of the court’s own discrimination in imitation medical language perpetuates the discourse around the medicalization of IS and implies Wood was wrong to even file this case as sexual discrimination instead of medical discrimination. This language contributes
to the discourse that doctors know intersex bodies best and how to advocate for them and the intersex individual’s assessment of the discrimination they face can easily be overlooked.

Intersex legal standings differ based on the country, but OICs flow easily across country lines since they are Internet based. Intersex individuals in the U.S. learn about intersex standings in other countries and reference them in conversations about U.S. legal policies. The most commonly referenced country in these conversations is Columbia. The Constitutional Court of Columbia has done something all other countries — besides Malta — have failed or neglected to do: limit the ability of doctors and parents to surgically alter the genitalia of intersex infants and children for appearance based reasons (Greenberg). Parents’ authority to consent in Columbia now relies on: how urgent the procedure, how risky the procedure, and the age and degree of autonomy of the child. The Court has set rules in place that restrict parents’ authority to have their children operated on based on the understanding that intersex individuals are a marginalized group who should be protected by the state (Greenberg).

Columbian Judges asked doctors to review and respond to materials from the Intersex Society of North America (ISNA)\(^7\) and the resulting discussions helped lead to the new policies. Many other countries’ legal systems — the U.S.’s included — ignore or misrepresent the stances of ISNA and other intersex-individual-based organizations (Greenberg). Columbia now has a system of intersex surgical consent in which parents can only consent if they have been given accurate information of risks and alternative options,

\(^7\) ISNA’s aim was to end secrecy and shame around IS and end unwanted surgeries on IS individuals; it was the largest intersex organization in North America until 2008 when they disbanded.
if they have given written consent on multiple occasions over an extended period of time, and if their child is under five years of age (Greenberg).

While the benefits of Columbia’s policies only directly affect intersex individuals who are Columbian citizens, the movement by the judges to listen to intersex voices, and the resulting decisions, brought, and continue to bring hope for change to many people across the world. Columbia’s new ‘informed consent’ model has been taken up by intersex organizations as a model for other countries to aspire to. The publicity that has occurred thanks to the Constitutional court has also brought a human-rights lens to representations of intersex individuals. This is in stark contrast to the lenses of humor and anatomical deformation evaluated in previous sections. However, for many individuals, the advancements in Columbia, while exciting, also highlight just how opposed to such changes the U.S. legal system appears to be, creating bittersweet feelings of simultaneous hope and despair.

My final example of IS in the legal landscape is referred to as the ‘MC case’ since the plaintiff’s initials are MC and he is a minor so his full name is kept confidential (MC). MC’s adoptive parents brought suit against the Medical University of South Carolina and the South Carolina Department of Social Services for the surgery that was performed on MC when MC was an infant and in custody of the foster system. They claimed that the surgery caused medical bills, pain and suffering, psychological damage, and physical impairment (MC).

The suit was successful and in 2017 the family was awarded $440,000 (MC). MC, an intersex Person of Color, was operated on to make him look ‘more female’ when he was a baby, and as he grew up he did not identify as a girl. In the last couple years, the MC case
has been blasted over OICs as both a heartbreaking story and a hopeful glance at what the future of intersex case law could look like. The founder of ISNA, Bo Laurent, testified in the case, and the aftermath online has further indicated the lengths intersex individuals will go to, banding together against discriminatory practices in order to change the legal system for intersex people.

How the law treats intersex individuals is inconsistent and unpredictable. The inconsistent legal frameworks for IS are notoriously difficult to navigate, and because the framework and its terms remain in flux, intersex individuals continue to struggle to frame themselves as legal subjects. Legal representations of intersexuality are as variable as the representations in medicine and popular culture. This project’s aim is to document this fluctuating discourse that is happening in the world, but to center existing intersex voices. With an understanding of the patterns that occur in dominant representations of IS in medicine, popular culture, and law, we turn to intersex individuals’ works to develop a comprehensive analysis and discussion of hegemonic intersex discourse and counter-discourse.
‘I Remain A Member Of Society’: How OICs Have Responded to Medical Discourse

Yet our society still perpetuates the lies against us and expects us to abide by. I just hope to maintain the courage of those who went before me. Doctor is a word that seethe from my teeth! Grrrrr... (Susan’s Place)

When interviewing Michel Foucault in 1972, Gilles Deleuze asked about the “injustice of speaking for others” that Foucault emphasizes in his work. They had been speaking about the power structures of ‘justice’ systems and the naked power viewable in prison and Foucault continued on this line for his response, saying that when prisoners speak “it is this form of discourse which ultimately matters, a discourse against power, the counter-discourse of prisoners and those we call delinquents—and not a theory about delinquency.” (Deleuze & Foucault, 209) (emphasis added). Theories, like history and knowledge, are almost always produced by those in power. Presumably, Foucault was not interested in establishing absolute theories about truth: instead he was interested in disrupting accepted theoretical ideas established by systems of power within a given time (“Questions of Method”). Marginalized groups, like prisoners, have their speech limited by different forms of hegemonic discourse and power and while Foucault and Deleuze were using the example of those literally put behind bars by society, they were applying the theory of counter-discourse to marginalized groups more generally (Deleuze & Foucault, 209). In the spirit of Foucault, I aim to center the discourse of the intersex community and
consider the ways their discourse can disrupt hegemonic discourse; I look towards our
dominant ideologies about sex to see what work ‘counter-discourse’ can do as a theoretical
tool for an intersex narrative. The counter-discourse produced through OICs in particular is
complex and important in the ways individuals use their own experiences to counter
hegemonic ideologies of ‘normalcy.’

2.1 Reimagining the Theorist’s Role in Counter-Discourse

In “The Practical Theorizing of Michel Foucault: Politics and Counter-Discourse,”
Mario Moussa and Ron Scapp argue that other philosophers have misunderstood Foucault
when they say he was attempting to produce counter-discourse himself. Instead, Moussa
and Scapp argue that Foucault’s conception of counter-discourse was such that counter-
discourse has to come from members of marginalized communities themselves. They write,
“Foucault hoped to clear a space in which they [those oppressed by a certain discourse]
might speak up and begin defining themselves through their counterdiscourses.”
(Moussa&Scapp, 93).

I want to complicate this vision of the role of the theorist/philosopher/academic with
the work of Gayatri Spivak. Spivak is an Indian scholar, literary theorist, and pioneer in
postcolonial studies. In “Can the Subaltern Speak” — her most famous work, which looks
at women in ‘third-world’ post-colonial countries in particular as a marginalized or
‘subaltern’ group — Spivak makes a number of important distinctions between types of
representation and discourse (Spivak). She notes a shift from asking ‘who is
speaking/should be allowed to speak’ to ‘who is being heard and by whom.’ Moussa and
Scapp’s work interpreting Foucault implies that those who have been oppressed by a
discourse should speak and the academic — assuming they are not one and the same — must make space so that they can do so. Spivak draws attention to the dangerous implications of such a move; it implies that people oppressed by a discourse cannot themselves speak until someone such as Foucault gives them the ability.

Responding to Deleuze and Foucault’s theorizing on counter-discourse Spivak says, “there is a contradiction within a position that valorizes the concrete experience of the oppressed, while being so uncritical of about the historical role of the intellectual” (Spivak, 69). This ‘role of the intellectual’ is not only one who has historically been aligned with power, which Foucault and Deleuze recognize, but one who acts as gatekeeper allowing others to speak. Spivak then uses Deleuze as an example, saying his quote ‘there is no more representation there is only action’ is problematic in its conflating of academics’ representations of oppressed voices and practice of ‘making room’, and the voices of subjects representing themselves. Spivak reminds us that many people may already be representing themselves: relevant here, of course, are intersex voices on OICs.

Intersex individuals have historically been spoken for, and represented, by dominant spheres of society and this is still the case today. But considering Spivak’s take on Foucault and Deleuze, we should remember this doesn’t mean there aren’t countless representations of IS out there that are produced by intersex individuals themselves. Since OICs exist, in part, for intersex individuals to ‘speak up and define themselves,’ we should understand OICs’ very existence as counter-discourse.

Looking instead at ‘who is listening’ I want to shift the role of the academic to one who listens. Even further I want to suggest projects such as this one can be listeners in and of themselves: emphasizing the voices that are already out in the world to allow others in
the academic community to take on a self aware listener role themselves. In praxis this includes a few components. First, academics should work not to ‘produce’ their subjects but instead be conduits for them, amplifying their voices to more and different audiences if this is something subjects have said they want. This includes resisting efforts to shape subjects’ voices to fit certain pre-set agendas and resist assuming these voices need to be shaped beyond what the subject has done already. Instead, the academic should work to recognize and note that first person voices were speaking the whole time and academics just weren’t listening. My work specifically focuses on relaying how those affected by the harmful discourses surrounding intersexuality create counter-discourses and exemplifying how a project’s role as ‘listener’ can play out.

2.2 Countering the Medical Community

Chapter 1 outlined some of the most common words medical and scientific papers use to talk about intersex patients and bodies more generally. I return to these words and consider them in relation to medical practices surrounding IS, particularly surgeries on intersex infants and doctor/patient interactions. Looking at posts and comments from ten online sources, I explore how OICs speak about intersexuality, and how that speech works to counter traditional medical narratives by redefining the ‘truth’, advocating acceptance of all bodies, and creating a sense of belonging to an intersex community.

---

8 The Intersex Society of North America (ISNA), Transgender Pulse Forums, Intersex Roadshow, Pidgeon Pagonis, Accord Alliance, Intersex and the City, Organization Intersex International, Intersexualite, Intersex Aotearoa, and Bodies Like Ours.
2.3 The Pushback to ‘Chromosomal Primacy’ in Determining Sex and ‘DSD’ Nomenclature

OICs respond to words and phrases the medical community uses in conjunction with intersex bodies in a multitude of ways. Some of the words people respond to are those which appear in the word cloud analysis in chapter one (Figure 1.1), such as ‘DSD’, and ‘disorder’, but it is important to note that some types of rhetoric, while not frequently attested in published work, are heavily prevalent in the language doctors use when speaking to intersex patients or making public statements. OICs are an important source of information on how some doctors speak to intersex patients and how the gap between medical literature and doctor/patient interactions and statements can be beneficial in some situations, and incredibly harmful in others.

The following comment is from ‘Transgender Pulse,’ an online-based organization whose mission is to stop the transgender suicide epidemic. In addition to resources such as directories and live chats, Transgender Pulse offers forums, one of which is an intersex support group. In 2012, someone posted who was unsure if they were intersex, Felicia responded the following:

I always advise a karyotype test for children who present with relevant symptoms (Ambiguous genitalia / leukemia / Developmental delays / Multiple birth defects), but one needs to be wary of relying totally on just one test. It is possible for a person who is otherwise male to be XX and a female to be XY. There are also examples of individuals whose body cells show the presence of 46,XX/46,XY (termed a mosaic) in each cell or whilst some body cells contain XY others show XXY. In some children there is just one X in each cell (Turner Syndrome). (“Intersex Discussions”)

In terms of counter-discourse, this post is significant for a number of reasons. First, it questions the validity of the current DSD method of determining sex through chromosomes, by stating that someone can be female with XY chromosomes and male with
XX chromosomes. While many medical professionals would undoubtedly agree that a female could have XY chromosomes, and many do, it is not a recognized fact under the current medical system of DSDs, which claims the ‘underlying sex’ is the one the chromosomes represent with XX being female and XY being male (Damiani). The policy around DSDs is a chromosomal primacy approach to sexing; genitalia primacy, gene primacy, and hormonal primacy are all other methods various groups and individuals have advocated for. By neglecting to honor the DSD classification system and instead allowing sex to be based on more than just chromosomes, this author — who may be a doctor themself⁹ — gives importance to other sex factors, revealing how ambiguous and imprecise the tactic of sexing through chromosomes is.

Doctors are often understood to be the authoritative guardians of the truth. While this can understandably be comforting for some, it makes many others uncomfortable since what doctors say is the truth about intersexuality may not align with what some people believe about their own bodies — as has certainly been the case for many intersex individuals. In response, counter-discourse can serve as a questioning method. In the above example, the author’s neglect to acknowledge chromosomes primacy circumvents the ‘gatekeepers of truth’. When community members provide advise to one another on OIC spaces such as a Transgender Pulse forum, it broadens the circle of expertise outside of just medical establishments.

⁹ It is important to remember that just because someone is a part of the medical community does not mean they are part of perpetuating medical discourse harmful to intersex individuals. Many doctors work extremely hard to fight with intersex activists. Regardless, it is important to talk about the hegemonic medical discourse that is damaging if it is to be changed, and many of the best medical professionals advocating for intersex rights would undoubtedly agree that harmful medical rhetoric is omnipresent and difficult to change.
Organisation Intersex International (OII) also responded to chromosomal primacy by advertising an article first published on intersexualite.org titled “Ambiguous Medicine and Sexist Genetics” in 2008. This cross sharing is common in social media but especially important for effective counter-discourse in OICs since IS issues are even less visible than those of other marginalized groups, making access to resources even more difficult. While not a new concept — ‘cross-sharing’ through story telling, oral history, and even gossip have functioned as ways for marginalized communities to produce and share knowledge outside of Dominant Cultures for a long time — cross-sharing over social media allows for faster and easier knowledge distribution between affinity group members: creating counter-discourse and knowledge pathways that circumvent Dominant Culture (Flinn). Understood this way, cross-sharing itself helps redefine the truth by creating networks of citation outside of medical journals, thereby redefining the truth of who the ‘experts’ are.

Amplifying intersex voices broadens readers’ conceptions of the size of the community. Recognizing that many individuals proudly identify as intersex, are wiling to talk about it, and want to spend their time creating and distributing resources to other intersex individuals, helps us see not only the prevalence of IS, but the importance of advocating acceptance of one another’s bodies and creating a sense of community where members care about one another. ‘Intersex Aotearoa’ published a brochure that touches on the importance of recognizing a broad online intersex community (Figure 2.1). In it, two cartoon people explain the difficulty of being intersex, and how big of a revelation the existence of OICs can be. The brochure itself works almost as meta-cross-sharing since it advocates the work online social media communities do while simultaneously circulating as a resource itself.
This tactic of online community building and sharing is especially important in light of the echo-chamber outcry. Many people in the world are worried that sharing information across the Internet in apparently closed communities creates an ‘echo-chamber’, where the only opinions you ever hear are your own (Liao, 194). However, it is important to remember that when it comes to OICs, and online communities of other marginalized groups, dominant culture is already supplying a heavy stream of other viewpoints. Our Dominant Culture creates its own ‘echo-chamber’ through its discourse by non-marginalized perspectives. Online communities produce counter-discourse precisely because information sharing, validation, and banding together are possible and necessary given dominant discourses. It wouldn’t be ‘counter’ discourse if another discourse didn’t already exist, and universally condemning all echo-chambers overlooks the role power plays in determining which communities have the privilege to overlook other viewpoints.

The article referenced above that originally appeared on intersexualite.org — “Ambiguous Medicine and Sexist Genetics” — goes into depth on why DSD nomenclature and its methods of chromosomal primacy “are not only demeaning, but also scientifically flawed” (Italiano). The article mentions a number of ways an individual could be diagnosed with a DSD — possibly due to a mix of 46XX and 46XY cellular makeups — but have solely male or female anatomy in terms of hormones, gonads, and genitals: making the diagnosis unnecessary and stressful. Similarly, the article criticizes proponents of DSD’s methods for emphasizing chromosomal makeup when it has been well known for decades that for testicular tissue to grow it is not just XY chromosomes that are necessary but other substances that cause differentiation and development, without which ovaries will begin to form. The authors argue that too much emphasis on so-called ‘sex chromosomes’
overlooks the importance of other genes and this leads to ambiguous medicine (Italiano). One of their examples is that under DSD methods people with very different anatomies can receive the same diagnosis (such as 46XXDSD) solely because their 46 chromosomal makeups are the same. Above all, the article expresses the worry that chromosomal differentiation prescribes what sex one ‘should’ be over what one’s phenotype actually exhibits (Italiano). Doing so promotes further confusion and oppression by allowing medical and psychological professionals immunity to seemingly concretely ascribe a sex and gender to individuals who may not mentally or physically fit those boxes.

The article’s appearance on multiple intersex communities’ platforms indicates the importance of information sharing among affected individuals. The article itself is part of a medical conversation around IS: it was written by doctors and speaks extensively about the medicine involved. It is important to remember that there is not a clean dichotomy between intersex communities and the medical community. While I consider the damage hegemonic medical discourse causes, and amplify intersex counter-discourse, sometimes (maybe even often), medical literature and medical professionals are vital parts of OICs’ creation of counter-discourse. While the article by no means represents the viewpoints of every individual who identifies as intersex, it does provide an argument for complicating DSD nomenclature and as such is part of an effort to redefine the truth of what constitutes a sex.
Figure 2.1 shows a brochure published by Intersex Aotearoa. It acts informatively and contributes to multiple forms of counter-discourse we investigate in this chapter.

“ambiguous Medicine and Sexist Genetics” is far from the only example of counter-discourse attempting to redefine the truth by describing the role of genes to complicate a simplistic chromosomal primacy sex differentiation model. While chromosomes are themselves packets of genes, the chromosome primacy model as it stands works to shove people into XX-female and XY-male boxes, and many believe a more comprehensive account of the ways multiple genes, on different chromosomes, interact to create a person’s sex would be a more accurate and just method for the individuals involved.

The following 2011 posts are from ‘Bodies Like Ours’, a website dedicated to ending the shame and secrecy around people born intersex. The posts illustrate how the site
not only complicates the chromosome story but also gets into the importance of ‘accepting all bodies’ and ‘creating a sense of belonging to an intersex community’:

In the same way that the genes for coloring and stature compete, so do the genes for sexual development and function. During critical developmental stages of fetal growth, the presence of male androgens in a female or the presence of female estrogen in a male can create an array of uniquely looking genitals and functioning sexual organs. Bodies like ours are not created in one way, but rather many. While sometimes there is a life threatening illness that causes atypical genitals to be formed, often it is simply a unique firing of chemistry that changes outward genital appearance and/or reproductive function. Our bodies may not be clearly male or female, but rather may be somewhere uniquely on a sliding scale of nearer to male or nearer to female (“Our Bodies”).

You’ve made one positive step toward claiming your sexuality by visiting Bodies Like Ours. By beginning to discover your history and share it with people who have similar histories, you start to define yourself and be valued by others just as you are. Some people come here because they are worried they are gay or lesbian, that their infertility or sexual discomfort will prevent them from finding a loving partner, or that they are too physically or emotionally damaged to ever feel close to anyone else. Participating in chat rooms, listservs, and bulletin boards are relatively easy ways to listen to a variety of people talk about their social and romantic relationships and to learn that loving, healthy people practice a range of sexual activities (“Our Sex”).

The first post doesn’t talk about chromosomes but instead about genes, androgens, estrogen, genitals, and sex organs: complicating understandings of what ‘makes’ sex. It also demystifies the binary presumption of sex by comparing it to ‘coloring and stature’, which society already acknowledges exists outside of a binary. These tactics redefine the ‘truth’ of sex by complicating the scientific language and de-stigmatizing the medical aspect, saying that life threatening conditions do occur but sometimes bodies just form outside of the binary.

This counter-discourse is strengthened by the website’s title, ‘Bodies Like Ours’, which not only emphasizes the strength of the intersex community but redefines ‘normal’ by centering intersex individuals as the ‘us’ and those who fit in the female/male binary as the ‘other’. While the hegemonic discourse in medicine is that of intersex bodies being
‘disordered’ and ‘abnormal’, the use of personal pronouns as a form of counter-discourse effectively refocuses intersex people as the norm. This tactic is used throughout the website in the body of texts and post titles: centering intersex people as knowledge producers and encouraging the acceptance of all bodies.

The second post from Bodies Like Ours uses words like ‘positive’, ‘value’, and ‘loving’, in addition to agent-oriented language — ‘your sexuality’, ‘your history’, ‘define yourself’ — to remind readers that to talk about IS doesn’t necessarily mean a conversation about genes, genitals, or doctors. The second person pronouns in this OIC-setting don’t distance the intersex audience: they remind readers of their own agencies in defining their intersex identities, and that their bodies and identities are uniquely their own, while part of a larger community that is supporting them. Centering the purpose of counter-discourse on the individual’s well-being encourages readers to put their needs first and to accept themselves, while simultaneously indicating that a beneficial way to do this is to engage in a community of affiliated individuals: through chat rooms, listservs, bulletin boards, etc.

The next post I look at engages DSD nomenclature, specifically the first D of the acronym: ‘Disorder’. The following abridged article comes from Dr. Cary Gabriel Costello’s blog ‘Intersex Roadshow’. Dr. Costello is an intersex activist who is also a professor of sociology at University of Wisconsin. The post picks up when Costello is talking about the adoption of ‘DSD’ and the medical community’s expectation that members of the intersex community would benefit from the new nomenclature:

---

10 The title of Costello’s blog is likely a move at reappropriation: highlighting the fact that historically medicine has put intersex bodies on display as ‘freak’ accidents that must then be corrected, but subverting this by using the platform to speak up about how the intersex community is mistreated.
In fact, what happened is that most out intersex advocates quickly rejected DSD language as repugnant. We didn't see ourselves as "disordered."¹¹ We saw the problems we faced as socially and medically produced. The forced genital surgeries and other treatments imposed on us without our consent didn't "save" us, they caused us terrible suffering. They constituted intersex genital mutilation. Our problem did not lie in our sex-variant bodies, it lay in a society that framed such bodies as horrifying rather than just an eternal part of natural human diversity.

But you know who loved DSD language, and rushed to embrace it? The medical community, which used it to justify continuing, even intensifying interventions into sex-variant bodies. Disorders, after all, should be cured! Oh, and many parents of intersex kids quickly adopted DSD language, too, after hearing it from doctors, because it supported their desire to have their children "cured" and become "normal." These parents and doctors alike had a shared vision of intersex children being transformed into "regular" girls or boys who would gratefully grow up to be gender conforming and happily, heterosexually, married.

So in 2017 what we find is that in the U.S., we have two competing terms being used to describe those born sex-variant. Advocates call ourselves intersex, as do human rights organizations supporting us, while the medical community and those seeking medical "cures" use DSD language. (Costello)

A number of important moves are made in the post above. First, the post parses out language that is used around intersex issues and attributes it to different ideologies. The medical community ‘loved’ DSD language and the words like ‘disorder’ and ‘cure’ that go along with it because, according to Costello, it fits an ideology of intervention to create ‘regular’ girls and boys. But the word ‘intersex’ is attributed to the ideologies of ‘advocates’ and ‘human rights organizations’. Costello uses terms like ‘social problem’, ‘imposed treatment’, ‘human diversity’, and ‘sex-variant’, which align with their self-identified ideology of honesty and acceptance of bodies outside the M/F boxes. This parsing of language works to show how ideologies and systems of incentives affect what

¹¹ This is supported by quite a bit of anecdotal evidence, which can be found online. Additionally, the Journal of Pediatric Urology published a study with similar findings that “the updated ‘disorders of sex development’ (DSD) nomenclature formally introduced in 2006 has never been universally accepted by members of the affected community, particularly advocacy groups. Use of this nomenclature by medical professionals may unintentionally negatively affect access to healthcare and research for individuals with DSD conditions.” According to the study only 24% of participants use ‘disorder of sexual development’ to describe themselves/their child. A majority, 69%, had a negative emotional association with the term and only 17% reported liking the term. About one-third reported that they would not even attend a clinic named the Disorder of Sex Development Clinic (F1000)
different groups propose to be ‘the truth’ of the matter. Costello not only shifts the axes of ‘truth’ about the best nomenclature but also shifts the conversation from an ‘objective’, distancing approach, to a subjective and personal one. Along these lines, Costello aligns their place in IS counter-discourse as part of a larger intersex community by using plural personal pronouns such as ‘we.’ Not only does this indicate that there are larger intersex communities in existence but also that the author is a proud member.

Accord Alliance has also addressed problems with DSD nomenclature. The ISNA sponsored and helped put together ‘Accord Alliance’ in 2007 and they define their mission as promoting comprehensive approaches to care that help people and families affected by DSDs (Accord Alliance). Accord Alliance has the following posted on their website concerning DSD nomenclature:

The term “disorders of sex development” (DSD) is used to refer exclusively to a category of medical conditions described in the 2006 Consensus Statement; in this context, DSD carries no implications for the identity of the person. Some people with these conditions apply “intersex” to themselves as an identity label. In general, we adopt the principle of “people-first” language, which refers to the person first, and the associated medical condition second, for example “a person with a DSD.” Nevertheless, some believe the first “D” (disorder) in “DSD” necessarily implies the need for medical or surgical intervention. For this reason, we adopt the more neutral term “differences of sex development” which avoids equating biology with identity, and replaces a word that offends and worries some with one that is more neutral (Accord Alliance).

While certainly less radical than Dr. Costello’s post, Accord Alliance makes a similar move, acknowledging different perspectives when it come to medical language, even if their solution only partially addresses the concern. Accord Alliance recognizes that the language they use will reach many people and will affect how other individuals and institutions talk about IS. Regardless of how much of an effect their solution really has — since in most places on the site the spelling will remain as ‘DSD’ and most people will
associate the first D with ‘Disorder’ not ‘Differences’ when you say ‘a person with a DSD’ — Accord Alliance sets an example by acknowledging the effects language purported by the medical community can have on individuals and altering their language accordingly.

2.4. (Fill in the Blank) Surgery

‘Unwanted’ surgery, ‘corrective’ surgery, ‘reassignment’ surgery, ‘genital mutilation’ surgery: depending on who it is coming from in intersex discourse, a lot of different qualifiers will come before ‘surgery’. Counter-discourse acts as a tool of complication: questioning dominant assumptions and allowing many voices to be heard. As such, ‘(fill in the blank) surgery’ acts simultaneously as a representation of counter-discourse’s multiplicity, and as a gateway to introduce different perspectives. This section looks at statements from groups and individuals and evaluates how the different quotes help constitute counter-discourse within OICs.

The ISNA states its mission on the homepage. It reads as follows: “The Intersex Society of North America (ISNA) is devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female” (emphasis in original) (Intersex Society). Shame, secrecy, and unwanted genital surgery are the three forces ISNA seeks to end. It is significant to note that these three priorities align easily with three major forms of counter-discourse we see in OICs. Ending shame is important to groups and individuals who advocate for the acceptance of all bodies. Ending secrecy is likewise vital to the creation of intersex communities and the spread of a sense of belonging for intersex individuals. Lastly, ending unwanted genital surgeries fits with people’s desires to restructure the truth:
advocating that these surgeries are not in fact medically necessary as advertised, but often imposed by fearful parents or doctors upholding the binary presumption.

The second half of the statement also speaks to a practice of complicating the assumed truth. ‘Anatomy that someone decided is not standard’ is a phrase that forces readers to consider who is this ‘someone’ is, and what authority they have to make such a large declaration. These efforts to reframe the truth show us the falsity in oversimplification. Oversimplifying all intersex surgeries as medically necessary, or oversimplifying ‘standard’ anatomy to a certain model, not only has the potential to cause harm to those operated on, but also erases other lived truths if those lives are attached to so-called ‘non-standard’ bodies.

The ISNA chose the designation ‘unwanted genital’ surgery, but this is far from the only possibility. Transgender Pulse forum users have also commented on ‘(fill in the blank) surgeries,’ calling them many different things. In 2017 one user wrote, “such surgeries seem like flipping a coin and hoping it comes up right, when you consider that gender isn’t even determined down there” (“Intersex Discussions”). This ‘coin-flip’ post gets at an important aspect of redefining the truth when it comes to intersex issues: the relationship between sex and gender. Every individual has decisions to make about their gender, how they wish to express it, and what role they want their genitals to play in that expression. In trans communities, different types of surgeries have different popularities, with some trans individuals opting for no surgery at all, as a choice of preference, or for financial or access reasons. While the body doesn’t make the gender, everyone decides for themselves what bodily morphology they need to have for survival and the best quality of life. For a surgeon or parent to make this decision necessarily assumes that this person is an adequate source of
truth, an assumption that is clearly invalid if we give primacy to the intersex person in self-determination.

To illustrate how this ‘coin flip’ has affected another Transgender Pulse user, Camila, I include her story from 2012 (content warning: attempted suicide):

apparently, i had a vagina when i was born. being my fathers decision, and since i also had a penis, he couldnt bear to chose to condone surgery to remove the penis, so he decided to have them take steps to make me a boy. they sewed it up. i dont think it was fully developed for that stage in my life. he admitted he made the wrong decision then, and apologized in a tearful conversation with me. 
i forgave him of course, hes my dad.
i still couldnt help but think: if i had known this earlier, like as in all along, and had proof, i wouldnt have been afraid to tell someone how i felt all those years. could have avoided the dozen suicide attempts and loads of misery and suffering. kinda felt like, so now u tell me dad! and i thought he was just having normal, and some abnormal issues with my transition (“Intersex Discussions”)

Psychological trauma often haunts individuals who are operated on as infants, especially those who are never told about what happened. Another user commented to this story: “we are living examples of what happens when humans feel that they know better than nature”. This use of ‘nature’ works to redefine the truth since it goes against the hegemonic practice of appealing to ‘natural sexes’ to justify surgery. It further advocates body acceptance by resisting the rhetoric of ‘normal or natural male and female bodies.’

Turning away from the ‘coin-flip’ designator, Dr. Costello has another section on Intersex Roadshow in which they talk about the ‘laws of natural sex’ and how surgery works to promote this ‘law’. Their ‘(fill in the blank) surgery’ words of choice are ‘intersex genital mutilation’ and ‘nonconsensual genital surgery’. The post has many important examples of counter-discourse at play and I include an abridged version as an important example of how counter-discourse can wrap various forms and targets into a picture of resistance:
Now, if ever you want to know when to suspect an ideology is at work, you can be sure it is the case when someone tells you something is unnatural and should not occur. Because here’s the thing about true natural laws: they function whether you want them to or not. Nobody needs to urge or force anyone else to obey them. Consider gravity. It’s a natural law, so nobody needs to enforce it. No religious tracts or psychological textbooks have been written urging people to obey the principle of gravity and refrain from floating about bumping into ceilings. Or consider this example: people may argue over vegetarianism, and whether it is healthy. But you have never seen a letter to the editor or an internet comment war complaining about how kids these days are engaging in the unnatural practice of giving up both meat and vegetables and choosing to engage in photosynthesis instead. There is no #PhotosynthesisIsUnnatural hashtag because it truly is unnatural for people to turn green and live off sunlight directly instead of eating things for energy. Truly unnatural things do not occur, so they generate no outrage squads decrying their transgression.

As for the “laws of natural sex”—well, it’s another story.  
 […] There is a war being waged over the ideology of “Natural Sex” today. And in that war, religion and science stand hand in hand on the same side. Who stands on the other? Intersex people whose genitals are surgically mutilated without their consent to force their bodies to resemble binary sex expectations.

The goal is to restore the “natural order” through techniques developed by science: eugenic programs, surgical “normalization,” and psychotherapies. Consider intersex status right now. There is a growing social movement of intersex people to put an end to the nonconsensual genital surgeries that have been imposed on intersex children since the 20th century. But doctors are extremely resistant to this movement. Living with a sex-variant body is presented by doctors as a fatal condition. It will lead to social death, which may lead in turn to suicide. Without a body that conforms to binary sex expectations, it will be impossible to find a mate, so even if one lives, it will be an empty life, a painful one full of strange nonconforming behavior and self-loathing. Surgeons claim they are compelled to continue intersex genital mutilation to preserve life and quality of life, dismissing the cry of intersex advocates that these “treatments” in fact degrade their quality of life. (Costello)

The way Costello uses humor, reason, semantics, and personal experience to switch the dominant discourse of ‘laws of unnatural sex’ indicates what is possible with OIC counter-discourse. Costello writes about how people make the argument for surgery on moral grounds — whether because morally there ‘should’ only be two sexes, or because someone can ‘only’ be happy in the M/F binary and not performing surgery on an infant is robbing them of this happiness. But they turn this on its head by emphasizing the ideologies at work. Further, they point out how surgeons continue to promote surgery long after many
people have stepped forward and provided testimonial evidence to these surgeries having degraded their quality of life.

Another individual who has come out adamantly against surgery is Pidgeon Pagonis, an intersex activist of color who runs a blog titled ‘Pidgeon is my name.’ In December 2017 they posted the “Intersex People of Color for Justice Statement for Intersex Awareness Day (IAD)”. The statement drew links between the present day intersex movement especially for people of color, and an enslaved woman who was violated by her master:

For IAD 2017, we want to reclaim and reaffirm the life of Anarcha. Anarcha is our patron saint. Anarcha is one of our movement mothers. We uphold her life because, like us, she was unjustly exploited by the medical industrial complex. Anarcha was an enslaved African woman in Alabama during the mid-1800s. Similar to many enslaved African women, she toiled in a heinous environment where her body was under constant attack from the lechery of the fields, overseers, mistress, and master of the plantation. Because of complications during childbirth, her value as a slave sharply decreased and she was sold to J. Marion Sims, who used her and two other enslaved women, Betsey and Lucy, to perfect his gynecological instruments and techniques. In the course of him perfecting his technique, Anarcha's body was violated over 30 times without anesthesia. Recently, Black Youth Project 100 demanded the removal of Sim’s statue from Central Park stating that the "memorializing of imperialist slaveholders, murderers, and torturers like J. Marion Sims is white supremacy." We agree, and as for intersex people, we too share that humiliation and trauma and can relate to the experiences of having our bodies desecrated by the medical establishment for their gain, not ours. On this day, in solidarity with reproductive justice movements led boldly by women of color, we reclaim our sovereign right to our bodies, and through our activism we will atone for the pain and sacrifice of our ancestors. We believe in intersex people. We especially believe in the power and magic of intersex people of color to protect and defend ourselves from the medical industrial complex. We are a just movement that has our vision set on attaining bodily autonomy for all. We’re coming. We will win. #EndIntersexSurgery (Pagonis, “Intersex”)
Pagonis’s powerful post ends with their equally powerful take on the ‘(fill in the blank) surgery’ multiplicity: #EndIntersexSurgery. In comparing the treatment of intersex bodies to desecration, Pagonis and their partners would likely agree with qualifiers such as ‘nonconsensual’, ‘genital mutilation’, or ‘unwanted’ to go before ‘surgery.’ But they took the opportunity not only to describe the state of the situation but link the word ‘surgery’ with an uncompromising call to action: End Intersex Surgery. Unlike White intersex individuals, intersex People of Color and especially Black intersex individuals have to resist not only a dominant system which wishes to erase their bodies and experiences because they do not fit the M/F boxes, but systems which have historically and systematically attempted to erase them through enslavement, murder, gaslighting, imprisonment, and poverty.

The Intersex People of Color Statement for Justice’s incorporation of American slavery into an Intersex statement works double time to redefine the truth: not only drawing attention to the violation of human bodies and genitals but showing how disregarding the history of slavery and race in conversations about intersex issues does not provide a sense of ‘universality’ — it fails to acknowledge the intersection of oppression that the most marginalized of intersex individuals face. The phrase ‘the power and magic of intersex people of color’ is a direct rhetorical effort to redefine power and value and produce counter-discourse that goes much deeper than the already powerful hash tag #EndIntersexSurgery alone.

Pidgeon Pagonis also wrote an article on their blog titled “A Doctor Asked Me for a Dialogue on Why They Shouldn’t Cut Up Intersex Babies - Here’s My Response”. The post came from an interaction that started with a Washington Post article. On October 5th, 2017,
the *Washington Post* did an amazing thing: they posted a lengthy article on intersex activism and the potential harm of surgery on infants. The article is titled “Their Time” and follows the story of Marissa Adams, who was operated on as an 18-month old and has attempted to undo the damage ever since. It weaves in pictures, stories, statistics, and blurbs to paint one of the most just representations of IS I have seen while doing this research. Pidgeon saw the article and tweeted about it, affirming their friends and fellow activists who featured in it. But they also saw that University of Michigan children’s hospital was tweeting about the article too, advertising their faculty investigator, Dr. David Sandberg, who performs surgeries, including clitorectomies, on intersex infants. In the tweet, they mention the ‘difficulty’ of treating intersex patients (Figure 2.2). Pagonis tweeted at the University of Michigan’s children’s hospital and Dr. Sandberg ended up sending Pagonis an e-mail asking them if they ‘wanted to talk’ (Figure 2.3). Pagonis felt enough medical discourse happened behind closed doors and they responded to Dr. Sandberg in an open letter. As far as I have been able to find, Dr. Sandberg has not responded to the letter.
Figure 2.2 shows the tweets University of Michigan’s Children’s Hospital released.

Figure 2.3 shows the e-mail Dr. Sandberg send Pagonis that Pagonis published and wrote an open letter in response to.
Pagonis’s post with their letter to Dr. Sandberg is a beautiful example of counter-discourse for many reasons. It questions many of dominant culture’s conceptions of truth, it repeatedly reaffirms intersex bodies, and it references both the importance, and the differences, of opinion and experience present in intersex communities. The post should be required reading for anyone attempting to understand the types of discourse and counter-discourse that surround intersex individuals, and so I include the article in full:

On October 5th, the Washington Post published this amazing long-form article on the intersex movement—featuring a number of my dear friends and fellow activists. It’s not often that a major publication dedicates 6,000 words of thoughtful, nuanced journalism to our community. The piece featured intersex people talking about our painstaking work to end a decades-old and thoroughly debunked medical paradigm that says our bodies are so wrong that doctors should be able to surgically alter us however they want—without our consent and when we are too young to participate in the decision. This is what happened to me at Lurie Children’s (formerly Children’s Memorial) in Chicago; I was operated on three times as a kid, for no medical reason, and without my knowledge or consent. I’ve been living with the fall-out ever since. It was mutilation. And I’m not alone in my conviction—three former US surgeons general came out against the practice, as have the Board of Trustees of the American Medical Association, the United Nations, the World Health Organization...and the list goes on…

The Washington Post article reflected our ongoing struggle to end this medically unnecessary genital surgery on intersex kids. No one should operate on us without our consent, let alone perform procedures that have been universally condemned by our community and international human rights bodies. But not all doctors agree: the reporter interviewed a handful who defend non-consensual “cosmetic” surgeries on intersex infants. And there are even more out there—like this guy at Cornell who not only performs clitorectomies on intersex children, but tests out his technique by putting vibrators on what’s left of their clitorises afterward.

After I tweeted affirmations to my beautiful intersex friends featured in the article, I saw the University of Michigan children’s hospital was tweeting about it too. They tweeted how proud they were of their faculty investigator, Dr. David Sandberg, for discussing “the difficulty of treating intersex patients.”

Our bodies might be a little more complicated than most, but we aren’t any more “difficult to treat”—start with dignity, respect, informed consent, and take it from there. But Sandberg and his friends are completely illogical. For over 20 years they’ve hidden behind the “need for more data” excuse, and yet they continue to promote and do surgeries while failing to produce said data. Since when does medicine need data to STOP doing super invasive and medically unnecessary surgery on people? Even Human Rights Watch
called Sandberg out, saying “as if the dearth of reliable data on precisely how many kids have suffered harm because of these surgeries was a reason to keep doing them.”

It’s 2017 and I can’t believe we are still fighting this battle. Pediatricians should be looking out for kids, not dismissing them like data points. Imagine if my doctors had actually thought of me like the healthy little kid that I was rather than a nail that needed to be hammered back into the gender binary?

So, I tweeted at University of Michigan and called Sandberg out.

It turns out he’s not on Twitter, but his friends are, and he emailed me asking for a dialogue.

Since intersex activists--starting back when Bo Laurent first spoke her truth and launched the Intersex Society of North America 25 years ago--have been in polite, private dialogue with doctors for so long, I thought: Sure, let’s have a chat Dr. Sandberg, but let’s do it in public. Let’s show everyone where we’re at.

Here’s my open letter to Dr. David Sandberg. Since he received taxpayer money for his research and works at a state university, we all deserve to know what brought him to tell the Washington Post he should be allowed to keep promoting a First Do Harm model of care for intersex kids.

----

Dear Dr. Sandberg:

Thank you for your email dated October 5th requesting a discussion about your quotes in the recent Washington Post article and your approach to care. Here are my questions. I kindly request a response by October 26th, which, as you might know, is Intersex Awareness Day.

1. You state that you believe it would be “hubris” to advise a parent to delay surgery on their intersex child—to imply that a doctor knows better than a parent what the child’s best interests are. How would you respond to a parent who came in asking for sterilization or female genital mutilation to be performed on their young child? For a cosmetic rhinoplasty? For a healthy limb to be removed?

2. You emphasize the lack of data on intersex children who grow up without medically unnecessary surgical procedures. That appears to be an inversion in basic medical ethics. What do you believe is different about treating intersex children that justifies procedures for which there are no affirmative data showing the results are beneficial?

3. Speaking of data, can you describe the study that you would personally consider sufficient to support a shift in care so that all medically unnecessary, non-consensual surgeries on intersex children are delayed? Is such a study feasible and likely to ever be performed, or is the lack of data going to persist indefinitely as an airtight excuse to continue performing surgery?

4. As a psychologist, you are familiar with the kinds of distress associated with gender dysphoria. Surgery also carries risks. So then, what is an acceptable level of risk a doctor
should take when he is conducting a medically unnecessary surgery that could create a body different from that individual’s gender identity when they grow up?

5. And finally, when the MC case was settled in South Carolina – in which adoptive parents sued the state for genital surgery the government had elected to do on him when he was a baby that conflicted with his later gender identity—you told Buzzfeed that “The plural of anecdote is not data” --as a way of saying you didn’t think horrific outcomes like MC’s, mine, and so many others were reason enough to change. What, then, are doctors who pledge to “do no harm” waiting for? How many more people need to suffer before you and your peers will support changing this paradigm?

6. Can you think a bit about how you would feel if that had been done to you.

Sincerely.
Pidgeon Pagonis
They/Them/Their
Chicago
(Pagonis, “A Doctor”)

Although the Washington Post article does not constitute counter-discourse in the ways I have defined it, it does amplify intersex voices instead of relying on dominant medical discourse. Additionally, all the intersex people who contributed to the article participated in various forms of counter-discourse along the way. Pagonis’s taking up the article, sharing it, and using it as a springboard into this new conversation is an excellent example not only of what OICs make possible, but the layers of counter-discourse that occur when marginalized people communicate and create new networks of knowledge production. This takes ‘cross-sharing’ even further in that it involves conversations with hospitals, doctors, a major news source as well as many different intersex activists.

Pagonis’s work not only contributes to OIC counter-discourse by repeatedly questioning systems of power and forms of ‘truth’, but it also encourages others to participate by calling people in and displaying a model of unashamed intersex beauty that is not afraid to speak out against the medical establishment.
2.5 Talking Back: Questioning Doctor/Patient Interactions

OICs produce counter-discourse directed at dominant methods of sexing, ‘disorder’ nomenclature, and surgery. But where hegemonic discourse around IS can be the starkest, and can haunt individuals for years after, is in direct interactions with specific doctors. Writing about these experiences contributes to an important manifestation of counter-discourse since it is looking back at the discourse that was used, complicating it, and warning others who are part of the OICs. My first example comes from the comment section of a 2009 Transgender Pulse forum post on the physical scars genital surgery leaves and concerns an experience with a surgeon. Rose was adopted and tells her story from when her parents came to the hospital.

Once they arrived, a surgeon met them and told them I was born a little girl with some male parts showing. The surgeon asked what my mom and dad want him to do. My mother being very ill-versed in medical procedures said the did not know, what would be best?. The doctor told her well she couldn’t stay this way. Mom asked what would be best? The surgeon said it’s is easier to make her a boy, and that’s what they tried to do. 10 days later they picked me up, mostly healed from the surgery. That's where my scar came from! wow. I did find out why my mother did not tell me sooner, as she thought I was doing "ok" as a man, and did not want to cause confusion for a problem... (emphasis added) (“Intersex Discussions”)

Rose’s story reveals a common trend in doctor/parent interactions: the parents’ desire to lean on a surgeon’s expertise to make life-altering decisions. While this is not an unfair move on parents’ part, it indicates a system in which surgeons are able to make these decisions without supplying the parents with resources around other options: such as OICs or in person groups with intersex individuals. Such groups would undoubtedly have told the parents that the sentiment ‘she can’t stay this way’ is misleading. Not only the choice for surgery, but the rhetoric that often gets used promoting the binary presumption of sex, and
that a child’s appearance is not beautiful just the way it is, has lasting impressions on how parents conceive of their child’s body. How parents think and talk about their child’s body undoubtedly has lasting impacts on how the child thinks about their own body. This surgeon’s desire to ‘make Rose a boy because it was easier’ raises questions about whom the role of ‘ease’ benefits here. Parents, intersex individuals, and doctors all have different motivations and influences that affect their opinions about what ‘should’ be done when it comes to surgery, and their courses of action. This disconnect can cause major problems for intersex individuals and is the reason many intersex activists don’t trust the medical establishment.

Pidgeon Pagonis posted an article titled: “First Do Harm: How Intersex Kids Are Hurt by those Who Have Taken the Hippocratic Oath”. In it, they compare parts of the Hippocratic oath to relevant parts of their own experience growing up intersex in the U.S. Figure 3.2 is an abridged representation of Pagonis’s article, juxtaposing the oath to the actual experiences Pagonis had with doctors. I formatted Pagonis’s post this way to highlight the contrast between medical discourse and lived experience. The visual representation literally shows the divide between the two discourses, what Pagonis is grappling with in writing this post. Counter-discourse, unlike hegemonic discourse, is forced to be intimately familiar with other forms of discourse. But by directly responding to pieces of the dominant discourse with personal experience, giving much more space to the counter-discourse, Pagonis engages the hegemonic discourse in a way that cannot be ignored.
"First, do no harm."

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.

I will not be ashamed to say "I know not," nor will I fail to call in my colleagues when the skills of another are needed for a patient's recovery.

Most especially must I tread with care in matters of life and death. Above all, I must not play at God

"The phrase ‘first, do no harm,’ synonymous with the oath, actually doesn’t appear in the original, or in today’s modern version. Yet, similar principles are strewn throughout the modern version that doctors, entrusted with my care as a young intersex child, neglected to honor."

"During bi-annual check-ups, my doctors stressed—as they palpated my breasts and peered between my legs—that I not only was, but more importantly, looked normal. In spite of this, I never felt quite normal […] This scripted version of the truth, an offensive play the doctors told my family to run on me, made me believe that my doctors saved my life […] As the doctors lied to my parents, and my parents lied to me. I began to lie to my peers […] The facade came crashing down the day I retrieved my medical records from my children’s hospital, whose front doors were just down the street from my college dorm-room. Reading the pages of my medical records, which began in 1986, turned me into a red-hot sobbing puddle in the middle of a tiny cinderblock dorm study room. What I read in those records transformed the way I saw my doctors who before were trustworthy life savers. Afterwards, they seemed like people who got away with violating my human rights."

"My medical records illuminate not only how my physicians fell for the trap of over-treatment, but also that they weren’t ever humble enough to admit they didn’t have all the answers. They failed to call in colleagues, such as therapists […] they decided, with no input from myself, to surgically assign my sex-uncertain body to appear phenotypically female. It must have seemed like a no-brainer for my parents when my doctors presented them with surgical fixes for their kid. The clinicians told them that I was born with underdeveloped ovaries—which they referred to as gonads but in actuality were undescended testes—that would most likely become cancerous if left intact. While there is a valid cancer concern in cases of intersex, it’s not as dire as some providers make it seem. A 2013 Australian Senate Inquiry Report on Involuntary or Coerced Sterilisation of Intersex People in Australia cites the risk of gonadal malignancy for CAIS and PAIS to be .8 per cent and 15 per cent respectively, and concluded a ‘serious shortage of quality information’ when it came to truly understanding this risk […] Surgeons don’t routinely remove people’s prostates after birth because they have a likelihood of developing cancer later in life. Instead, people are allowed to have bodily autonomy, and clinicians may monitor for cancer down the line. This shouldn’t be any different for intersex people who are born with undescended testes. Removing our healthy testes, and other reproductive organs, before we are of an age to give fully informed consent, is an affront to our human rights."

"I was given a clitorectomy because the doctors felt my clitoris—a mere centimeter and a half ‘when stretched’—wasn’t something a girl should have […] It was that unnecessary, and purely ‘cosmetic,’ genital mutilating surgery in 1990 that prompted the reoccurring dream I had as a child of blood soaked toilet paper between my legs. It wasn’t just a bad dream, but a chilling memory of being over-treated by clinicians who were too stubborn to say ‘I don’t know’. I also found out that when I was 11, and admitted for what I was told was a bladder surgery, I actually underwent a non-consensual vaginoplasty. My ‘excellent results,’ the records boast, would allow for ”normal adult relationships.” Normal sex, was of course, defined by my surgeons […] The majority of intersex people are not born with any related life-threatening health issues. Yet, doctors consistently pressure parents to act, not to save our lives, but to save our outdated and fragile binary understanding of sex and gender. Instead of stating ‘I don’t know,’ and waiting to ask intersex children what they want for themselves when they grow up, our doctors instead play God."

Figure 2.2 shows how intersex activist of color Pidgeon Pagonis responds (right) to various parts of the Hippocratic oath (left) given their experiences (Pagonis, “First”).
Pagonis’s comparative piece works extensively to redefine the truth and advocate the acceptance of bodies outside ‘our outdated and fragile binary understanding of sex and gender.’ They reference the doctors’ ‘scripted version of truth’, which illustrates how the ‘truth’ that their doctors perpetuated — about the necessity of a clitorectomy and how Pagonis’s life was in danger — was made up and not an accurate or just representation of the situation. Pagonis goes on to explain how the doctors affected their parents, their parents affected them, and they navigated the world regurgitating these ‘truths’ that they would come to find out were not only lies, but lies that violated their human rights. Pagonis also makes an important move by discussing how a common medical worry for undescended testes — the risk for cancer — can be handled very differently than it was by Pagonis’s doctors.

Pidgeon Pagonis ends their article with a call towards the future of intersex communities. They write:

This new chapter is already being written, and you just have to type intersex into a search engine to see it. Every day, there are brand new activist projects and resources popping up all over the world. Intersex people across the globe are doing the necessary work to build this brighter future for our children, and yours, by lifting up our stories (Pagonis, “First”).

As many writers we have seen so far have remarked, there are a multitude of ways to be sex-variant. Communities have formed under the umbrella term of ‘intersex’, creating intersex activist projects and resources, based on the affinity intersex individuals feel with one another. This affinity is the result of marginalization due to the discourse of sex-variance (and lack of) in our Dominant Culture. The way intersex individuals are treated by the medical community gives them grounds to fight a common fight and band together.
This unity is expressed throughout OICs on multiple blogs and is articulated in a number of ways.

Intersex and the City published a post that gets at this idea of identity based on affinity. Intersex and The City is a blog that was started in 2009 by an anonymous intersex individual and includes posts and comment discussions. This 2015 post centers interaction with the medical community, and not ‘similar disorders’ as the bonding agent between intersex individuals. The post simultaneously advocates for this identity and produces counter-discourse around any essentialist notions of sex and sex variance. The post is titled “I is For Identity Politics” and ends with the following:

The intersex movement is a great example of identity politics. Removed from all sociopolitical context we are talking about several different medical conditions. Ironically it was our treatment by the medical community that was what gave us common grounds to form an identity. This realization of our shared experience was the consciousness raising event that allowed us to find our voice and started the movement. We have been using these experiences to gain mainstream support for over two decades now. It is likely that if intersex people were hidden, but not operated on, there would be no intersex movement. We would be entirely unknown to the mainstream and would all think we were the only one like us, and that would be tragic. (Intersex & the City, “I”)

The concept of treatment by the medical community as a form of common ground to build an identity on is important in itself. But the author takes this a step further by explaining how this identity has helped people find their voices as individuals and groups. This version of ‘2015 intersex consciousness raising’ works as a tool for survival not only to help intersex individuals realize they are not alone, but also to affect change through group activism. ‘Intersex’ as an identity outside the binary is only necessary because of the already socially constructed binary of sex. This author’s work to embrace a constructed
identity based on affinity helps fight the forces that render intersex bodies invisible to our Dominant Culture’s binary sexual construction.

Bodies Like Ours published two stories that focus on how individuals have been treated by the medical community, specifically in doctor/patient interactions. The first is Julia and her child’s. After Julia was told there was something wrong with her baby she was made to rush to a hospital ten hours away. This is where the story takes off:

We were recommended to a urologist who was the “best”. He said everything we wanted to hear. Fixable, low pain afterwards, not have to stay overnight. Then he sort of slipped in that there could be reduced sensation. Whoa. This is just mentioned in passing?!? No big deal? But we still left intending to have the surgery done in a couple of months. Sooner the better, right? Then I started researching. The urologist had mentioned intersex activist and that they were a little off and don’t listen to them. So of course I went right to them. I gathered many more questions and faxed the urologist my list. He called me back right away with most of the answers. But he couldn’t tell me about the exact procedure as he said everyone is different and he won’t know until he gets in there and that it’s hard to explain over the phone as it’s three-dimensional. Ugh. I didn’t like that. He also compared this HUGE decision with someone else’s body to not buying her a new car when she’s 16. […] I canceled the appointment, claiming to myself I needed more time. I knew I couldn’t go through with it. No way. […] She will have surgery to open the labia for menstruation just before puberty. As for now, she has no need for a vagina. She can make her own decision about her clitoris. We will support whatever decision she makes when she is old enough to fully comprehend the possible consequences. It is her body after all, not mine. (“Julia’s Story”)

This story shows just how difficult it is for parents to navigate the medical system and make decisions for their children’s bodies based on the information they receive from doctors. Especially interesting here is the doctor’s comment about intersex activists being ‘off’ and how parents shouldn’t listen to them. This is starkly different from many other non-intersex related doctor/patient interactions where doctors commonly recommend support groups and community members. This post, while not from an intersex individual, is from a parent who has been greatly impacted by the medical system’s treatment of IS.
Julia says things extremely important for other parents to hear about her child making their own decisions about their body when the time comes.

The second story from Bodies Like Ours is Caitlan’s and comes from an intersex individual, not the parent. Caitlan’s doctor assumed she was a ‘typical’ female and sent her to have her hymen punctured since it was ‘too thick’, in fact, Caitlan was born without a vagina. She writes:

Being born without a vagina is not inherently dangerous. I do not need any surgery or dilation to have a happy sex life. Some people choose to have a vagina made and I support 100% their right to make an informed decision to get one. At this point in my life I am choosing to keep my body the way I was born. I have major problems with the way myself and other wimmin with MRKH are treated. No thought is given to our psychological state after being diagnosed–only to making us “normal” wimmin with vaginas that we can use in heterosexual sex. I have read so many horrible stories about MRKH wimmin’s experiences with doctors. And I totally relate to them. I should not have been sent for surgery before my doctor made sure that I had a hymen. This could have saved the physical and possibly some of the emotional trauma of my diagnosis. The first “specialist” I saw should have respected my wishes and given me information about the various treatments and let me decide for myself if I was old enough to handle surgery or dilation.

I am still struggling with accepting myself and my body. Don’t get me wrong, some days I wish that I had been born with a vagina and I wish that I didn’t have to deal with all of this shit. However, the thing that hurts me the most and threatens my self-esteem the most is other people’s attitudes and ignorance. (“Caitlan’s Story”)

Caitlan spells out the issues she has with the way she and others have been treated and why certain practices are unacceptable. She emphasizes something we see again and again in OICs' counter-discourse: the call for doctors to honor individuals’ bodily autonomy, to wait to perform surgery when possible, to avoid reinforcing the language of ‘fixing’ bodies that don’t fit the binary, and finally, to honor patient’s own requests and wishes, whatever those may be.

Each story that is told in an OIC is unique. There are many differences in experience and many differences of opinions in how the medical community should engage intersex
individuals. But what is less ambiguous in the counter-discourse of OICs is the idea that not enough talking is happening between doctors and intersex activists and individuals. From the conflation of different types of anatomy and experience under the DSD’s methods of chromosomal primacy, to the constant message intersex individuals receive that says they are ‘disordered’, there is oversimplification going on that hurts and erases people and their experiences. Without multiple stories, opinions, and types of discourse — such as all the ways ‘(fill in the blank) surgeries’ are talked about on OICs — the hegemonic medical discourse is not questioned. Through online community building, the truth can be redefined for intersex individuals, families, doctors, and the public.

When doctors tell intersex individuals they are ‘disordered’ it can be incredibly traumatizing. So when an intersex individual is watching television and sees a fictional doctor tell a fictional patient the same thing, it can be not only a problematic representation of IS, but extremely triggering. How OICs produce counter-discourse around representations of IS in popular culture is where I turn to next.
Hi,

I'm looking for some good books on Intersex [...] everyone knows about Middlesex but are there other/better ones?

Thanks!
Jessie (Susan’s Place)

The way representations of IS affect intersex individuals is like a boomerang. A certain depiction of intersexuality — say Cal in Middlesex — could affect intersex individuals who read the book for many different reasons, such as triggering certain memories (good or bad), eliciting a feeling that their existence is being conflated with incest, or causing them to wish they could have run away from genital surgery or to be grateful that they had. The depiction of Cal could also affect non-intersex people who read the book, giving them information on 5-α reductase deficiency syndrome, ‘ambiguous genitalia,’ and the very term ‘intersex.’ Then, the boomerang comes back. And intersex individuals are affected again when non-intersex people base their ideas about what it ‘means’ to be intersex off of the character, and create new discourse about IS with all their ‘new knowledge’. Too often, intersex people and voices are made invisible, but even when there are representations of intersexuality, it’s an upward battle.
3.1 Intersex in *Middlesex*

The sense I get from my own research is that *Middlesex* is currently the most contested book in intersex communities. In literary circles the differences in opinion often reside in what people perceive the moral responsibility of an author of fiction to be. Viola Amato describes this in an intersex context in the following way:

The question how ‘authentic’ a literary representation of intersex lives should be becomes, in the face of social, political and legal discrimination against intersex persons, a question of fair representation. While one might or might not agree whether an author has a moral obligation to tell a particular story about intersex, harmful (mis)representations of a group of people that is constantly at danger to be culturally and physically erased, mutilated, or disowned, who are subjected to violations, have necessarily an ethical dimension (Amato, 200).

With the stakes so high, it is understandable that among intersex individuals and communities disagreements over the book are less about whether Eugenides had an obligation to represent intersexuality in a fair way, and more about whether he did or not. This begs the question: how do we define ‘fair representation’? A distinction should be made between an intersex voice and an intersex representation. Whenever a non-intersex person writes about intersexuality they can only achieve the latter: they will not produce an intersex voice, they will always be constructing an outsiders’ version of an intersex story. In general, I advocate for more intersex voices and fewer productions of intersex representations by third parties, but both are necessary if IS visibility is going to be raised. Once a representation exists its ‘fairness’ is up for debate and the ‘fairness’ of *Middlesex* as a representation of intersex is discussed heavily in OICs.

The novel centers a nuanced intersex character, a plus for intersex activism since most hegemonic discourse silences intersex individuals’ very existence. However, Jeffery Eugenides’s frequent use of the historically derogative term ‘hermaphrodite’ in place of
'intersex’, his questionable research, including no interviews, for the novel, and his defensive and dismissive responses to criticisms from intersex activists leave much to be desired (Mullan). Within queer literary criticism (not the same as intersex communities though often aligned) the novel has been called “a book that endorses a narrative of heteronomativity and ethnic assimilation” (Lee, 199). What I illustrate below is only a cross section of innumerable opinions about Eugenides’s novel: examples, among many, of individuals complicating narratives surrounding representations of intersex bodies like theirs and thereby participating in counter-discourse.

In 2004 The Intersex Society of North America posted the following review of *Middlesex*:

Yes, it is fiction, but I cannot imagine a more authentic and sensitive voice. Because our interactions usually take place in limited and structured settings such as offices and hospitals, pediatricians have scant opportunity to learn how our young patients think. One way to sharpen our awareness is to listen to children’s voices as they are expressed in books. In *Middlesex*, the voice is loud and clear. The moral of the story is, doctors need to learn to think of people with intersex conditions as people, not conditions or problems. (Bergman)

What I want to draw our attention to here (and in the following examples) is not the ‘thumbs up’ or ‘thumbs down’ response an individual or group gives to the novel, but the nuance they bring. For instance, Bergman starts by resisting the assumption that fiction is not a useful medium for telling intersex stories since it is ‘inauthentic’. Presumably the assumption that fiction is ‘inauthentic’ comes from conflating physical, recorded, reality, with authenticity. Bergman pushes against this conflation with the image of an authentic fictional voice, presumably one that is relatable, at least as a person if not also an intersex person.
What Bergman points to in Eugenides’s writing — ‘authenticity’ and ‘sensitivity’ — reveals what they value in representations of IS, and presumably what they feel is missing in other representations of intersex individuals. These ideas are furthered with Bergman’s explanation of the lack of listening space structured into medical settings for doctors to hear intersex individual’s thoughts, and the possibility books have to break this silence. The review’s ‘moral’ resounds across OICs: people are not conditions, people are not genitals, people are not sexes, people are not disorders; people are people.

Five years later, a contributor on the blog “Intersex and the City” took a slightly more critical and detailed approach, though they too appreciated aspects similar to the ones Bergman highlighted. I include their response to Middlesex in full:

the problem with Middlesex
For my first post after introducing myself I wanted to talk about the book that helped make intersexuality more well known. That book is Middlesex by Jeffery Eugenides. I want to preface this by saying that I very much enjoyed reading Middlesex, it is very intelligent and well written, and I am glad that it has helped bring intersex issues into the public eye. That being said, the problem is there are some inaccuracies in Middlesex that need to be addressed because they could cause intersexuals and their families to be misunderstood. This should set the record straight and help you to avoid any major faux pas in dealing with intersexuals.

INCEST - In Middlesex Cal's grandparents are siblings and his parents are second cousins. This incest lead to Cal's birth with 5 Alpha Reductase, an intersex condition. The truth is the chances of having a child with an intersex condition, including 5 Alpha Reductase, are not increased greatly by incest. The birth of an intersexed child in no way means that the family is incestuous.

SEX CHANGES - Cal was raised female, but chose later to live as male. While some intersexuals choose to change genders from the one their parents assigned them at birth, statistically most do not do this (same as people who were born entirely male or female). If you are lucky enough to meet an intesexual, you should not assume they transitioned, because most likely they did not. Odds are they have lived that way their entire life.

SURGERY - It is a very sad fact but in America almost all intersexed babies, including me, are forced to undergo genital "normalization" surgery and are made to look more female,
usually with terrible outcome in terms of sensation and functioning. Even worse, they are lied to by doctors and parents to promote "normal" gender identity formation. In Middlesex, Cal is lucky enough to have his condition undetected by an incompetent doctor. He later finds out about his condition by his own research and runs away before they can operate. This is how his experience differs from pretty much every other intersexual. Never assume that an intersexual has different, special, in-between parts, most of us wish we still did. Also, never ask us about this, it is an incredibly painful topic. (Intersex & the City, “The Problem”)

From the beginning this review has a different tone. Instead of ‘authentic’ and ‘sensitive’ the novel is ‘intelligent’ and ‘well written’. While all positive attributes, the former indicate an emotional level that the latter two descriptors don’t bring to mind. The use of second person pronouns brings up the question of audience: most OIC posts are directed either at other intersex individuals or the world at large, but this one could be geared specifically at a non-intersex audience (or possibly as a resource for intersex individuals to point their non-intersex friends and family to). Efforts to fight stereotypes and correct simplistic and erroneous assumptions about intersex individuals, which is presumably the aim of this review, occur both within OICs and between intersex and non-intersex groups. From family members to allies, to non-intersex people with opinions, to the multiplicity of opinion within the intersex community itself, discourse around IS does not follow a linear trajectory and instead counter-discourse published on OICs can address a variety of audiences and be recognized by different people and groups in a variety of ways.

This author wants to address the stereotypes that might arise out of Middlesex and complicate some of the points the novel seems to make. They commend the novel for bringing intersex issues into the public eye but are worried about some ‘inaccuracies.’ This is where we begin to see that what this author implies is just as important as what they say straight out. The author says that the inaccuracies in Middlesex could lead a reader to enact
‘major faux pas’ when interacting with intersex individuals. Superficially, this doesn’t sound of dire importance; faux pas are a matter of etiquette, embarrassing for the producer. But the author is clearly concerned about the effect these faux pas would have on intersex individuals, given that they wrote a whole article on how to avoid them. ‘Major faux pas’ can now be seen as a euphemism, signifying social interactions of importance to intersex individuals’ emotional well-being. Intersex activism revolves around recognition of intersexuality’s existence and bodily autonomy. If one of the major representations of intersexuality available to the public can lead readers to further stigmatize and misunderstand people, that is a major problem, not least because it has the potential to affect the emotional well-being of intersex people themselves.

‘Incest’, ‘sex changes’, and ‘surgery’ are the three ‘inaccuracies’ this author writes about. In the first case the author is worried readers will walk away assuming intersexuality is a result of incest, which introduces moral considerations not inherent in intersexuality itself. This was the first of the listed inaccuracies and implicitly this signals the level of concern the author has that linking intersexuality and incest will further stigmatize individuals. There is a link here between this review and the last one, even if they had different conclusions: stigmatization of intersex individuals is a huge problem and books can have an impact on this.

Middlesex, in particular, was an impactful book, receiving the Pulitzer Prize and getting chosen for Oprah’s book club list; the book touched many people. The New York Review of Books published a lengthy review of Middlesex that likewise reached many

---

12 I use ‘sex changes’ here to stay consistent to the author’s language. However, it should be noted that the term is outdated and problematic for a number of reasons, including conflating ‘transitioning’ with genital surgery. The phrase is also inaccurate to describe Middlesex since Cal never undergoes any type of surgery, his gender expression changes when he ‘realizes’ he was ‘male all along.’
people titled ‘Mighty Hermaphrodite.’ In addition to using the derogatory term ‘hermaphrodite’ throughout, the article over simplifies IS with statements like, “One part [of the book] has to do with hermaphrodites—with Callie’s condition, and how she comes to discover what she really is.” (Mendelsohn). Even with nuanced intersex characters, offensive reviews can further push hegemonic discourse to dehumanizing language of ‘what’ intersex individuals are (think: people). This power is true not only of books but all cultural productions, especially those within the realm of popular culture. Counter-discourse that is published online is a vital part of complicating the powerful trends of hegemonic oversimplification.

‘Sex changes’ and ‘surgery’ are the other two inaccuracies this author brings up, both of which are noted in ISNA’s mission statement. The statement reads, “Intersexuality is primarily a problem of stigma and trauma, not gender” and “Parents’ distress must not be treated by surgery on the child” (Intersex Society). All intersex individuals and groups do not agree on the place of gender identity in intersex discourse. ISNA claims that ‘intersexuality is primarily not a problem of gender’ but for activists such as Hida Viloria, their gender and how they express it are of upmost importance and relevance to conversations about intersexuality. While it is important not to conflate sex and gender, they are linked in our society and intersex individuals are forced to consider what gender they identify with and how they want their bodies to be part of their gender. Different intersex individuals, just like different non-intersex individuals, will have different takes on this, and intersex individuals will have different takes on whether gender is a ‘primary problem’ for them in identifying as intersex.
The inaccuracy of ‘sex changes’ this author brings up is ultimately one of oversimplification. Some intersex individuals transition, others do not, and some use different words to describe the processes they have undergone by choice and involuntarily regarding gender. What Eugenides does, however is depict Cal’s thinking process as quite straightforward: once he finds out he has XY chromosomes he ‘realizes he’s male’ and, as our review author notes, chooses to live this way. What our review author indicates here is that by assuming this was the way events had to go, *Middlesex* contributes to the hegemonic assumption that intersex individuals have an underlying male or female sex and if the parents get it right at birth they will be raised ‘correctly’ and if they don’t, the individual will transition later, when in actuality it is much more complicated.

Surgery is generally accepted as the number one issue facing intersex communities at present, and it is the main focus of activism on and offline. Regardless of one’s feelings about authorial social responsibility, it is undeniable that while *Middlesex* has brought intersex issues into the public eye, surgery is not one of those issues, or if it is, this is only because intersex activists have forced it onto the conversational stage that *Middlesex* has helped to expand.

By enabling Cal to literally run away from genital surgery, Eugenides obscures the prevalence of nonconsensual surgery in the intersex community. Cal is able to escape due to his age and resources, but other intersex individuals, especially those who were operated on as infants, do not have these privileges. The novel depicts an agency that does not usually exist in surgical situations. Eugenides arguably puts the onus of responsibility on intersex individuals themselves for their own surgery because they did not too ‘run away.’ The review author ends their post with is an excellent example of why OIC counter-
discourse around depictions of intersex surgery in popular culture is so important: “Never assume that an intersexual has different, special, in-between parts, most of us wish we still did. Also, never ask us about this, it is an incredibly painful topic.” (Intersex & the City, “The Problem”). By complicating *Middlesex*’s portrayal of intersex surgery and calling on people to recognize the pain of the subject of surgery for intersex individuals, this author works to redefine both the ‘truth’ of intersex surgery stories and the ‘truth’ of what is acceptable to ask an intersex individual about.

The final example of a response to *Middlesex* has less to do with the content of the book itself and more to do with the aftermath of its publication: another main consideration when looking at cultural productions and their effects on popular culture. This response was published in Thea Hillman’s memoir, *Intersex: For Lack of a Better Word*. It is a response that has been referenced in OICs and I quote the original from Hillman, a fairly well known Intersex and queer activist. It is important to note that Hillman is White and has a much wider audience than most other intersex people and certainly more than most intersex People of Color. While the struggle she faces getting her voice heard compared to Eugenides’s is extremely important, we should be aware that her voice still attracts a great deal of attention. Hillman writes:

I couldn’t begin to explain what it had been like when *Middlesex* was first published. How I had been in touch with the editor of *The New York Times* op-ed page; how, when the book came out, I spent every minute for a week trying to write the perfect op-ed about the intersex response to *Middlesex*; and how, after writing nine versions, consulting with famous writers and journalists about the piece, and submitting two to this op-ed editor, the piece didn’t get published […] I started crying […] because Eugenides, who’d never actually talked to an intersex person before he published the book, had access to so many millions of people, and that I couldn’t get an op-ed published. Crying because I sat there while he read from his book and while he answered questions as if he were an expert, as if he knew about intersex, and I sat there, an expert, silent and fuming and hot with shame as he called me and people I love hermaphrodites. (Hillman, 24)
Hillman’s response to *Middlesex* and Eugenides’s engagement with popular culture and intersex communities post-publication brings Amato’s ‘ethical dimension’ into sharp focus. When a piece of fiction, intimately wrapped up in a certain affinity group, is published, taken in, and consistently referenced by popular culture — such as *Middlesex*’s Pulitzer Prize and its places on the New York Times bestseller and Oprah’s book club lists — this can have severe ramifications on the affinity group in question. This is especially dangerous if the author does not understand the potential for harm and they are still involved with publically talking about their work and the issues in it. What Hillman points to isn’t that Eugenides did a terrible job representing an intersex person — though she does believe he could have done better. Instead, she believes that after publication he put himself in a position of authority that should have gone to those with expertise, and especially to intersex activists. We can see Eugenides’s inability to recognize this problem and engage these communities as ‘an injustice of speaking for others’. By pointing this out, critiquing ideas of expertise, platforms, influence, and power, Hillman engages in counter-discourse, which is taken up and renewed online any time an individual gets on a forum and references Thea Hillman’s response to *Middlesex*.

3.2 (Mis)representations of Intersex on Television

The television representations of intersexuality I described in Chapter 1 from the shows *Friends* and *House* are less explorations of the difficult positions society forces intersex individuals into, and more throwaway plot devices. Neither *Friends* nor *House* does much to investigate the complexity and depth of intersex issues in the United States. But they are both extremely popular television series so unfortunately many more people in
the United States and around the world will be exposed to these two episodes than any intersex activist’s work. In this section I draw from OICs as well as the writing of Phoebe Hart — an intersex activist, writer, and filmmaker — to illustrate responses individuals have had to these two episodes — Friends’ “The One With the Rumor” and House’s “Skin Deep”, and the way they use IS to provoke laughter from the audience.

A member of the ISNA wrote the following in response to NBC’s airing of “The One With the Rumor”: “Intersex youth was the butt of a joke in the thanksgiving episode (Nov. 22, 2001) of NBC’s popular sit-com, Friends, and intersex activists and allies are talking to NBC to address how hurtful and offensive it was to us.” (“NBC’s”) Attached to the post was a letter another member of ISNA wrote to NBC, I have included it here in full.

Dear NBC and producers of "Friends",
Your Thanksgiving episode (the one featuring Brad Pitt) was ignorant, insulting, degrading, and absolutely unprofessional. Was any research done before creating the script? Did the writers have any understanding of the reality of intersex people before thinking up the "hermaphrodite cheerleader from Long Island" rumour?
Every day in this country, children are born with "ambiguous" genitalia. And every day, at least five of those children are subjected without their consent to harmful and medically unnecessary surgeries recommended by doctors who want the children to fit their definition of "normal". Their physical and mental health and future sexual pleasure are completely disregarded.
In this environment, you created a "joke" in which Rachel (Jennifer Aniston) was mocked by her entire high school for being born with "both male and female reproductive parts", and had her parents "flip a coin" to decide to raise her as a girl, even though she had "the hint of a penis". How horrifyingly similar to intersex youths’ history. How disgustingly close to what actually happens to innocent children every day.
But to you, it's comedy.
Maybe you didn't know. Maybe at NBC it's standard to mock and humiliate groups of people without any sort of education in regards to the characters created. How completely repulsive.
You have offended one of your biggest fans. You have the potential to fix it. Please visit the Intersex Society of North America (ISNA)'s website: http://www.isna.org. While there you can educate yourself and then understand how insensitive this episode was. When the new episodes start showing again, I strongly suggest they air accompanied with a much needed apology to intersex people. (“NBC’s”)

83
As the blurb from the ISNA member and the letter suggest, there is little ambiguous about NBC’s horrifyingly damaging work representing intersexuality to millions of people. The response letter is an excellent example of OIC counter-discourse. It takes the oppressive dominant discourse represented by *Friends* — that intersex variations are funny, worthy of mockery, freakish, and not something ‘popular’ people would ever have experience with — and fights it. The response combats assumptions of humor with terms like ‘repulsive.’ It complicates what is an acceptable way to represent people and the process of screenwriting by questioning NBC’s research methods and their professional integrity. It highlights the responsibility of a platform after doing something damaging by demanding a public apology. All of these moves come from a position of being directly affected by the offensive discourse and illustrate productive counter-discourse.

Emi Koyama, the Director of ‘Intersex Initiative’ — a national activist and advocacy organization founded in 2001 — also wrote a response to “The One With the Rumor” that gets at similar ideas to the letter published by ISNA. Koyama posted it on the Intersex Initiative blog with the title “NBC’s Friends: Is Invisiblization Better than Simply Being Invisible?” It is here in full:

Some people have suggested to me that being used as the butt of the joke is better than no publicity at all, especially when so few people are even aware that intersex people exist. But just how far can we take this conventional wisdom?

The thanksgiving episode (Nov. 22, 2001) of NBC’s popular sitcom *Friends* featured a story revolving around a high school rumor other students spread about Rachel, one of the main characters. The rumor suggested that she was born with "both male and female reproductive parts," and her parents "flipped a coin" before deciding to raise her as a girl. However, she still had a "hit of a penis," the rumor went. The rest of the show consisted of everyone making fun of her, calling her "the hermaphrodite cheerleader from Long Island", staring at her crotch asking for "proof" that the rumor wasn't true, and Rachel crying "you told people that I was half and half!" At the end, another character resolves the situation by declaring "even with that rumour, you were the most popular girl in school," as if it would be so surprising.
While nobody is actually born with two complete sets of genitals, about one in 2,000 babies are born with reproductive organs that are visibly different from most boys or girls. This condition is called intersex; "hermaphrodite" is an older, misleadiing term. The standard "treatment" for intersex conditions involves surgeries that modify the appearance of the genital so as to make it conform to what is considered socially acceptable, although they generally do not address any particular health issues. There is a growing movement among intersex people and allies to halt these medically unnecessary surgeries until the child is old enough to decide for herself or himself whether or not such a surgery would be desirable. The "flipping a coin" method, followed by the surgery, is very close to what intersex children actually go through when they are found to have a "hint of a penis." However, this very sensitive topic is treated not as a real-life experience, but simply as a bad rumor—something that is not true, further mythologizing the existence of intersex people. I wonder which is better or worse: being explicitly made invisible inside the show, or being just plain invisible in the first place? (Koyama)

Koyama is grappling with really difficult questions. Is it better to have your experiences erased by a representation of IS that makes a joke out of the concept of sex variability and silences intersex voices? Is it better for the entire concept of sex variation and intersex existence to be invisible? Does what is ‘better’ even matter when all the options seem terrible? Intersex individuals are forced into positions such as these often — where they have to wonder which type of erasure is really the worse evil. By drawing attention to the depth and complexity of the damage representations such as NBC’s cause, Koyana partakes in a form of counter-discourse that seeks to do more than redefine the truth. Koyana’s piece forces us to recognize the agony of having to wonder if ‘presenting the truth’ is even a worthwhile goal, or whether hiding would be less traumatic.

Unfortunately, Friends isn’t the only show that has harmfully misrepresented intersexuality. After watching House’s “Skin Deep” April Herndon posted on their blog (which is not longer online) and the post ended up being cross-shared by ISNA. It is a beautiful example of the courage many are forced to enact by being alive and continue to
embody by participating in OIC counter-discourse. The post, slightly abridged, is as follows:

Last night I was shocked and horrified as I watched the plot of Fox’s popular medical drama, “House,” unfold. Fans of the show stay tuned each week to see Dr. Gregory House take on medical mysteries with a sarcastic wit and his own special personality. Last night’s episode, entitled “Skin Deep,” proved that much more is flawed about this show than the protagonist. It was, without a doubt, one of the most offensive and hurtful portrayals of people with intersex conditions that I’ve ever seen. 

 [...] When House enters the hospital room to tell the young supermodel and her father what the team has found, he immediately questions the young woman’s sex identity, calling her “him” and announcing that he will schedule “him” for surgery. In what appeared to be an incredibly bungled and inaccurate explanation of AIS, House tells the young woman and her father that she is really a man because her DNA says so. He refers to the young woman as a male pseudohermaphrodite and callously comments that the ultimate woman (the supermodel type) is really a man. When the young woman becomes upset and protests, crying out that it is a woman and ripping her hospital gown off to show her body to the doctor as proof, House quips that he’s going to “cut her balls off” and then she’ll be fine. In a final offensive twist, House tells the father that he supposes knowing his daughter is really a man will keep him from sexually abusing his daughter again because doing so would now be “gross” and would mean the father was a “homo.”

From the use of the supermodel stereotype to represent a woman with AIS, to the backward assumption that chromosomes reveal the “truth” about sex, to the refusal to listen to the young woman when she clearly states that she is female, this episode mocks both people with Disorders of Sex Development and the work that the intersex community has done to end shame. The frequency of Disorders of Sex Development is grossly under-estimated in the program at one in 150,000 (one in 1,500 is a more accurate frequency). Dr. House also claimed, inaccurately, that ovaries differentiate into testes. And, of course, there’s also the trivialization of sexual abuse and the homophobia inherent in House’s comments about why the father won’t abuse his daughter again. Frankly, the episode was so flawed that I can’t even begin to address all its sins in this blog.

[Name erased for privacy reasons] happens to be a woman with Complete Androgen Insensitivity Syndrome, the condition likely referenced in the “Skin Deep” episode of House. [Blank] found this program particularly disturbing and states “My biggest fear is that some poor gal with Androgen Insensitivity Syndrome or a similar condition is going to watch this program and be profoundly damaged as a result, wrapping herself in a shroud of shame, avoiding medical care and the excellent peer support currently available. Shame on the producers of this show and medical consultant/writers including David Foster MD for not only being mean-spirited but squandering a golden opportunity to inform.”

[...] Please take a moment and post on the message boards or send an email. (Herndon)
There is a lot going on in Herndon’s piece but a few key elements should be parsed out. First, Herndon notes the effect of being surprised by a hurtful misrepresentation of IS. They ‘watched the plot of the episode unfold’ and were ‘shocked and horrified’: presumably the episode did not provide the escapist unwind time evening television is famous for, and in fact was very painful to be surprised by. The potential to catch an intersex individual off-guard, and/or trigger them, is one of the first dangers at stake with representations of IS in pop culture.\footnote{It would be a stretch to assume intersex individuals are always on high alert for misrepresentations of IS, given that intersexuality is usually so thoroughly erased from popular culture.}

Herndon goes on to explain how the show’s medical explanation of intersexuality and particularly AIS was flawed, correcting the numbers and explanation of gonadal development. This is a form of redefining the medical truth that came up a lot in chapter two, only this time, it isn’t even the real medical establishment producing problematic medical discourse, it is FOX and ironically the medical discourse FOX produces about IS will probably reach more people than the discourse most physicians create.

Herndon ends with a quote from a woman with AIS and with a call to continue the conversation, among OICs and with FOX. The quote indicates how painful and damaging the episode could be for a young person with AIS. It advocates for internal intersex support communities and peer groups, presumably on and offline, that are currently available as ways to resist dominant discourse such as that represented in the episode of House. Advocating engagement — whether it is between intersex individuals, or with organizations that are causing harm, or just the public — pushes back against erasure tactics and is a prevalent form of counter-discourse in OICs.
Phoebe Hart published her work “Writing Characters With Intersex Variations For Television” through the Journal of Screenwriting and I have seen the article surface throughout OICs. Phoebe is a brilliant intersex activist and her analysis of this *House* episode is incredibly relevant. Phoebe’s work deals intimately with representations of IS in film and television and I would be amiss to exclude her work. The quote picks up when Hart is talking about House’s line that Alex’s ‘outburst’ is just the cancer talking and ‘he’ will be fine once ‘his’ balls are cut off.

Perhaps, rather than the ‘cancer talking’, Alex’s anger is the result of an infuriating encounter with the medical fraternity. Aside from the medical inaccuracies of the script itself (wildly under-estimating the frequency of the variation), the narrative suggests that the intersexed woman has no claim to femininity due solely to her chromosomes and gonads. The intersex stereotype re-emerges, the one of the AIS woman as the ‘ultimate woman’ being ‘a man’. At the initial broadcast of the episode in the United States there was a strong response posted through the Intersex Society of North America (ISNA), a peak body at the time for intersex support and advocacy, which considered the episode ‘so flawed’ and ‘one of the most offensive and hurtful portrayals of people with intersex conditions’ (Herndon 2006). Tony Briffa, former President of the Androgen Insensitivity Syndrome Support Group (Australia) described the episode more succinctly in a personal interview on 13 June, 2008, as ‘total garbage’. (Hart)

Hart engages with a specific line here to counter the television doctor’s authority in saying what the cause of an emotional response is. The term ‘infuriating encounter with the medical fraternity’ brings how much authority and respect the medical establishment should get into question, especially if they mis-gender and offend patients. ‘Infuriating encounters’ are far too common for intersex individuals and using the term ‘fraternity’ elicits images of the patriarchy and ‘old boys clubs’ imposing norms onto others. The fictional medical world of the show may be even worse at treating intersex patients than the medical system in the United States at the time. The episode undoubtedly left viewers with problematic
ideas about intersex individuals, their treatment by doctors, and their autonomy both to identify as they wish and also over their own bodies.

Hart’s work to point out inaccuracies, offensive language, and problematic ideas of ‘womanhood’ is yet another example of the complexity of discourse that is produced when intersex individuals speak against misrepresentations of IS and hegemonic oversimplifications. Eugenides, NBC, and FOX all clearly produced representations of IS that had their problems, but what happens when cultural productions are crowd written and edited? The Wikipedia page on ‘Intersex’ is not like any other form of discourse that I have found on the Internet — given it’s position of high readership and ability to be crowd edited at any time — and as such, it occupies a lone island in the world of OIC counter-discourse.

3.3 The Power of Wikipedia

The Wikipedia article on ‘Intersex’ is a very different type of manifestation of pop culture from those we have considered so far. It requires an ‘opting in’ that the intersex content found on Friends or House, or even Eugenides’s novel, does not. One is less likely to stumble across the Wikipedia page for Intersex, than to be watching NBC or FOX or grabbing a book off the best-seller shelf and run into a reference. This being said, the effort it takes to get to the Wikipedia page isn’t high — a three second search of ‘intersex’ would do it. This difference in medium — from television shows and novels to the ‘online free encyclopedia’ — is one we should value. Not only does it provide an easy access education resource, it adds depth to our understanding of ‘manifestations of popular culture’ by being crowd created and not requiring the backing of a publishing company or television network.
Figure 3.1 shows the most common words (the larger the word the more times it is used) in the Wikipedia page for ‘Intersex’ (“Intersex” Wikipedia).

The first topic listed on the page after ‘definitions’ and ‘history’ is “human rights and legal issues” (Figure 3.2) and ‘rights’ is one of the most used words on the entire page (Figure 3.1). This is significant as ‘intersex rights’ is an issue that the other popular culture representations of IS completely glossed over, if didn’t further violate. This indicates a level of humanity and recognition of struggle that is more reminiscent of OICs’ counter-discourse than popular culture’s often damaging, or at the very least controversial, portrayals of intersex individuals. For this reason I propose we see the Wikipedia page as a hybrid. It is a manifestation of popular culture and dominant narratives, which is simultaneously influenced by intersex individuals and consistently being molded to fit broader intersex and popular culture agendas.
Figure 3.2 shows the broad list of topics the Wikipedia page on ‘Intersex’ covers (“Intersex” Wikipedia).
“So the message is that if you’re intersex, make sure you’re born in Malta. Personally, I can’t understand why an intersex person would allow themselves to be born anywhere else.

Kidding aside, this is a great start, but other countries need to adopt these measures as well. You can’t choose where you’re born, and Malta is really a drop in the bucket.” (Susan’s Place)

This comment from ‘Susan’s Place’ — a trans and intersex online discussion board — uses humor to weave together both the importance of looking at legal decisions made in other countries, due to the effects they can have on the rest of the world, and the simplicity of only celebrating them or getting too wrapped up with one ‘drop in the bucket’. The final section of this project looks at how intersex individuals and communities have textually interacted with: an intersex discrimination case within the United States, a legal declaration from outside the U.S., and a U.S. constitutional case of infantile surgery after the fact, and how these interactions constitute counter-discourse.

Compared to OICs’ counter-discourse engaging medical discourse and representations of IS in popular culture, OIC engagement with legal issues is difficult to find. I think this is the case for a number of reasons. Firstly, ‘intersex’ is not a protected group; there are no laws or policies that I have found that address intersex people specifically. This makes the likelihood of an intersex person bringing a suit (related to their
intersexuality) to court less likely. In addition, the push to change policies and laws to include intersex individuals is mostly within intersex activist circles, and like many elements of IS, rendered invisible by the hegemonic binary sex presumption. This makes it less likely that a member of an OIC would hear about something from the legal landscape and respond to it, than a specific experience with a doctor, or a popular television episode. The inaccessibility of legal language makes it extremely difficult for individuals who would otherwise engage with legal discourse to participate. The patchiness of my sourcing speaks to how legal frameworks require specialized knowledge and are difficult to navigate.

Presumably, one of the largest barriers to intersex individuals seeking legal counsel is money and not knowing where to start. Sam, an intersex follower of Intersex and the City posted the following as a comment:

We need lists of lawyers willing to take intersex clients from different countries. We need someone to do research on lawyers and doctors who would be willing to help on more than one case. unfortunately, unless a rich intersex person initiates court actions this genocidal mutilation will continue. I've had doctors LAUGH at me in the office when I asked for a specialist. More than one! (Intersex & the City, “Legality”)

When looking at OIC counter-discourse related to the legal system gaps emerge. What isn’t said and who isn’t talking, is at least as important as what and who is. Sam’s comment gestures toward the causes of these gaps: a lack of resources, no class action lawsuit for discourse to rally around, a fear of rejection. Susan’s Place, Intersex Talk, and Transgender Pulse have very little, if any, posts about legal discourse around IS; many people are not taking part in these conversations. The difficulty of finding statements and stories shows the erasure legal forms of discourse cause when it comes to researching intersex perspectives.
4.1 interACT and Online Legal Intersex Activism

Earlier, I included a quote of Pidgeon Pagonis’s that states, “Every day, there are brand new activist projects and resources popping up all over the world. Intersex people across the globe are doing the necessary work to build this brighter future for our children, and yours, by lifting up our stories” (Pagonis, “First”). The focus of this project has been OICs, where individuals can learn and tell their stories to people who will listen, publishing their work and producing counter-discourse. But there are many types of activist projects and resources that, while still undoubtedly producing counter-discourse, are not solely online platforms for individuals to tell their stories and instead have other missions.

‘interACT’ is such a platform and I would be amiss to talk about intersex counter-discourse with and within the legal system without mentioning them.

interAct’s mission statement reads as follows: “interACT uses innovative legal and other strategies, to advocate for the human rights of children born with intersex traits.” (“Mission Statement”). interACT centers intersex youth, and especially intersex youth of color in their legal work. interACT works to protect intersex youth in court, to influence policy decisions, and to conduct research on issues put forth by various intersex communities. While the focus of this project is on online blogs and forums and the platforms they provide for individuals to engage in counter-discourse, it is important to remember the intersex activist world is much broader. Other intersex activist organizations intersect with OICs’ self-publications at many turns, such as the ways interACT fills access gaps created by the inaccessible legal landscape.
4.2 Intersex Discrimination: Wilma Wood v. C.G. Studio

Like many things that happen to and within intersex communities, the Wilma Wood case\textsuperscript{14} did not receive much media attention. But individuals in various OICs were paying attention, especially given the power the case had to establish critical precedent. The following response takes the case and legal language and makes it accessible. It puts legal discourse in perspective of the author’s own intersex existence and advocates for hope, thereby working to change the script of the legal decision — which contributed to intersex erasure by stating intersex bodies are not protected since they are not included in the ‘traditional’ understanding of sex (“Employment Discrimination”). The post was published on Intersex and the City in 2014 and here in full:

D is for Discrimination

Today D is for discrimination. In most countries intersex people are not a legally protected class against discrimination. Wikipedia defines discrimination as “action that denies social participation or human rights to categories of people based on prejudice.” Intersex is not well known or understood by the general populace. As such we are not usually discriminated against for being intersex, but for being confused with transgender or gay people. The methods of discrimination can be big and small and are too many to get into here.

Intersexphobia is a new word that is starting to float around to describe discrimination against intersex people, but as I have said a lot of that comes from confusing us with other groups (if homophobic/transphobic people understood intersex, they would probably discriminate against it as well). I would argue being socially hidden and expected to live binary lives (which happens in many ways, big and small) is the biggest discrimination we face specifically for being intersex.

Most western countries have laws protecting discrimination based on sex and sexual orientation, and a few protect transgender people.

In my home country, the United States, Wood vs. CG Studios is the only case filed for employer discrimination under Title VII of the Civil Rights Act of 1964. In 1987 Wilma Wood claimed her employer, CG Studios, fired her after learning she was intersex and underwent genital surgery prior to her being hired there. The judge ruled that this was not discrimination. Like previous cases involving transgender people, sex was defined as strictly binary with any variance not considered a protected class. Things are looking

\textsuperscript{14} This is the case explained in chapter one where Wood filed suit for discrimination based on sex and the Judge ruled discrimination based on sex only occurs when it is due to being ‘male’ or ‘female’ (“Employment Discrimination”)
up. More cases are interpreting transgender as being cover under Title VII and 17 states have laws specifically protecting transgender people from workplace discrimination, and 14 stated protect them from discrimination at school. Federal law protects transgender people from hate crimes. Most judges would interpret these laws to cover intersex people, but strictly interpreted, they do not. The right to use the public bathroom of the gender you identify as is usually not protected.

Ever since the sexual revolution in the 60’s and 70’s society has slowly become more tolerant of sexual/gender nonconformity. I sincerely believe things are getting better and will continue to do so. The question is how do we speed the process along? I believe the best approach is education. Most discrimination comes from a place of ignorance and fear. By being open about ourselves and friendly to everyone, even those who work against us, we become good ambassadors for the intersex community. The more people who see this will move to our side and the discriminators will become fewer. If you have any ideas of thoughts on this, or other topics to cover, leave me a comment (Intersex & the City, “D”).

The Wilma Wood v. C.G. Studio example shows how cases can be, and have been, used to set legal precedent on how to consider intersex individuals as legal subjects. The author sets up the reference to the case by talking about the invisibility of IS in our Dominant Culture, and how if people understood IS better they would probably have more direct modes of discriminating against intersex individuals. This tactic produces a number of literary effects that are important to consider as tools of counter-discourse.

The author references how our Dominant Culture erases and ignores intersex individuals and how this is one of the largest forms of discrimination they face. This forces the reader to consider invisibility when reading the description of the case. While it is hard to imagine reading about the Wood case and not immediately wondering how intersex individuals are supposed to be represented if their sexed experiences are ignored, this author’s set up makes it impossible. By conditioning the reader in this way, the author undermines the hegemonic way of thinking about law where ‘all citizens are equal.’ Instead, they center for the reader how the two-sex system creates gaps, forcing the reader to consider this when reading the description of the case.
The second way the author conditions the reader is by describing agents of discrimination. When they say ‘if homophobic/transphobic people understood intersex, they would probably discriminate against it as well’, the author brings our attention away from just the systems of discrimination to the people who are behind, enacting, or replicating those systems in extreme ways. Conditioned to be thinking about agents of discrimination, it is difficult to read the short description of the Wood case without wondering how the biases of the people involved factored in. When cases are shrouded in legal language it is hard to parse out important considerations, but the way this author set up their post to condition the reader to be thinking about certain things, is an excellent example of OIC counter-discourse engaging legal language.

The author ends with a call for education and for intersex individuals to be kind and good ‘intersex ambassadors’. While this sounds like it puts the onus on intersex individuals to do more, and condemns intersex activists who get angry at the binary world, it is important to remember that intersex individuals are already the ones doing all the work, our Dominant Culture has done very little in support, and the post undoubtedly assumes most readers will be intersex individuals who want to continue this work.

4.3 Columbia and the Legality of Consent

Counter-discourse around the status of intersex bodies in legal systems often takes the form of quick references to Columbia. Things like ‘this doesn’t happen in Columbia’, or ‘if only the U.S. would follow Columbia’s lead.’ By referencing Columbia as a country who is making great strides for intersex rights, this method of intersex counter-discourse also works against problematic conceptions of ‘progress’ born out of colonialist and

---

15 There are important exceptions, such as the Washington Post article.
imperialist discourses. For example, when intersex individuals center less affluent countries in conversations about intersex rights and progress, most often Columbia, it not only produces counter-discourse on the sex binary but also on what ‘progress’ means and what countries are ‘progressing’ the quickest. An example of such a ‘shout out’ occurs in Figure 4.1, posted by a Canadian organization dedicated to provide safe houses for women, especially trans, intersex, and queer women.

Intersex and the City also has a post about the legality of intersex surgery in different countries, in which they give Columbia’s constitutional court a standing ovation.

The post is as follows, in full:

Legality of Intersex Surgery
Non consensual genital mutilation is ethically abhorrent, this begs the question, is there any grounds to render it illegal?
To drag their misguided surgeon to court for restitution, and perhaps set a legal precedent against genital mutilation is a pipe dream for many intersex activists. The trouble is that it is very much an uphill legal battle. Since intersex surgery is accepted medical procedure, it is not considered malpractice. Also, since the surgery is done on infants, by the time they are mature enough to realize what has happened and speak out, the statute of limitations has long passed. Because of all of these difficulties, it would be hard to find a lawyer to take such a case. It would also be almost impossible to find expert testimony, doctors know the cost, both financially and professionally, of a lawsuit, and will circle the wagons to protect their own. They have been doing this to the intersex community for decades, in spite of a warning by the Yale Law and Policy Review that the conditions for consent are arguably not given.
A favorable legal trend for intersexuals might be starting. In Germany Christiare Volling successfully sued the surgeon who removed her uterus and ovaries without her consent. With a favorable lawsuit seeming highly improbable, there has been some movement to create legislation to change this. An example was an attempt to add intersex to the Federal Prohibition of Female Genital Mutilation Act. So far congress has not taken notice of the issue.
Right now there is only one country in the world that has made intersex surgery illegal, Columbia. They declared that intersexed people are a minority that need special protection against discrimination and harm from their differences. The Colombian Constitutional Court claims that parental consent depends on the urgency of the situation, the invasiveness of the procedure, and the age and autonomy of the child in question. The Colombian model allows parents to consent only if all the risk, and alternatives are made known, and even they have to give consent in writing several times over a period of time (not panicky
decisions), and they cannot consent after the child turns 5. We can only hope that the US will see the wisdom of the Columbia law.” (Intersex & the City, “Legality”)

The author of this post asks a lot of important questions about the legality of intersex surgery and forces the reader to consider how ‘just’ the justice system really is for intersex individuals. Columbia is used here as the turn, the lone star shining in a sea of cynicism and ‘pipe dreams’. The author emphasizes the justification Columbia’s constitutional court used for making these changes: recognizing intersex individuals as ‘a marginalized group who should be protected by the state.’ People have bias, discrimination is everywhere, and unfortunately, too often the legal system perpetuates and exacerbates the problems of society; for intersex individuals a major problem of our dominant society in the U.S. is invisibility, and how IS is ignored in the legal sphere speaks heavily to this invisibility.
4.4 The MC Case

‘Omg omg omg it’s finally over!’ are the six words that start the post that Pidgeon Pagonis shot off to Facebook when the MC decision came out (Figure 4.2). Intersex activists, individuals, and allies have followed the MC case for years, many even participated as witnesses or support for the family (Ghorayshi). In 2015, ‘Transgender/INTERSEX Civil Rights Community’ posted an article from AIClegal.org
saying, “for the first time, a federal court has concluded that a medically unnecessary sex-assignment surgery on a child with an intersex condition could be a violation of the Constitution” (Figure 4.3). The settlement of the case was huge for the intersex community and the celebration around it constitutes a type of counter-discourse in itself.

Figure 4.2 shows Pidgeon Pagonis’s Facebook post following the MC settlement.

Figure 4.3 shows the 2015 post from Transgender/INTERSEX Civil Right Community commenting on the MC case.
A lot of OIC counter-discourse focuses on the traumatizing, physically and psychologically damaging, and heart breaking effects of our Dominant Culture’s discourse on sex. But the $440,000 settlement was a huge win for the intersex community and the online celebration that followed directly fought hegemonic discourse that renders intersex people ‘disordered’, silent, and invisible.

The last intersex voice I quote is Sean Saifa Wall’s, the former president of interACT and an intersex and Black rights activist. An abridged transcript of their response to hearing the news of the MC settlement follows:

I do feel like the precipice of this case sits on the heels if not the shoulders of the organizing and the movement that has been done by both the intersex community as well as the Black community. I’m talking about Black liberation that’s been happening for well over 20 to 30 years and its recent iteration, which is Black Lives Matter. The case is very complicated, you know? He was an intersex child of color, who was adopted by White people who had a really high power legal team behind them. And the Medical University of South Carolina as well as the state really had to, it wasn’t a case that they were gonna sweep under the rug. So I think they were not prepared. I don’t know if they actually acknowledged that what they did was wrong, what they did was a human rights violation but I think it is important, this case is gonna set precedent for intersex organizing in the United States. […] but we can’t get too comfortable (“Intersex Lawsuit”).

Wall went on to thank MC and talk about how much he, as a child, claiming bodily autonomy, and going through the legal process, did for the intersex movement. Wall referenced the ability of MC’s adoptive family to pull resources to make the win happen, which echoes the sentiments of Sam we saw earlier.

The barriers to accessing the legal landscape and producing counter-discourse span from financial burdens, to lack of intersex acknowledgement in the law, to difficult to understand language, to the difficulty of claiming malpractice. But the more Wall, Pidgeon, and the others talk about IS and Blackness, the more interACT helps families win victories like MC’s, the more we cite their work and resist promoting the presumed sex binary, the
less people will be operated on without their consent and erased after the fact. The gaps in OIC counter-discourse around intersex issues in the law, and the difficulty of finding sources, make amplifying the voices that are out there all the more important.
Conclusion:

What Happens When the Internet Changes?

Without the strictly assumed sex binary the affinity group ‘intersex’ wouldn’t necessarily exist. Perhaps there would just be an accepted range of bodies, spectrum of phallus sizes, variety of 46 chromosome types, array of gonadal tissue makeups, and scales of muscle mass, body hair, and hormone levels. Medical and biological research can do their part by maintaining scientific rigor in specificity: instead of talking about ‘male’ and ‘female’ bodies, effort must be made to talk specifically about whichever of the above ranges is being studied, and never, ever, talk about sex without mentioning intersex individuals and the work many of them are forced to do to fight invisibility. The affinity group ‘intersex’ does exist, and they are constantly being operated on without consent by the medical establishment, misrepresented and erased through popular culture, denied representation and rights in the legal realm, and gaslighted by all three.

By understanding OIC counter-discourse as the words intersex individuals publish on online forums to engage dominant discourse about IS and talk about their bodies and experiences on their own terms, academic projects such as this one can begin to center counter-discourse and act as listening and amplifying agents. Major phenomena that we have seen OICs respond to, engage with, and critique include surgery, ‘DSD’ nomenclature, IS in entertainment such as popular television shows, and the legal standings of intersex individuals in the U.S. and across the world.

When medical journals and doctors overwhelmingly use the words ‘disorder’, ‘manage’ ‘DSD’, and ‘treatment,’ it not only reinforces the sexual binary but leads to
overtreatment through unnecessary surgeries and rushed decisions regarding infantile care. It also results in potential psychological damage from the repeated message that ‘your body should look more normal.’ Counter-discourse within OICs engaging medical discourse works to redefine certain ‘truths.’ The ‘truth’ of what treatment is medically necessary for a baby, the ‘truth’ of what body parts are required to a happy, fulfilling life, the ‘truth’ that intersex individuals who were not been operated on as babies wish they had been, the ‘truth’ that chromosomes are the most important factor in determining sex, the ‘truth’ that having a one and a half inch phallus makes a body disordered. Experiences and discourse around experiences are messy and oversimplification is what counter-discourse and the amplification of counter-discourse seek to avoid. But I think it is safe to say most intersex individuals have had some other people’s ‘truths’ imposed on them that they are working to redefine them.

‘The hermaphrodite cheerleader from long island’ sounds like a ‘Goosebumps’ mock horror title and the conflation of horror and humor is often what popular culture turns to when it comes to intersexuality. The Friends episode makes being a ‘hermaphrodite’ seem terrible and impossible, totally erasing the possibility of real (and proud) intersex individuals and voices. The Intersex Initiative article from chapter three complicated conceptions of ‘truth’ when it asked, “which is better or worse: being explicitly made invisible inside the show, or being just plain invisible in the first place?” (Koyama). While it is true that intersex individuals exist, when representations are as bad as this, maybe it could be desirable to have non-intersex individuals remain ignorant. This ties back to another user’s point in chapter four about how if people knew more about IS they would think of more direct ways to discriminate against it, making intersex individuals’ lives
harder and making it more difficult to internally and externally promote acceptance of all bodies. It is not my goal to advocate for continued erasure: only to demonstrate the complexity of OIC counter-discourse surrounding representations of IS in popular culture.

There is less directly analyzable hegemonic discourse around intersexuality in the legal landscape than there is in popular culture or in medical research and treatment. But there are similar oversimplifications. Only two sexes are legally recognized, the law often conflates intersex and trans people, and more often then not, intersex individuals are totally ignored in conversations about bathroom bills and marriage equality. The law erases intersex individuals at multiple turns, but specific methods of counter-discourse help complicate these stories. Questioning the logic of a ruling that says someone cannot be discriminated against based on sex if they are intersex, giving shout outs to other countries that are doing better by their intersex citizens, and celebrating the victories that are won (not to mention using them as motivation), all function as methods of counter-discourse. All these forms of engagement complicate and combat hegemonic discourse to show how the execution of the oversimplifying two-sex system plays out in real (intersex) lives.

OICs are a beautiful example of the Internet’s potential as a platform for empowerment, amplification, and unity. In the top right box of Figure 2.1 a cartoon person is saying “But since the Internet became a thing we’ve been able to connect! We’ve realized there’s LOTS of us around! And we’re no longer isolated through the shame of medical diagnosis.” This is of course a simplified version of the situation, but it does show the power having an online community can have; thankfully, OICs appear to be here to stay.
The research presented throughout this work was limited in scope. There is much more published work online from intersex individuals and groups that engage in literary methods to counter hegemonic discourse and the ramifications of it. As the social manifestations of technology continue to grow, discourse and counter-discourse will continue to change and these platforms should be recognized as literary spaces for organizing, publishing, and thought exchange.

I use blogs and forums as sources in particular because they are spaces where longer stories can be published. But the more research I did, and the more recent a specific event I was looking for responses to was, the fewer blog and forum posts I saw, and the more Facebook, Twitter, and Instagram posts. I don’t think these later three platforms have the same literary potential to tell longer stories as blogs and forums, however, OICs’ needs have perhaps begun to shift. Speculatively, intersex individuals may now be looking to create social media networks where longer stories are less common but cross-sharing is ever-present. The cross-sharing of articles, resources, brochures, flags, lists of lawyers/doctors/therapists, encouraging memes etc. is incredibly valuable; as people realize they are not alone, more and more people may want to mobilize through these resources to fight the injustice of intersex erasure, instead of focusing so heavily on story telling and question asking. Since Facebook, Twitter, and Instagram are such popular platforms, it could increase intersex visibility to build social networks on those sites, especially given the intersections intersex activism can have with Black liberation and queer justice work.

I believe the future of literary analysis regarding OIC counter-discourse is going towards these three ‘quick post’ sites. Blogs, forums, and chat rooms remain invaluable for the space they provide to share stories and experiences. But shorter posts may also have the
potential of redefining the truth — 140 characters at a time — not to mention creating larger and more connected communities to belong to, love, organize with, and use to create discourse around the acceptance of all bodies. As the social manifestations of technology continue to grow, discourse and counter-discourse will continue to change. I hope the academy is up to recognizing these platforms as literary spaces that give the power to organize, publish, and exchange thoughts to people our Dominant Culture attempts to marginalize.
Acknowledgments

I would like to thank Dr. Ellen Rentz for the consistent support, advice, edits and check-ins.

I would also like to thank Dr. Nancy Williams for her ability to always tell me what I needed to hear, when I needed to hear it, in addition to the guidance she provided at multiple stages of this project. Dr. Brian Keeley has been with me since day one, helping me mold my interdisciplinary English/Neuroscience/Philosophy interests and introducing me to Dr. Rachel Levin who launched me into this research that I love with a cornucopia of resources and new ideas. I would be amiss to not also thank the two of them. Finally, I would like to thank my support system of loved ones, in particular my parents who helped me get through college in more ways than one, and my second pair of eyes and partner in everything, Raquel Selcer.
Glossary

**Counter-Discourse**: The discourse produced when those who are part of a marginalized group talk about their positionality and experiences. Counter-discourse exists whether or not people outside the community — including scholars/academics — recognize it.

**Discourse**: Written or spoken communication on a specific topic: either referring to a specific quote/set of quotes, or an immeasurable but observable collection of thoughts/productions/representations of a subject.

**DSD**: Disorders of sexual development. After the suggestion came from the Chicago consensus in 2015, the majority of the medical community adopted ‘DSD’ as the umbrella term to describe what intersex individuals ‘have.’

**Dominant Culture**: As a concept, Dominant Culture is the force that is able, through economic, political, or social power to impose values, language, and ‘truths’ on those who live with and within it. In the United States, and much of the world, ‘the’ Dominant Culture is White, Christian, Straight, upper class, and able bodied and when the work says ‘our Dominant Culture’ this is the Dominant Culture it is referring to.

**Gender Identity**: Most commonly, ‘woman,’ ‘man,’ or ‘nonbinary’ but not confined to these options. An individual’s gender identity is their decision regarding how they want to think of their own gender and their gender expression. This looks different person to person and can involve various combinations of pronouns, sexual identities, clothing presentations, mannerisms, and any and all other forms of interacting with the world the individual identifies with gender.

**Hegemonic**: Ruling or dominant, in this work it refers to the ruling or dominant opinions, assumptions, or thoughts in our ‘Dominant Culture.’

**Intersex**: An identity that can develop when someone’s body exhibits sex characteristics that do not fit typical binary notions of male or female anatomies. This can occur when someone has chromosomes that are not XX or XY, or when they have chromosomes that are XX but genitals, gonads or other physical features that are commonly associated with male anatomy or XY chromosomes but genitals, gonads, or other physical features that are commonly associated with female anatomy. Individuals decide for themselves whether ‘intersex’ is the right term to describe their anatomy and identity.

**IS**: Abbreviation for Intersex and/or intersexuality.

**Legal Landscape**: The actions, institutions, discourses, people, events, places, and perceptions regarding a country’s law and the justice system.
**Medical Establishment:** The compilation of the people, policies, institutions, motivations, and discourses that relate to the science of medicine and treatment of patients.

**OIC:** Online intersex community. An OIC is a group of people who use an intersex blog, who follow an intersex page, who engage in a comment discussion, etc. It can be conceptualized as a finite group of people engaged in a specific conversation around an intersex issue online or a more ambiguous network of multiple sites, people, and mediums engaging in multiple conversations about intersexuality.

**Popular Culture:** Culture that is consumed by and influences large numbers of people, as well as culture that is produced by the perceptions of large numbers of people.

**Sexual Identity:** The sex one identifies with (not to be confused in this work with ‘sexual orientation’ which is: who or what types of bodies one is sexually attracted to).

**Trans:** Term that each individual chooses to identify with or not, that broadly encompasses many gender identities of those who do not genderly identify with the sex they were assigned at birth. In non-intersex communities the converse is ‘cis,’ in intersex communities ‘ipso’ is gaining popularity (one who does identify their gender with the sex they were assigned at birth).
Works Cited


Intersexualite.org.


Susan's Place. “Intersex Forum.” *Susan's Place Transgender Resources*,