# Hida Viloria Maria Nieto, PhD

# THE SPECTRUM OF SEX

The Science of Male, Female, and Intersex

"This book combines the genetic mechanics found in a Genetics textbook with the usually not mentioned details leading to intersex variances. The biology is presented in a 'non-scary' and even entertaining manner, along with the social context, including the legal rights/status of intersex persons. The text also features vignettes from the lives of intersex persons, along with more extended biographical profiles. Overall, this is a welcome addition to the limited literature concerning being intersex."

—Dr. Martina Giselle Ramirez, Professor of Biology & Director of the Center for Teaching Excellence at Loyola Marymount University, co-author Happier as a Woman: Transforming Friendships, Transforming Lives

"Rarely do we see the conversation between biology, identity, and sociology seamlessly melded together in the way that Viloria and Nieto have accomplished. *The Spectrum of Sex* provides a critical resource about the many aspects of intersex identity, and does so in a way that's engaging and accessible."

—Liza Brusman, University of Colorado, Boulder

"It's time to take off the blinders and recognize and embrace the reality of a third sex—intersex, a diverse biological spectrum between male and female. *The Spectrum of Sex: The Science of Male, Female, and Intersex* helps us to do just that by integrating science and social, cultural and linguistic analysis of binary and non-binary sex. The inclusion of personal stories makes for an engaging book that is accessible to the lay reader, yet also beneficial and appropriate for medical students and academic professionals alike. This book opened my eyes to the need for activism and education to achieve the right of intersex people to exist and be recognized in society."

—Denice Lombard, Intersex Woman, Racial Justice and Anti-War Activist "This book provides a fascinating explanation of the wide range of gender expressions and biological sex traits that are a natural part of the human experience. The authors simplify very sophisticated scientific concepts and explain how the failure to acknowledge them marginalizes segments of our society. Their analysis makes clear that we must eliminate the binary classifications of gender and sex if we are to achieve equality for all"

—Michelle Waites, Civil Rights Advocate

"This extraordinary book needs to be required reading in all medical schools, by parents of intersex infants and everyone who cares about humanity. We are over due in our understanding of the beautiful spectrum of human diversity."

— Cheryl Cohen Greene DHS, author of An Intimate Life: Sex, Love, and My Journey as a Surrogate Partner

# The Spectrum of Sex

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The Science of Male, Female, and Intersex

> Hida Viloria and Maria Nieto, PhD

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#### Chapter 1

# Introduction

#### Hidden in Plain Sight

In 1994, after 26 years of living happily as a female, I (Hida) found myself being asked by a sexual partner if I'd been "born a woman"—while naked. For one deep, perplexing moment everything stopped as I took in the gravity of the question. "That's what they told me," I finally answered.

No one had questioned whether I was female throughout my childhood. I'd been easily accepted as a girl and started menstruating before most of my friends; I had even participated in the most stereotypically "girly" of activities, such as cheerleading. Later, when I became sexually active as a teenager, my first serious sexual partner, a man, proposed marriage. He told me he thought my body was beautiful.

Given this history, you may be wondering how I could be asked such a question. The answer is rather simple. Our understanding of the category of sex, and its expression in humans, is often limited in a way that does not include everyone's existence.

While many imagine sex to consist of only two categories, the truth, as biologists and other scientists have explained for decades, is that variations of sex are natural and plenty. In fact, sex is so diverse that even the three categories of male, female, and intersex—those born with bodies that do not fit typical definitions of male or female—don't quite do justice to describe the spectrum of its expression. For within the umbrella of the category of intersex, there are many different variations resulting in bodies with very different sex traits and appearances that can be male, female, or in between.

However, the fact that most people still say "male or female" when speaking about sex is evidence that we have not acknowledged its true diversity. That is why this book was written. *The Spectrum of Sex* will examine seven variations of sex, commonly considered intersex, in order to provide an accurate overview of sex expression in humans. In addition, it includes several personal accounts from sex and gender-diverse community members in order to bring this diversity to life for readers.

In my case, the question of whether I'd been born a woman ignited something—something that had been perplexing me since I'd started dating women in college. My body was different than theirs—in a way that made it look somewhat male. Not only was my figure not typically female—with small hips and breasts, and a long torso—my genitals were different too. Still, there was no way for me to even conceptualize that I was anything other than female.

Everyone said that you "become a woman" once you start menstruating, which I had, so what else could I be? *I must just be a different variety of female*, I thought, and in one way, I was exactly right. Most intersex people I know who appear and live as women feel, and can be viewed, this way.

There is also a visual component, though, to being male or female in the world. Once the feminine clothing comes off, my sex becomes questionable to some. Most had not seemed to notice or care, except for two male partners who questioned whether I was born female—the aforementioned, and another before him, who'd asked if my clitoris was a penis.

Mind you, as a child I hadn't been unaware of any of this. Like most, my genitals remained clothed and private. When I was 11, I did catch a glimpse of a female classmate's privates once, but I assumed she was the one who was "missing something." And I didn't say anything because I didn't want her to feel self-conscious.

Doctors often recommend clitoral reduction surgeries based on assumptions that having a large clitoris will cause women "psychological suffering," but for me the opposite has been true. Once I became sexually active I loved my body's peculiarities. Why? As I said in an article on this topic, "…having an overabundance of the only organ in the human body whose sole purpose is pleasure is far from a negative thing!"

Contrary to doctors' grim predictions, having an "uncorrected" intersex body didn't bring me grief or make me any less attractive. If anything, it made it easier to be. Unlike my female classmates, who were often dieting to "maintain their figure," my musculature and fast metabolism ensured I could eat whatever I wanted and still be toned and fit.

Although dating and sex were easy and fun, my growing awareness of how different my body was from other women's created deep confusion by my mid-twenties. I sometimes doubted whether I was female but didn't know what else I could be because I also doubted that I was male and was unaware of the existence of intersex. The world at large perceived and accepted me as female, but the issue of my sex remained a searing secret question within my psyche.

The answer to this question, and the biggest news I've ever received, came from an article in a free newspaper. A year after my birth sex had been questioned I came across an article about people who were "intersex." As I read it, I realized it was describing a very personal aspect of myself that I'd lived with, privately, all these years—yet I'd never heard the word

"intersex" before. As the article explained, it was a newer term for people who used to be called "hermaphrodites."

The word made me think back to a Greek mythology book I'd looked through as a child. I was thrilled to see that there were "goddesses" as well as "gods" in the ancient belief system, and quickly read about as many as I could find. Then, while reading about Aphrodite, I found a particularly fascinating story.

Apparently, Aphrodite and Hermes had once had a child together whom they named, aptly, Hermaphroditus. He was one of the Erotes, a collective of winged gods associated with love and sexual intercourse. One water nymph, Salmacis, became so taken with Hermaphroditus that she begged the gods to unite them forever. They did, but not in the way that she'd hoped: the gods merged their bodies together into one androgynous male/ female form.

I remember finding the notion of a half male, half female human fascinating and appealing, but I didn't think anyone like that actually existed. After all, I was reading a mythology book. I assumed the concept of Hermaphroditus was just a very interesting myth.

This belief was confirmed every time I had to fill out a form that had only two options to check for sex or gender (the two words are used synonymously in many cases, as Chapter 7 explores). Though I'd grown very aware of my body's differences through my late teens and twenties, how could I think I was anything other than male or female when those were the only two categories of sex I'd ever been given?

Yes, I'd heard the term "hermaphrodite" by the time I was a teenager. The summer after my freshman year in college I'd even found and read the book, *Herculine Barbin: Being the Recently Discovered Memoirs of a Nineteenth-Century French Hermaphrodite*, and related to parts of her story a lot. But the things Barbin endured once she was discovered to be intersex

made me think my difference wasn't extreme enough to make me a hermaphrodite.

Barbin was put through an invasive court trial to determine her "true sex," and then forced to legally re-register as male. The distinctions between how males and females could live in the world were stricter then, and she committed suicide shortly afterwards. She was only in her thirties. And her story was not only tragic; it seemed to be unique. This was one book, about one intersex person, and the only one I'd ever heard of. Like many intersex people I've met over the years, I assumed that there was no way I could be something so rare.

However, seeing pictures of two, living intersex humans in the article I'd found made something shift. What was once only a mythological rarity in my mind became real; even more real after I went to an intersex conference and met others like myself. But there, I learned something else I hadn't known: another reason more people don't know about us is that there have been medical efforts for over half a century to eliminate intersex existence.

As we'll explore in depth later, starting in the 1950s, doctors have been performing medically unnecessary genital surgeries and gonad removal on intersex babies in order to send parents home with typical males or females. Parents were also told not to talk about it, and to raise their intersex children to develop and express the gender identity corresponding to the surgically enhanced sex assignment chosen for their child. It's a practice that has been widely condemned by human rights bodies and bears startling similarities to eugenics.

Imagine, if you will, if every time an Asian baby was born they were sent to medical specialists to have their eyes surgically Westernized, because Asian eyes were considered less attractive than others. And then these children grew up being told they were something other than Asian, in a society that never spoke about Asians. Later, when they were asked to declare their race or

ethnicity on forms, Asian wasn't one of the options. So they had to check the box of the race they had been surgically modified to resemble. As this hypothetical scenario reveals, while the population forced to live under these circumstances would still technically exist, such dynamics would systematically eliminate their cultural identity and the physical traits associated with it.

Intersex people have experienced all of this and more, and this modern-day form of eugenics has erased the essence of our population from the fabric of society. Unlike other population groups, our existence has not been openly acknowledged or educated about until very recently. And the parts of our body that are routinely altered are not our eyes, as in the hypothetical situation above, but ones containing sensitive, pleasure-inducing nerve endings that can never be reinstated.

Those of us who escaped these practices—either by fortunate circumstances, as in my case, or because they were born in parts of the world such as the global south where they are unavailable—are nevertheless often kept in the dark about who we are. Or if we are aware, we often live secretly with the information. Sometimes the secret saves our very lives, in parts of the world with extreme intolerance to difference. Other times, we live secretly with our difference because it's difficult to speak openly about something that every socio-cultural cue and message we encounter tells us isn't supposed to exist.

Once I was aware of the extent to which I differ physically from other women, I told myself that I must just be "a different kind of female." It was all I knew. Even when I learned that I'm intersex, I still hesitated to admit that my identity was truly outside the male/female binary.

Our society is deeply invested in the idea that sex comes in two, opposite, categories. We see this expressed in recent events,<sup>3</sup> and I also know it firsthand. I'd been so indoctrinated with binary thinking that it was extremely difficult to let it go and

move beyond it—especially when there was so little awareness and representation of this "beyond."

We have all been lied to every day by the societal reduction of sex to "either male or female." This not only erases people, but portrays anyone who doesn't naturally embody one of these "opposite" body types—such as small-breasted women, for example—as inferior to those who do.

Intersex people have not only been lied to, we have also been encouraged to lie about ourselves. Every time I've filled out a form that requires me to select a sex/gender, I have been asked to lie. Every time I have allowed people to think I am a typical "she," because alerting them otherwise would be awkward, to say the very least, I was also lying. After decades of lying and having these lies readily accepted, it becomes easy to see them as the truth.

I probably would have kept up the farce and not come out as intersex had I not attended that intersex conference in 1996. After all, my difference has to do with the part of the body that we literally refer to as "privates." I'd never wanted or expected to speak publicly about it, but what I learned from other intersex people at the conference changed me forever. I couldn't deny the results of these infant genital surgeries that I saw with my own eyes. And I couldn't remain silent after hearing that doctors were justifying these surgeries using fear and lies about what living in a body like mine is like.

But although I was out about having an intersex body, I struggled to accept that I didn't actually *feel* like a man or a woman either. I'd stopped wearing makeup and women's clothing and cut my hair after learning I wasn't typically female. Almost overnight, everyone, including my own mother, mistook me for a young man. It was a surprise. Even more surprising was that I enjoyed being perceived as a man in the world as much as I had a woman.

#### The Spectrum of Sex

It was the mid-1990s, and the other intersex, trans, and gendernonconforming people I knew identified as men or women. While we had learned that sex isn't always binary, gender identity and expression remained so. I struggled for years, attempting to choose between a masculine or feminine gender expression in a world that wasn't comfortable with me embodying both. But each time I thought I'd finally settled on my "true" binary gender identity and expression, it would shift once again.

It finally dawned on me that the truth about my gender is that it shifts. Sometimes I felt, expressed myself, and was perceived as a man, and sometimes as a woman. Sometimes I felt neither, or in between, regardless of whether or not I was perceived that way. By the late 1990s I began speaking publicly about this—which today is known as being "gender-fluid"—as well as about being intersex.

Eventually, I came to realize that everyone experiences and expresses their gender in a slightly different way. As I wrote about in a 2009 essay ("Genderprinting the Population," shortlisted for *Gender Outlaws: The Next Generation*), our gender identity is as unique as our fingerprints: it is our *genderprint*.

These days, anyone who's paid attention to developments in the LGBTQIA+ community is familiar with the fact that not everyone is born typically male or female. Many are now aware that intersex people exist—so many more than when I came out over two decades ago. However, most are still encouraged to believe that we are incredibly rare anomalies at best. Or at worst, males or females with "correctable disorders" to be fixed at birth. I know from personal experience that nothing could be further from the truth.

Before discovering that I'm intersex, I lived, as I shared earlier, happily as a woman—yet I was still an intact, visibly intersex person. Being intersex did not negatively impact my

ability to be a woman. Neither did it prevent me from being well liked and received as a man during the years I was perceived as one.

Ultimately, truly accepting myself entailed admitting that I was neither a man nor a woman in my mind, heart, and soul. I embraced this non-binary gender identity although it was, and still remains, uncommon. And I have been loved and accepted as this person, too.

When I was asked if I'd been born a woman all those years ago, I didn't answer "Yes" but rather, "That's what they told me." Somehow, without ever being told I was intersex, or taught about it, the truth still permeated my being. All people should be allowed this experience: the right to know and be who we truly are.

It is simply not true that intersex people will face insurmountable difficulties if allowed to grow up in our natural bodies and to make our own decisions about our bodies and identities. This belief is a pessimistic projection by people who have, apparently, not learned that being different can be a gift as much as a challenge. I know this because, unlike the "experts" who specialize in speculating about intersex people, I am an intact intersex person and the experience has been nothing like the one that is often predicted. It has been so immensely enjoyable and enriching that I wouldn't change it if I could.

I invite you to forget all the myths you've learned and to open your mind fully to the reality of human diversity examined in *The Spectrum of Sex*. If you do, you'll find that the truth is not only more interesting than the fiction, but also a more freeing perspective, for everyone.

#### A note on language usage throughout this book

For the sake of clarity and accurate representation we will not conflate sex and gender terms. The terms "man," "woman," and, "non-binary" (whose noun form is "enby") for those who feel themselves to be neither, will be used when referring to gender identity. The terms "male," "female," and "intersex" (or "intersex individuals") will be used when referring to biological traits.

In addition, out of respect for accurate representation of all people, we will also refrain from using certain terms in ways that have been commonplace but that are no longer accurate, given the social emergence of trans and intersex communities. These uses apply as follows:

- Sex/gender: Sex and gender terms are often used synonymously in both social and legal contexts. Accordingly, we will use the term "sex/gender" in situations where it is accurate to note that both sex and gender, or either sex or gender, are being referenced together.
- Boy/girl: The current usage of the terms "boy" and "girl" is a holdover from the pre-1950s era when the sex and gender terms "male/man" and "female/woman" were used synonymously (which is explored further in Chapter 7). As we are well aware today, only sex traits are determinable at birth, not one's future gender. Thus, we will use the sex terms, "male, female, and intersex" along with the gender-neutral terms "baby" or "child" when referring to infants and minors whose gender is unknown.

• *Male/female*: As this book will explore in depth, the way the terms male and female are applied to living individuals is not always consistent when it comes to people born with bodies that fall outside these terms' definitions. In addition, the substitution of the term *sex* with the term *gender* in modern discourse and law (which we will explore in Chapter 8), has resulted in transgender individuals being required to use sex terms to describe their gender identity, as witnessed in the statement: "I just submitted the gender change request form to be registered as female instead of male."

Both of these situations illustrate that, when it comes to actual citizens, the terms male and female do not always mean what science says they do. Out of respect for these factors and these communities, we will use the terms "born with male sex characteristics" or "born with female sex characteristics" when possible.

- Gendering of sex traits: As this book will explore in depth, certain sex traits that are commonly considered male are found in females, and vice versa. This is due to the fact that sex is naturally expressed in a multitude of ways not encompassed within the two categories of male and female. Thus, we will avoid gendering sex traits such as XX chromosomes as "female" or testes as "male," as doing so is unnecessary and does not accurately reflect the lived experience of all humans.
- Differences or disorders of sex development: In 2006, intersex variations were pathologized and labeled "disorders of sex development," or "DSD," by the global medical community. Thus, it is common to hear intersex referred to this way, particularly within healthcare settings where doctors may be reluctant to acknowledge the intersexness of their patients in an effort to maintain

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the male/female sex binary. More recently, "differences of sex development" has been used in an effort to avoid the pathologization of "disorder." However, this change still maintains the DSD acronym. Also, it continues the trend of marginalizing intersex people as different and thereby, "other."

A person born intersex represents a natural variation of sex, and we support the advocacy by intersex individuals<sup>1,4</sup> and the collective community, most recently epitomized by a joint statement to the World Health Organization,<sup>5</sup> to change DSD to "variations of sex characteristics" (VSC). In place of DSD this new term will be used when needed to reference one of the many variances an intersex person can be born with.

#### Chapter 2

# We Are All Mutants

Is the ultimate goal of our society (1) to secure individual rights regardless of factors such as sex, race, ethnicity, or ablebodiedness, or (2) to do away with those rights in pursuit of a society comprised of physical traits deemed "pleasing" and "acceptable"? If the latter is the choice, then who decides which traits should be maintained in the population and which ones should not? Historically, it has been whichever group is in a position of cultural and political power.

For example, renowned proponents of eugenics from the 19th and 20th centuries, most notably Adolph Hitler, favored physical traits that included white skin, blond hair, and blue eyes. In addition to persecuting those who did not fit his preferred physical and cultural paradigm, Hitler also victimized individuals who defied traditional gender roles and heterosexual orientation.<sup>2</sup>

The historical consequences of fulfilling the eugenics "dream" have been fraught with pain and misery, as evidenced by the Holocaust. Although the death smoke that emanated from concentration camps in the 1940s is an indelible example of injustice and depravity resulting from policies built on eugenics, it is by far not the only one.

Our more current history informs us that there are many who continue to espouse the value and benefit of certain traits that

are visual in nature, such as skin, eye, and hair pigmentation, and also, the look of one's external genitalia.<sup>3</sup>

As mentioned in Chapter 1, there are deep correlations between eugenics and the system of sex and gender classification that has been enforced, and continues to be, in the majority of nations across the globe.

#### Mutations: it's in the DNA

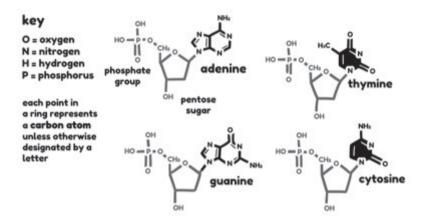
Other than perhaps the fictional characters in the X-Men movies, for most, the word "mutation" is pejorative and conjures a negative image. It denotes change, often an unanticipated, undesirable one. However, change is a given, not just in life, but with all biological forms, as demonstrated in the acquisition of new traits that occur across a species over time. While environmental factors alone can play a role, much of the change that transpires is the result of mutation.<sup>4</sup>

Despite the negative connotations, without mutations all humans would share basic external traits such as brown hair and brown eyes. In essence, without mutations the diversity present within our species and across different species would not exist to the same extent that it does.

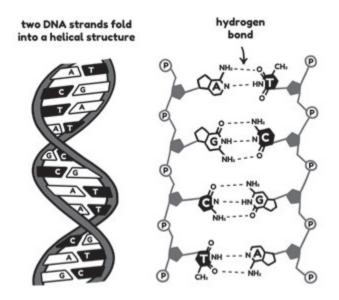
For biologists, a mutation is an alteration in DNA (deoxyribonucleic acid) sequence. Depending on the type and location of the alteration, the impact of the mutation can range from negligible to significant. Given that DNA is the hereditary material of life, since it is passed from parents to offspring, a significant mutation could impact how living organisms look and function across generations.

Structurally, human DNA is double-stranded and helical in shape. Both DNA strands are comprised of a sequence of linked

molecules called nucleotides. Each nucleotide is comprised of three smaller molecular components, a phosphate group, a 5-carbon sugar (pentose), and a base. There are four different nucleotides found in DNA, and each differs from the others depending on the base type present. The DNA bases are: A for adenine, G for guanine, C for cytosine, and T for thymine (see below).



The two strands of DNA are held together via bonds between particular bases—A bonds with T and vice versa, and C bonds with G and vice versa, to form what are called base pairs (see below).



Roughly 2 per cent of our DNA is organized into genes that possess the instructions to make a protein or a portion of one. It is estimated that humans possess approximately 20,000 of these protein-coding genes, and although there is tremendous variation, on average each of these genes is comprised of approximately 67,000 base pairs. Humans have enough genes to make thousands of different types of proteins that are needed to carry out specific functions and/or provide for specific traits, such as the color of one's hair or eyes.

Unlike people with brown hair, those with red hair most often possess a change in their DNA that results in the production of an altered or mutated version of the protein melanocortin receptor 1 (MCR1).<sup>7</sup> MCR1 functions to regulate skin and hair color, and several variants of this protein have been shown to cause melanocytes, pigment-forming cells in the skin, to overproduce a yellow-red pigment (pheomelanin). When there is an abundant amount of yellow-red pigment in comparison to dark brown (eumelanin) that gets injected into hair, a red hue can manifest.

Red hair, found in approximately 1–2 per cent of the human population, is therefore caused by a trait variation that results from a DNA mutation in the MCR1 gene. When a mutation(s) leads to a trait change, then the individual affected is called a "mutant," as cited in the *Oxford Dictionary of English*.

*Mutant.* Resulting from or showing the effect of mutation.<sup>8</sup> Thus, by the term's very definition, it is fair to say that all of us are mutants of one type or more, as this chapter will explore.

As is the case with redheads, people with blue eyes are considered mutants too, with the DNA mutation involved causing a reduction in the amount of melanin pigment found in the iris of the eye. In fact, when it comes to eye color, all but those with brown eyes are mutants, scientifically speaking.

Traits are not restricted to what can be "seen," such as hair or eye color. The ability to digest the lactose found in milk products into adulthood also qualifies as a trait. It appears that this particular characteristic arose in some human populations about 7500 years ago following one of several DNA mutation events. <sup>10</sup> In order to break down lactose one needs to make a protein enzyme called lactase, and if suitable levels of lactase are not produced, varying degrees of lactose intolerance or lactase non-persistence occur.

Genetic variation also plays out with sex. We have been conditioned to accept that there are only two sexes, male and female, and that each sex is outfitted with a prescribed list of traits needed to provide the capability, in most, to reproduce offspring.<sup>8,11</sup> However, if we look at the human population as a whole we see that 1–2 per cent do not fit within the male/ female binary. These non-binary-bodied individuals are most commonly known as intersex.

Intersex people are born with internal reproductive and/or external sexual anatomy that differs from those who are typical males or females. Intersex is an umbrella term used to describe a wide range of natural bodily variations or "variations of sex

characteristics."<sup>12</sup> Even though intersex bodies are not typically binary, many people with intersex traits grow up to be typical boys/men or girls/women.

Boys/men and girls/women are gender terms, and a person's gender describes and defines how an individual expresses and perceives themselves within a cultural and social context.<sup>13</sup> Some intersex people do not grow up to be boys/men or girls/ women, but feel themselves to be a different gender/gender identity, as discussed in more depth in Chapter 7.

Independent of gender identity definitions or outcomes, from a scientific, biological perspective, intersex variations comprise a distinct, yet diverse, sexual category. There are many types of intersex variances—so many that we cannot discuss them all in this book. Their natural existence provides unwavering evidence that sex is a spectrum.

Some argue that the strength of binary thinking in our society limits our ability to accept intersex people as equal to males or females, but humans have been able to break out of a strict, binary model of thinking before—for example, when it came to hair color. An estimated 98–99 per cent of humans are either blond or brunette. Despite this, we have accepted—rather than denying, hiding, or attempting to eliminate—the existence of redheads, who, interestingly, make up the same percentage of the population as intersex people (1–2 per cent).

However, it's important to recognize that acceptance of redheads didn't happen immediately. At one time redheads were vilified and persecuted for being different from the majority. As a 17th-century scholar delineates:

During the height of the witch trials in Europe, for example, red hair was considered evidence of witchcraft. Judas Iscariot was often depicted with red hair in Renaissance art and the Spanish Inquisition even suspected that redheads had been marked by the fires of Hell itself!<sup>15</sup>

#### We Are All Mutants

Indeed, redheads were once depicted as flawed and even evil within a binary blond/brunette majority. These predominantly religious views were, for the most part, eventually discarded. Did accepting hair color as a non-binary trait usher in society's collapse? Of course, we know the answer is no.

We suspect that the acceptance of biological sex as not exclusively and strictly binary would likewise be non-detrimental to society, despite the fact that sex characteristics convey greater social significance than hair color. Acknowledging and accepting the existence of intersex people could be a powerful step toward acceptance of all body types regardless of height, weight, skin color, etc. It seems an approach worth trying given that the alternative, as we will explore later in this book, has been harmful to so many.

#### Chapter 3

# Two in One

#### One example of intersex: gonadal intersex

The term "hermaphrodite" was derived from the myth of Hermaphroditus introduced by the Roman poet Ovid. As covered in Chapter 1, Hermaphroditus was a young male renowned for his beauty. The water nymph, Salmacis, fell in love with him, and begged the gods to unite them. They fulfilled her wish by creating a chimera or hybrid, part female, part male.¹ Numerous pieces of Greco-Roman art, such as the sculpture *The Sleeping Hermaphroditus* located in the Louvre in Paris, depict the creation as a human figure with breasts and female facial features, but with the genitalia of a typical male.²

"Hermaphrodite" has been used to refer to living organisms, including humans, with congenital sex characteristics that are not typically male or female. From a scientific standpoint, however, the term "hermaphrodite," or more specifically, "true hermaphrodite," is reserved for humans born with a combination of testicular tissue (typically considered male gonads) and ovarian tissue (typically considered female gonads).<sup>3</sup>

A "true hermaphrodite," or one with a gonadal intersex variance (a preferred label by many), is just one of many traits that fall under the "intersex" umbrella.<sup>4</sup> The other variations in sex characteristics considered intersex do not include

possessing typically male and female gonadal tissue. We also note that while the variations in sex characteristics that we will examine are commonly defined, from a scientific perspective, as intersex, not all those who have these variations identify with and/or use the term as a label for their sex/gender.

Oftentimes, those born with variations in sex characteristics identify as either male/men or female/women. Indeed, those were the only categories that were available to intersex people to be legally identified as until this decade. The exception is a case in 2003 in Australia where intersex individual Alex McFarlane was granted a birth certificate recording their sex as "sex indeterminate," and the first Australian passport with an "X" sex marker, representing, at that time, "sex unknown." Today, the Australian "X" represents "intersex, indeterminate, or unspecified."

#### **Reverse twinning**

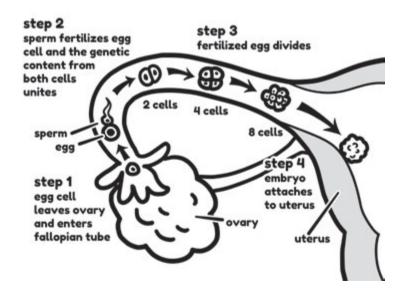
The gonads found in typical males are testes or testicles and those found in typical females are ovaries. The function of the gonads is to generate gametes (sperm and egg cells), the cells needed for sexual reproduction.<sup>6</sup> How the gonadal tissue presents among those with gonadal intersex can vary.

In some cases, the individual possesses one ovary and one testis, each located on opposite sides of the reproductive system. Others may possess a combination of testicular and ovarian tissue, known as ovo-testis. Still yet, an individual may possess two ovo-testes, one on each side, or possess only one that is paired with an ovary or testis located on the other side. Among those with a gonadal intersex variance, external genitalia that are not typically male or female, medically termed "ambiguous"

genitalia," may be present. In place of ambiguous genitalia we recommend and use the less stigmatizing term, "genital variance."

There are several ways in which gonadal intersex can arise, but in one example the process of "reverse twinning" is at play. Typically, a woman of reproductive age ovulates or releases one egg cell from one of her two ovaries each month in a process called ovulation. The egg cell is then swept into a fallopian tube, and if a sperm is able to make its way into the tube to fertilize the cell within 12–24 hours of its release, a zygote or fertilized egg will be formed.

The zygote will then set out on a path of cell duplication to become an early embryo as it travels to the uterus. In the uterus, implantation into the uterine wall will begin approximately six days post-fertilization. While in the uterus, the embryo continues on a course of development to become a fetus at eight weeks, and then finally an infant ready to be birthed at ten months, post-fertilization.<sup>6</sup>



In a given month, a small percentage of women ovulate more than one egg cell. If two egg cells are ovulated and subsequently fertilized, two zygotes will be formed, each developing into separate embryos that continue to grow as they both travel to the uterus. Ultimately, infant fraternal or non-identical twins will arise.<sup>8</sup>

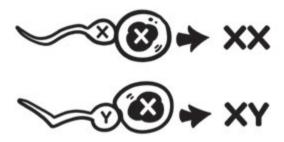
In the case of "reverse twinning" a woman ovulates two egg cells and each is fertilized to form two zygotes. However, along the path of development the embryos join together to form one embryo that will eventually become a single fetus and ultimately, one newborn. A gonadal intersex newborn arises when "reverse twinning" creates a child that is a genetic mix of typical male and typical female cell types. A review of the newborn child's chromosomes is required to understand how a child can be born with this dual genetic mix.

Except for gametes (sperm and egg cells), all cell types in typical males and females possess 46 chromosomes, 22 pairs of numbered chromosomes called "autosomes" and one pair of sex chromosomes. What sets cells in typical males and females apart is the composition of their sex chromosome pair: typical male cells have one X and one Y sex chromosome, and typical female cells have two X sex chromosomes. Whether the chromosome is a numbered autosome or a sex chromosome it will be a thread-like structure that contains a unique collection of genes composed of double-stranded DNA (see Chapter 2). Each chromosome type is distinct in its possession of particular genes. For example, the genes located on an X chromosome are distinct from those found on the Y chromosome, or, for that matter, on any of the numbered autosomes.

The chromosomes contained within a specific sperm and egg cell are integral to who we are genetically. Recall that each of us started off as a zygote, created when a sperm fertilized an egg cell. When fertilization occurs, the sperm and egg cell, each possessing one of each chromosome type (22 autosomes

and one sex chromosome) merge to form a zygote with two chromosomes of every type.

For sperm, the sex chromosome can be an X or Y, whereas in egg cells the only type of sex chromosome that can be present is an X. As seen below, if the sperm's sex chromosome is a Y, the resulting zygote will possess XY chromosomes. On the other hand, if the sperm's sex chromosome is an X, the resulting zygote will possess two X chromosomes (XX).



The genetic mixing found in those with gonadal intersex occurs when a woman ovulates two egg cells that become independently fertilized by two separate sperm, one carrying an X chromosome and one carrying a Y chromosome. If fusion occurs shortly after the two zygotes are produced, a single embryo that is a mix of XX and XY containing cells will be created. This chimeric or hybrid embryo would continue to grow and develop with half of the embryonic cells in possession of XX chromosomes and the other half in possession of XY chromosomes.

#### Hybrids abound

Hermaphrodites are not unique to humans. Across species there are many examples of hermaphrodites. For example, most flowering plants are hermaphroditic with the ability to generate both sperm (pollen) and eggs (ovules). Even among animals

#### The Spectrum of Sex

there exists a large number of species where single individuals are capable of producing both sperm and eggs.<sup>11</sup>

For some hermaphroditic species life as a male or female is sequential, as seen in sponges that begin their sexual life as one sex and then switch to the other. When sperm are released into the water by a sponge functioning as a male it can be picked up by a neighboring female sponge where fertilization of her eggs can take place. This same female is also equipped to foster the development of sponge larvae.

Like flowering plants, earthworms represent simultaneous hermaphrodites. In contrast to sponges, these species possess both male and female reproductive organs. When mating, two earthworms line up in the opposite direction. In this orientation they can release sperm that get deposited into the other worm's sperm receptacle where eggs can then be fertilized.

The biological existence of hermaphrodites in the human species proves that males and females are not the only types of individuals in existence. And although rare, fertility in gonadal intersex humans, as is the case with other hermaphroditic species, has been documented. <sup>12,13</sup> We cannot continue to ignore the presence of intersex people as they represent biological variation at its best, like all other members of the human species. Forcing sexual beings in this world to fit into a strict male/female sexual binary discounts many individuals, and indeed, many species.

#### **ON BEING NATIVE AND INTERSEX**

#### Nick Manchester

The Doctrine of Discovery is an oft-forgotten Papal Bull, or holy decree of the church, that still silently runs the world. This doctrine gave the Christians of Europe the "right" to go forth and claim all lands as theirs in the name of Christendom. Armed with the belief that they were superior in culture, religion, and technology, Europeans set out to "discover" new lands for God, King, and Country.

Europeans met with new people, and among nearly each culture of the New World, there were people outside of the male and female categories. Some Native/Indigenous cultures had three genders, some four, and still others acknowledged five. An offensive term, "berdache," was often applied to those in the other gendered categories.

Priests quickly came to believe that ridding societies of intersex, transgender, gender queer, and homosexual individuals was the quickest way to Christianize the people they encountered. There is no solid way to prove how many Native/Indigenous people were killed for being what is now considered LGBTQIA+, but the oral traditions as well as the written records of monks, priests, and "explorers" shed a chilling light on the destruction wreaked on Native/Indigenous LGBTQIA+ populations.

Historians estimate that upon the arrival of the first explorers on the lands now known as the United States, there were over 10 million Natives living within the time-distant borders. That number was less than 300,000 according to the Census in 1900. Our populations have thankfully grown somewhat, but we are still a diminishing and largely invisible group of people.

The European explorers, armed with murderous priests, began a systematic execution of those in the neither male nor female groups. The executions of these communities, such as the *Nadleehi* and *Dilbaa* (and their children) within my people, the Navajo, were used to successfully instill fear of intersex and trans people.

Navajo culture and language has traditionally recognized four genders:

#### Asdzaan

#### The Spectrum of Sex

- Hastiin
- Nadleehi
- Dilhaa

Our society is matriarchal, so our primary, or first, gender is feminine female, or *Asdzaan*. The second is *Hastiin*, or masculine male. Third comes *Nadleehi*, and refers to intersex people and to male-born people who function in the role of girls in early childhood and as women in adulthood (whom we would call trans women in Western culture). Fourth is *Dilbaa*, which refers to female-born people who function in the role of boys in early childhood and as men in adulthood (whom we could call trans men in Western culture).

Nadleehi is a word that translates as "one who constantly transforms." However, all of our many languages have undergone trials and are rapidly dying as they are still being eroded away due to being forbidden to speak our own languages during colonization, and decades of being sent to Indian residential boarding schools in which only English was spoken. This has impacted our use and understanding of our terms for gender.

Today, the word *Dilbaa*, which refers to the more masculine aspect of *Nadleehi*, is little used and often contested. Many use *Nadleehi* for both the third and fourth genders. Others sometimes say we have five genders by dividing *Nadleehi* into three subgroupings: male-bodied *Nadleehi*, female-bodied *Nadleehi*, and intersex-bodied *Nadleehi*.

Learned fear and loathing of intersex people persists within Native society. It is so strong that in 2019, my own Nation, the Navajo, hosted the largest Pride festival in Indian Country, yet intersex people, or people born between male and female, are recognized only in myth. The myths are positive—such as that of Changing Woman, Monster Slayer, Child Born Of Water,

and so on, who are part of our pantheon of yei (deity) who defeated Spider Man, Spider Woman (not to be confused with Grandmother Spider), and a host of other monsters who made this world, the fourth, uninhabitable—yet myths nonetheless.

As a child, I heard words in stories to describe people or beings that I didn't understand, and no one would explain them. It was as if the words were some guarded secret, rather like the good old, "I'll tell you when you're older."

I was raised female, but often excluded from certain things meant for girls. I was also not allowed to join in with the boys. I blame this largely on the colonization of my family. Some families are accepting, others are not. The words that they guarded were some like *Nadleehi* and *Dilbaa*, which would have given me a glimpse of my true place, in childhood, within a culture that was still in the process of being broken, but that thankfully never fully shattered.

As a result of colonialist oppression, I didn't like being intersex as a child. I was born with genital variance that made it obvious to people that I'm not a typical male or female. I was made to live in shame and secrecy, which was hard. I also survived a lot of trauma and pain caused by people who hate my body, because it is different from the Eurocentric male/female model that was enforced upon Native people.

It wasn't until I was watching a documentary on a hate crime against an LGBTQIA+ Native person, as an adult, that I heard the word *Nadleehi* again.<sup>14</sup> This made me decide to investigate it more fully. I have spoken with other Navajo intersex individuals, and we have all experienced this secrecy and exclusion. Speaking with Michael, a fellow Navajo who is also a chimera, he often expresses frustration with tribal elders for holding the belief that our bodies can and should be placed into the two Eurocentric categories of male and female—even though this is chromosomally impossible for chimeras.

#### The Spectrum of Sex

That is the basis for the Native intersex experience. We experience the erasure, racism, and gross "but we're honoring you" statements surrounding mascots, costumes, and fake artwork before we even understand what is happening to us as intersex people. We are erased or misrepresented both within our own culture and by the greater Eurocentric culture.

Despite our diversity, our Native cultures are often reduced to pan-Indian lore. Not all nations recognized five genders. Some had only two, some had three, some four, and some five. We have different social setups, different religions, different practices, and so on. There is no "Native American way/ culture/religion." It's painful when 500 tribes and nations are reduced to one gigantic, incredibly incorrect characterization of someone's ideal of what you should be in a fantasy world.

According to a recent initiative, Reclaiming Native Truth, whose findings were published in 2018, 40 per cent of Americans believe Natives to be extinct.<sup>15</sup> Another study, from 2014, showed that 87 per cent of American elementary and secondary school references to Natives speak of us as populations existing only before 1900.<sup>16</sup> This leads to most US college students believing that Native people are extinct.

As an adult, I often draw comparisons between my experiences as a Navajo and my experiences as an intersex person. Biology teachers tell us there's only XX and XY. When you're sitting in class with your XX/XY chimeric chromosomes, you know they are lying as much as your history teacher lied when they conflated Navajo, Hopi, and Zuni cultures into "Southwest Indian beliefs" during your government-approved propaganda...oops, I mean history class.

Native existence is typically covered only during Westward Expansion. Then there is a little about the forming of reservations, which are actually Prisoner of War camps that fall under the Department of Interior, not Human Services.

Then poof: we disappear from history books. Just as intersex people do within a two-sex system.

On the medical front, I often receive substandard care as an intersex and Native person. As an intersex adult, doctors often discounted my medical needs. I realize that my chromosomes are XX/XY, and that my body is a puzzle that doesn't always fit together neatly. This doesn't mean, however, that I want to be told, "that's just how your body works," when I have a pressing health issue that has nothing to do with my intersex chromosomes.

For example, it took nearly dying for a doctor to finally diagnose an illness, which is a mix of gastroparesis, food intolerance, and low production of digestive acids and enzymes, that could have been diagnosed over a decade earlier when I first sought help. It wasn't until I entered the early stages of liver and kidney failure that a doctor began to look for answers beyond the tiresome, "your body doesn't work like everyone else's—exercise more."

As a Native person, I also get dismissed by doctors, in this case, because of a belief in stereotypes that associate my ethnicity with criminal behavior. They assume I must be there for drugs, even if I've come in with a cold or broken bone.

The comparisons are endless, right down to sterilization. Thousands of intersex people have been involuntarily sterilized by operations they were subjected to as infants or minors to make their intersex bodies disappear. Similarly, thousands of Native people have been sterilized against their will in a failed attempt to control our population and complete our genocide.<sup>17</sup> Just as with intersex bodies, the government doesn't want to acknowledge how many sterilizations have taken place.

White people are often uninformed about the racist history surrounding homophobia, transphobia, and interphobia on our continent. This lack of understanding of the origins of LGBTQIA+

oppression is harmful to our entire movement and allows racist oppression to continue. For example, Native American culture continues to be misunderstood and co-opted.

A prime example of this cultural appropriation is the recent popularization of the term "Two Spirit." Not all tribes/nations use the term "Two Spirit," which was agreed upon in 1990, and is not a substitute for the terms "lesbian," "gay," "transgender," "intersex," and so on. Not all LGBTQIA+ Natives are Two Spirit, even if their tribe/nation uses the term, and no one who is not Native or Indigenous to North America is Two Spirit.

However, Americans of non-Native ethnicity have begun using the term so much that it has been added to the LGBTQIA+ acronym in some contexts when there are no Natives present. This co-opting of a term used to refer to our spiritual leaders is disrespectful and does not happen with terms for spiritual leaders from other ethnic communities. The fact that it happens to Native people is evidence of the racism we still face.

Two Spirit is a position of respect, honor, and duty within Native societies, requiring family approval. This means that, as a disowned person, I will never be Two Spirit despite being Native, intersex, transgender, non-binary, and gay. I am fine with that, as I'm not ready to shoulder the responsibility that comes with being Two Spirit.

Another example of the continuing racism Native people face within the greater LGBTQIA+ community is that I often get asked—as a Navajo who has been disowned by my family because of their heavily Christianized colonization and fear of eternal damnation—how I can possibly support a culture that doesn't support me. This question is particularly painful and maddening for me.

It is entirely understandable to me that my family can't accept me as I am. Why would I be angry at a culture that is dealing with generational trauma—trauma which, in addition to resulting from our near genocide, also caused the

defamation of LGBTQIA+ Natives. As a group, these outcomes are struggled with, dealt with, and handled to the best of everyone's ability.

Before asking an LGBTQIA+ Native/Indigenous person questions about why they'd be part of a culture that doesn't necessarily accept them, or doesn't get them, or hasn't fully made space for them, ask yourself the questions, do I ask this same question of the white folks who get disowned for being LGBTQIA+? Do I also ask them how they can stand maintaining their culture? Why do I feel it's okay to ask this of Native people?

Racism is rampant in the LGBTQIA+ community, and it needs to stop. Sexual orientation and gender expression were already accepted as diverse by numerous Indigenous societies—until white colonialism and religion eradicated these populations so violently that their existence was buried to the world. While it is easy for white society to overlook racism when thinking about interphobia, homophobia, and transphobia, it nevertheless played a critical role in enforcing these discriminatory ideologies across the globe.

If we want to successfully discuss and combat homophobia, transphobia, and interphobia, we must also fight the platform they all stand upon: racism. We have to move forward together, which doesn't mean defaulting to white cultural values. It means we all need to be able to bring our full selves to the movement, have space for each part of our lives, and move forward as whole people.

Many times we are expected to leave part of ourselves at the door of one type of advocacy or another. But I don't stop being Native because I am intersex. I don't get to walk away from one type of discrimination or injustice because I'm impacted by another. I don't get to think of only one aspect of my life when speaking about my needs in one area, because every aspect of my life is just as important as any other aspect.

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I can't lay down an integral part of myself for the "sake of the community." I don't lay down my intersex body at the door of being Native. I don't lay down my Native self at the door of being transgender. I don't lay down being non-binary at the door of being chronically ill. I don't lay down chronic illness at the door of being gay. None of us do. We all bring our full selves to the movement. It's time we act like it.

Today, I'm thankful that I have the body I do. I am not thankful for the abuse I suffered because of my body, but I am thankful to have a body that suits the way I view my gender: neither masculine nor feminine, but like water, flowing and beautiful. I am a man who wears a bra and doesn't worry if anyone knows it. I refuse to bind my chest, because why should I? I also paint my nails, occasionally wear wonderful and beautiful women's clothing, and am not afraid of basic makeup, although I'm not the best at doing it.

I'm thankful for a worldview that is different than most around me. I'm thankful that the shame and secrecy that defined my childhood no longer have power over me. I have a community who understand, and we teach one another so many things, most of which help me understand the world better. There are other intersex Natives, and we all have experiences as different as the people we come from. I am proud to come from a people whose original cultural values accepted me, and prouder yet to belong to a people emerging from pain into reawakened beauty.

# Chapter 4

# Behind What We "See"

As previously covered, the term "sex," as in biological sex, is used to refer to certain physical features found in humans, mostly with a focus on one's role in reproduction. Those who possess reproductive anatomy that has the potential to enable egg cell production and to facilitate embryo and fetal development have been scientifically designated as females. Those in possession of physical traits capable of producing sperm and impregnating females have been scientifically designated as males.

Even though the definition of biological sex is intricately tied to reproductive potential, many of us would have a hard time stripping an individual of that person's sex classification even if the individual were unable to produce viable and/or functioning sperm or eggs. In other words, society easily accepts people as male or female even if they are infertile and/or incapable of having their own children without reproductive assistance.

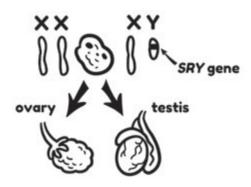
We typically accept individuals as female or male—the two sexes that are widely acknowledged—based in large part on physical appearance. For example, a typical female would possess a vagina in addition to other female associated parts, and a typical male would minimally possess a penis.

As covered earlier, the sex chromosomes possessed by a typical male are designated as X and Y, and for a typical female XX. Although other non-sex chromosomes play a role in male

and female development, the presence or absence of the Y chromosome, which happens to be much smaller in size in comparison to the X, is critical in cueing the early embryo to develop typical male or female parts.

#### Role of the Y chromosome's SRY gene

A 1990 study found that one particular gene on the Y chromosome called SRY (sex-determining region Y) was needed to initiate male reproductive development. Specifically, the SRY gene provides the instructions to make a protein called testis-determining factor (TDF). Once made, TDF cues bi-potential gonads present in a six-to-seven-week embryo to develop into testes as opposed to ovaries (see below).



Discovering the role of the SRY gene was groundbreaking because it told us the possession of one gene can initiate typical male sexual development in the embryo. In essence, the SRY gene is the proverbial first domino to fall in the pathway of typical male development.

To the mainstream majority, it might seem reasonable to assume that all males possess XY chromosomes and associated male physical traits such as a penis, and all females possess XX

chromosomes and associated female physical traits such as a vagina. However, nature itself, and all that is natural, is not always straightforward and simple. In actuality, there are many examples of how sex chromosome composition does not align with the reproductive or sexual anatomy a person possesses.

#### **XY**≠male

Most would expect that if a person "looks female," then that person would be in possession of XX sex chromosomes, but this is not always the case. People with a variation in sex characteristics called "androgen insensitivity syndrome" (AIS) can be completely (complete AIS, CAIS) "insensitive" to the effects of hormones called androgens (e.g. testosterone).<sup>2,3</sup> In all documented cases of CAIS to date, individuals look female buy possess XY sex chromosomes and testes that remain undescended in the abdominal cavity.

#### **Hormones**

To understand what is happening in cases of CAIS it is important to first describe the general role hormones, such as androgens and estrogens, play. Hormones are molecules that act as chemical messengers with the ability to impact cell function and activity.<sup>4</sup> A hormone delivers its message, in large measure, by regulating how and when gene information is used (gene expression).

Recall from Chapter 2 that genes possess the instructions to make proteins, but those instructions will remain unread on their own, without "help." If we think of a book filled with pages of instructions as representing a gene, then we can think of a hormone in this analogy as a component that can allow the book to be opened and read.

There are many types of hormones and one class of hormones, known as steroids, is made from cholesterol. Cholesterol can be associated with heart disease, giving it a negative connotation. However, cholesterol also happens to be an important molecule needed in the production of vital steroid hormones, such as androgens (e.g. testosterone) and estrogens (e.g. estradiol).<sup>4</sup>

## Androgens and estrogens

Humans of all sexes make both androgens and estrogens, except in rare cases.<sup>5,6</sup> Some of the effects of these hormones are universal, such as the case with estrogens, which promote cognition and maintain bone density in all humans regardless of sex. Androgens and estrogens can also promote outcomes that are not universal, but are rather more specific depending largely on the chromosome pattern and hormone-producing organs (e.g. gonads) present.

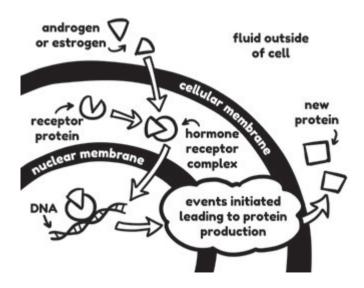
For example, estrogens also play a vital role in the development of sexual characteristics, but do so differently depending on sex. In typical males, estrogens are needed to foster sperm production and sexual function (e.g. erectile function). In typical females, estrogens promote development of internal and external reproductive tissues, such as the vagina, uterus and internal and external clitoris, and external features including breasts.

Androgens, too, are important for all sexes, in different ways. Although androgen levels are lower in typical females than in typical males, their effects are far reaching, promoting sex drive (libido) and playing a role in the production of estrogens. In typical males, androgens promote development of internal and external reproductive tissues (e.g. penis), and they also are needed to produce external features including, but not limited to, facial hair, increased musculature, and decreased fat deposition.<sup>4</sup>

Because those who are intersex make some form of androgens and estrogens too, classifying these hormones within a constructed binary is misleading. These facts call into question the referencing of androgens, particularly testosterone, as "male hormones," and estrogens as "female hormones."

#### Steroid hormone action

Cholesterol-derived steroid hormones (e.g. androgens and estrogens) have an effect on cell function and activity after they cross the membrane of a cell. Once inside the cell, they must bind to a specific receptor (e.g. androgen receptor) to form a hormone/receptor complex. The complex can then cross into the nucleus and bind to particular DNA regions to promote gene expression. Recall that when a gene is expressed its instructions can be used to make protein. Thus, through this mechanism, a hormone such as testosterone can promote the production of proteins, needed, for example, to drive the development of typical male reproductive anatomy.<sup>8</sup>



All proteins, including the receptors needed to bind hormones such as androgens and estrogens, are made from instructions contained within genes (see Chapter 2). Certain gene mutations can render receptors, such as the androgen receptor, nonfunctional, leaving testosterone unable to promote typical male development.

## Complete androgen insensitivity syndrome (CAIS)

In cases of CAIS, the developing embryo makes no functioning androgen receptors, the specialized proteins that function to bind androgens. Even though those born with CAIS make androgens, these hormones have no effect in sexual or reproductive development when the androgen receptor is functionally absent. A simple way of understanding this is the analogy that all the electrical wiring is in place, but there are no switches or outlets to access it.

As a consequence, those with CAIS do not develop as most with XY chromosomes do. In fact, they develop sexual traits such as breast tissue and external genitalia that "look" typically female (e.g. clitoris). This largely happens because the testosterone they produced was used to make estradiol, one form of estrogen.

The conversion of testosterone into estradiol is accomplished with activity from aromatase. Aromatase is a protein that functions as an enzyme, or, in other words, a molecule that can drive or catalyze a chemical reaction, such as the one shown below.<sup>10</sup>

Recall that those born with CAIS will possess internal testes. Moreover, due to the actions of another hormone made by the testes called anti-Mullerian hormone (AMH), those with CAIS do not develop internal female reproductive anatomy, including ovaries, fallopian tubes, a uterus, and in some cases, a vaginal cavity of typical depth. Individuals may not realize until later in life when they do not menstruate and/or they cannot achieve a pregnancy that they have CAIS. In a small number of cases, if a vaginal cavity is short, medical attention may be sought, leading to the discovery of CAIS.

Historically, the practice of removing internal testes was routine when a CAIS diagnosis was made. The reason given was and is that testes removal in those with CAIS limits cancer risk.<sup>3</sup> However, recent data have demonstrated that cancer risk prior to puberty is virtually non-existent.<sup>11</sup> These data support a delay in removing undescended testes while monitoring for malignancy potential until after natural puberty onset has occurred.<sup>12,13</sup>

Some have even argued that the compulsory removal of testes should be reconsidered altogether given that the testes in these individuals are needed to make vital estrogens. <sup>14</sup> Since those with CAIS lack ovaries, the testes are responsible for producing most of the testosterone, some of which is converted into estrogen in these individuals.

Recall that estrogens are needed to support bone density, in addition to so much more, including maintenance of cardiovascular health. Hence, estrogen replacement therapy is recommended following the removal of testes in those with CAIS to stem the onset of health issues such as osteoporosis (bone disease). However, some who engage in estrogen therapy may experience adverse effects. In those with CAIS who have had their testes removed, a preferable approach may be testosterone over estrogen replacement therapy. 16

## Swyer syndrome

Individuals with Swyer syndrome possess XY chromosomes, but their testes do not reach functional development (gonadal dysgenesis). Many cases are due to mutations within the SRY gene.<sup>17</sup> Recall from the beginning of this chapter that the SRY gene provides the instructions to make a protein called TDF. In the absence of functional TDF the bi-potential gonads do not fully develop into testes. And without testes, the requisite amount of testosterone, a hormone needed to spur typical male development, is not made.

As a consequence, those with Swyer syndrome "look" internally female as they possess a vagina, fallopian tubes and a uterus. However, because they lack ovaries, they are unable to make gametes (egg cells), and are therefore infertile. <sup>18</sup> Individuals with Swyer syndrome provide yet one more example of how XY does not inevitably equal male.

#### Sex chromosome number variance

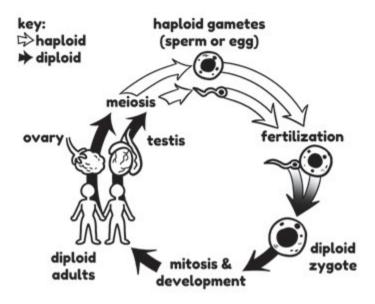
As seen in Chapter 3, a child can be born with a gonadal intersex variance and possess a mix of XX and XY cells. In these cases, barring any other atypical event, each cell possesses two of each chromosome type for a total of 46, as is expected. Beyond these cases, however, there are examples of people in the population who have a variant chromosome number within their cells. Cases include those born with three sex chromosomes (XXY, XXX, XYY) or even a single X sex chromosome (XO). These occurrences provide further examples of people in the population who do not adhere to the XX=female and XY=male binary.

For a child to be born with an atypical sex chromosome number, usually one of the gametes (sperm and egg cells) used to ultimately create the child had to possess a variant sex chromosome number. The cornerstone of sexual reproduction in humans and countless other species relies on the production of gametes through a process called "meiosis." As will be detailed below, meiosis is not a perfect process, and in some instances events called "non-disjunction" occur and lead to chromosome variance within gametes.<sup>19</sup>

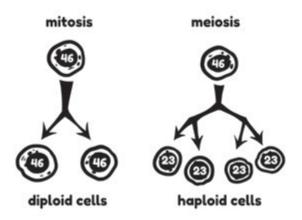
Human gametes possess one of each chromosome type (one sex chromosome and 22 autosomes; see Chapter 3). Cells with this chromosome composition are called "haploid" and referred to with the single letter designation, n. All other non-gamete cells are in possession of two of each chromosome type (one pair of sex chromosomes and 22 pairs of autosomes) and are called diploid and referred to as 2n.

When a haploid egg cell is fertilized by a haploid sperm, the chromosome content of each gamete merges to form a single cell called a "zygote" or fertilized egg. Now in possession of 23 pairs of chromosomes the newly created zygote is now considered diploid (2n), as it contains genetic material from both the original sperm and egg.

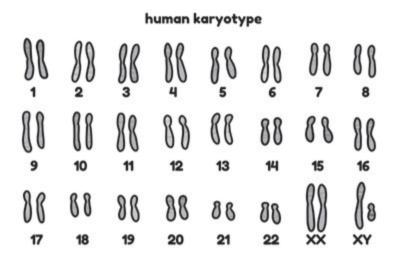
The formed zygote will then undergo duplication to create a two-cell stage embryo, each cell again considered diploid because they are in possession of 46 chromosomes or 23 pairs (2n). Diploid cell duplication, also called "mitosis," proceeds until new individuals equipped with the ability to generate their own gametes are produced, and the cycle of reproductive life continues.



Whereas meiosis depends on specialized diploid cells present within the gonads to generate four haploid cells, mitosis creates two new diploid daughter cells from an original diploid parent cell. In other words, meiosis is a process (see figure below) that reduces chromosome number by half, and mitosis maintains the chromosome number through cell duplication (division).

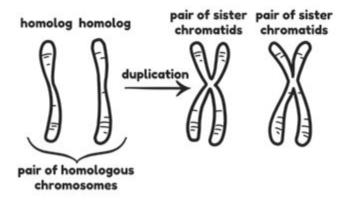


Illustrated below is a karyotype, a visual collection of chromosomes arranged by type that are found in typical diploid cells, including those within the gonads that are used to make gametes.

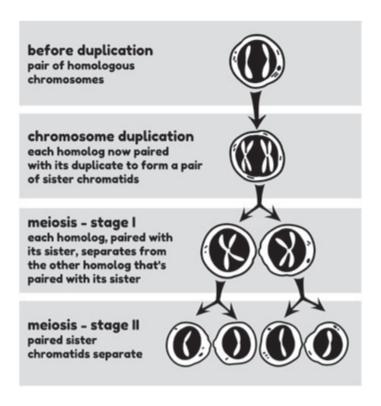


Each pair of chromosomes, for example, the pair of #1 chromosomes in the top left corner of the illustration (see figure above), is known as a pair of homologs. For each pair of homologs, one in the pair is maternal in origin (it came from the egg cell that went into creating the individual) and the other is paternal in origin (it came from the sperm that went into creating the individual).

Prior to meiosis the DNA present in each homolog is duplicated. Once created, the duplicated chromosomes associate with each other to form pairs (scientifically known as a pair of sister chromatids). A chromatid is the name given to a chromosome when it is paired with its duplicate or sister.

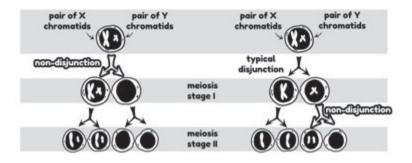


Once the pairs of sister chromatids are formed, the first of two stages of meiosis is ready to begin. In the first stage (Meiosis I), the paternal and maternal homologs, each paired with its duplicate, pull away from each other and move into separate cells (see third row, figure below). In the second stage (Meiosis II), the duplicates, or sister chromatids, pull apart from each other and move again into separate cells (bottom row). The four cells shown on the bottom row have the capacity to become gametes that are haploid, in possession of one of each chromosome type (one sex chromosome, X or Y, and one of each autosome, numbered 1–22).



As mentioned above, a non-disjunction event(s) can occur during the process of meiosis within males and females to create gametes with variant chromosome number. During a non-disjunction event, chromosomes do not correctly move into distinct cells as they typically do during Meiosis I and/or II.

Let's assume that the figure below is illustrating meiosis in the testis of a male with a focus on the sex chromosome pair, X and Y, that will be present in each specialized diploid cell used to make sperm. Prior to meiosis, the X and Y chromosomes will be duplicated and each will be paired with its sister (see top row, figure below). Focusing on the left panel, a non-disjunction event has occurred during the first stage of meiosis. As a result both X and Y sister pairs move to the same cell leaving the other cell without any sex chromosomes (see second row, figure below).



When the two cells in the second row are used in the second stage of meiosis, the process occurs correctly in this example, and the sisters pull apart and move into distinct cells (see third row, figure above). The cells in the third row possess the potential to become sperm, and if a sperm in possession of one X and one Y chromosome fertilizes an egg cell, the resulting zygote will possess three (trisomy) sex chromosomes (XXY). The additional X present in the XXY zygote comes from the egg cell. Note that in egg cell development within ovaries, the specialized diploid cells used will possess a pair of X sex chromosomes. Gametes produced in females will therefore possess the X chromosome, assuming no other non-disjunction events occur.

Returning to the figure above, if, on the other hand, a sperm lacks a sex chromosome altogether (see left panel, third row) and fertilizes an egg cell, the resulting zygote will possess a single sex chromosome (monosomy, XO), an X that was provided by the egg.

In the right panel of the figure above, the first stage of meiosis proceeds correctly but during the second stage a nondisjunction event occurs. What results are two gametes with variant chromosome number, one with two and the other with no sex chromosome (see third row).

## Turner syndrome (XO)

Variant chromosome number that arises from non-disjunction (see above) accounts for a large number of miscarriages, especially when a fetus lacks a chromosome and only possesses a total of 45. The exception involves Turner syndrome, where the individual possesses a single X sex chromosome (XO) along with 22 pairs of autosomes.<sup>20</sup>

Children born with Turner syndrome are the only known example where a live birth can occur with a chromosome number of 45. Those with Turner syndrome may be prone to heart defects and diabetes, but are otherwise healthy. They appear female at birth and are thus assigned and raised female, but do not undergo a typically feminizing puberty. As teens or adults they may be pressured or voluntarily opt to take hormone therapy to develop breast tissue and to increase fertility.

# XXY, aka Klinefelter syndrome

Similar to Turner syndrome, XXY results from non-disjunction (see above). People with XXY typically appear male at birth and throughout their lives, and most identify as such, although some also identify as intersex. They also possess sexual characteristics different from typical males, such as smaller than typical size testicles (testes) and penis, enlarged breast tissue, and sparse body and facial hair. XXY is fairly common (1 in 1000) and many do not even know they have the variance.<sup>21</sup>

#### Chromosomal mosaicism

Variant chromosome number present within an individual does not have to be an all or nothing prospect. For example, there are cases when an individual can have 46, the typical number of chromosomes, in a proportion of their cells, while having 45 or 47 chromosomes present within their remaining cells. Such an occurrence is seen, but not limited to, individuals with Klinefelter syndrome, where an additional X chromosome is present in only a proportion of their body's total cells.<sup>22</sup> These individuals are known as chromosomal mosaics, and one way this unique chromosome pattern can arise is through a non-disjunction event that occurs during cell duplication (mitosis) after the fertilized egg (zygote) has been formed.

#### **Conclusion**

As this chapter has explored, what we think we are "seeing" when we look at someone is, in fact, not always the case, even when it comes to such a basic human category as sex. There are individuals who appear male but do not always have the XY chromosome pattern that we typically use to define someone as male. There are also individuals who "appear" female, but likewise, do not have the XX chromosome pattern or ovaries that typically define someone as female. The awareness of this fact begs the question: is it necessary to define people based on biological sex traits?

# Chapter 5

# Clitoris, Penis, or Something Else?

During *in utero* development there is a period when a fetus has neither a clitoris nor a penis but rather an identical mass of tissue known as the "primordial phallus." This phallus cannot be taken to refer to only one sex. In essence, it is sex-neutral.

By the time babies are born, however, this originally undifferentiated sex-neutral organ will have typically developed into something else. In most cases, this development will result in what is known as a clitoris or a penis.

#### Godzilla versus the giant clitoris

Penis. Can you conjure an image in your mind? We imagine you can.

Clitoris. What do you picture now?

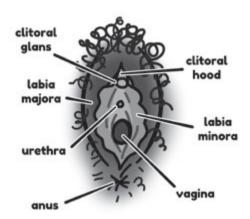
For most people born with XX chromosomes and ovaries, the typically female chromosome pattern and reproductive organs, the primordial phallus develops into a clitoris. Despite the fact that the clitoris is a prominent feature of external genitalia in approximately 50 per cent of the population, most

texts illustrating female anatomy fail to accurately depict the clitoris, reducing it to a small, external nub.

A lack in realistic images of female reproductive anatomy has kept the clitoris "in the closet," so to speak. Why the lack of attention, especially when the clitoris is the only known organ whose sole function is to provide sexual pleasure?

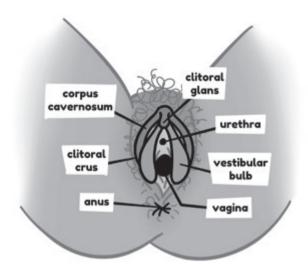
There is no single answer, but part of the reason most likely rests with notable figures like Sigmund Freud. As early as the turn of the 19th century, Freud dismissed the importance of the clitoris. He described the clitoral orgasm as adolescent and inferior to its mature vaginal counterpart.<sup>1</sup>

The ramifications of Freud's views exist today, but through the work of scientists, artists and activists, a clearer picture of the clitoris is emerging to show us a structure that is much more than a clitoral hood that covers an external shaft, that may or may not extend over the clitoral glans (see figure below).



Most clitoral tissue is internal, with roughly 9 centimeters (3.5 inches) hidden from view. This internal structure of the clitoris far eclipses the size of the external clitoral glans, which possesses average dimensions of 1.5–2 centimeters (0.59–0.787 inch) by less than 1 centimeter (0.39 inch) in length and width, respectively.<sup>2</sup>

The internal clitoris possesses two wing-like structures, each comprised of the corpus cavernosum and clitoral crus, and two leg-like structures called the bulbs of the vestibule.<sup>3</sup>



When a woman becomes sexually aroused, the "wings" and "legs" engorge with blood and can press against both the vaginal and anal walls. The view that there exists a vaginal orgasm that does not involve internal or external clitoral tissue does not appear to be accurate. It seems Freud had it wrong.

The clitoris not only plays a role in orgasms based on external clitoral stimulation; for some women it may also facilitate orgasm through vaginal and/or anal penetration. What accounts for all of this orgasmic pleasure? The clitoris is equipped with a large number of nerve endings, at least twice the number as those in the penis.<sup>4</sup>

In some cases the external tissue of the clitoris may grow larger, even much larger, than usual. However, the adage "the bigger the better" has not been historically applied when it comes to external clitoral tissue. In fact, if a female is born with an atypically large external clitoris, it is given the medical label

#### The Spectrum of Sex

"clitoromegaly," and nonconsensual cosmetic genital surgery has often been recommended to parents or caregivers to render the clitoris a smaller, more typically female, size.

Clitoromegaly—the name itself sounds inhuman, like one of the creatures that emerged to fight Godzilla, the fictional reptilian monster created from the fallout of a nuclear bomb. A large clitoris is not a monster and will not impede a woman's ability to achieve orgasm. In fact, a large clitoris can make it easier to experience sexual pleasure. Why, then, would anyone want to do the unimaginable and cut clitoral tissue away? We will explore the culturally driven rationale for this practice in Chapter 8.



## Congenital adrenal hyperplasia

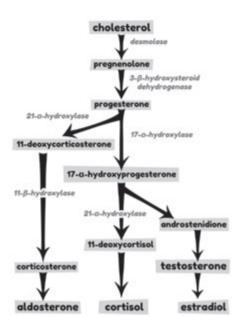
One cause of enlarged clitoris is due to a variance called congenital adrenal hyperplasia (CAH).<sup>5</sup> We note, however, that development of an enlarged clitoris is not the case for everyone with CAH. In addition, while CAH is often portrayed as a medical emergency with extreme health risks, this is not true in all cases; it depends on which type of CAH someone is born with.

Two types of CAH exist, classical and non-classical. In both types there is a breakdown in the production pathway for a number of hormones that are made from cholesterol. To understand how a female can develop an enlarged clitoris, it is important to first understand the hormone production pathway in question.

As described in the previous chapter, cholesterol is needed to make hormones such as androgens and estrogens. In addition to these hormones, cholesterol is also needed to make other hormones such as aldosterone (which regulates sodium and potassium levels and arterial blood pressure, etc.) and cortisol (which promotes the metabolism, maintains blood sugar and helps the body deal with stress and illness, etc.). In order to produce these hormones, specific enzymes are required in a biochemical cascade.

As briefly mentioned in Chapter 4, enzymes are specific types of proteins needed to drive chemical reactions. To better understand the functional role of an enzyme in the context of a biochemical cascade, the analogy of making a shirt using a piece of material can be used. By itself the material is not a shirt; however, in the process of making a shirt, a pair of scissors, symbolizing Enzyme #1, can create a pattern. The pattern by itself is still not a shirt. It needs to go through another conversion with the help of a sewing machine. Because the sewing machine will help to stitch the pattern into a shirt it acts much like a second enzyme (Enzyme #2) in a biochemical cascade.

In greater than 90 per cent of CAH cases the root cause surrounds the role of an enzyme called 21-alpha-hydroxylase.<sup>7,8</sup> As seen below, 21-alpha-hydroxylase is needed to make two chemical by-products: 11-deoxycorticosterone and 11-deoxycortisol, both of which are ultimately needed to make aldosterone and cortisol, respectively, with the help of additional enzymes (the arrows represent enzyme-driven conversions or reactions).



#### Classical CAH

An enlarged clitoris can occur in cases of classical and nonclassical CAH, but it is most often associated with the classical form. There are two types of classical CAH, salt-wasting and simply-virilizing (non-salt-wasting). Whether a child is born with salt-wasting or simply-virilizing depends on the type(s) of 21-alpha-hydroxylase gene mutation(s) present (see Chapter 2 for a review on mutations). For example, if a mutation results in complete loss of functional 21-alpha-hydroxylase enzyme activity, salt-wasting CAH, the more prevalent form of classical CAH, will occur. If, on the other hand, the mutation(s) the child possesses creates an enzyme that is partially functional (e.g. 20–60 per cent of enzyme activity is still maintained), then simply-virilizing CAH will occur.<sup>9</sup>

When 21-alpha-hydroxylase is completely non-functional, as in the case of classical salt-wasting CAH, two by-products in the enzymatic cascade, 11-deoxycorticosterone and 11-deoxycortisol, are not made at optimal levels. The consequence is a rise in 17-alpha-hydroxyprogesterone because, 1) when progesterone is no longer being used to make 11-deoxycorticosterone it's available for conversion to make even more 17-alpha-hydroxyprogesterone, and 2) 17-alpha-hydroxyprogesterone is no longer being used to make 11-deoxycortisol. Higher than typical levels of 17-alpha-hydroxyprogesterone lead to the production of higher levels of a third by-product called androstenedione. And when more androstenedione is made, increased production of testosterone can occur.

For XX females born with salt-wasting CAH, the presence of excessive levels of testosterone during development causes an enlarged clitoris in most cases. It is not uncommon for a female's enlarged clitoris to be referred to as "ambiguous genitalia," with the level of ambiguity dependent upon the amount of testosterone produced. In mild cases of enlarged clitoris, the clitoral shaft resembles a tiny penis. In more marked cases of salt-wasting CAH, the absence of a vaginal opening along with the presence of a penis that is more typically sized and capable of urination would not be unusual. There have also been cited examples where CAH females have been assigned a male sex at birth and gendered and raised as boys because the child's external genitalia resembled that of a typical male.

Males with XY chromosomes born with salt-wasting CAH may also display enhanced virilization (e.g. enlarged penis), but the external genitalia are not considered ambiguous, as they are in females. Males born with an atypically large penis still appear "male" and do not receive medical treatments for their natural sexual variation.<sup>12</sup>

In salt-wasting CAH the inability to make functional 21-alpha-hydroxylase not only results in higher production of testosterone, it also results in no production of the two important hormones, cortisol and aldosterone. Children born with saltwasting CAH will, in most cases, require hormonal therapy for the rest of their lives to curb the weight loss, vomiting, low blood pressure, dehydration, etc. that occurs as a result of no cortisol and aldosterone production.<sup>8,9</sup>

In simply-virilizing CAH, a child may or may not require life-long hormone therapy. Nevertheless, due to excessive testosterone production, virilization will occur in those with XX chromosomes (e.g. enlarged clitoris) and in those with XY chromosomes (e.g. enlarged penis, early puberty).

#### The case of Casimir (Kazimierz) Pulaski

Our collective history has left us with scant examples of intersex persons living prior to the 20th century. In large measure this has likely occurred because intersex people, knowingly or not, shielded their atypical biology from public scrutiny. Moreover, our awareness and understanding of the biological underpinnings of intersex, along with access to the scientific tools needed to test for the presence of certain intersex variances, did not exist until the 20th century.

Recently, new information has come to light surrounding the famed father of the United States Cavalry, Casimir Pulaski, a man who fought alongside George Washington in the American Revolution. Compelling evidence has emerged that strongly suggests Pulaski lived with the non-life threatening, or simply-virilizing form of classical CAH.<sup>13</sup>

Casimir Pulaski was born in Poland in 1745. At the behest of Benjamin Franklin, who took note of his military exploits in Europe, General Pulaski arrived in Massachusetts to fight for American freedom from the British. Today, Pulaski is revered for his courageous battle skills and for playing a pivotal role in helping George Washington escape during the Battle of Brandywine. <sup>14</sup> Until recently it was unclear whether Pulaski's remains were buried at a monument built in his honor in Savannah, Georgia. When the skeletal remains were exhumed, DNA evidence demonstrated a match to one of Pulaski's relatives buried in Poland.

The DNA results on their own do not definitively prove the remains exhumed from Georgia are Pulaski's. However, no other relative of Pulaski's is known to have traveled to America from Poland. Moreover, examination of the skeletal remains aligned with injuries Pulaski incurred, such as a right hand fracture. Results from the skeletal examination also aligned with Pulaski's known height of 5'4", age of death at 34, and hip joint and femur anomalies common among those who regularly ride horses. Finally, and most riveting, skeletal examination also revealed that the facial structure and pelvis were typical for a female.

Is it possible that Pulaski was born typically female and yet lived his life as a man? There have been several documented cases of females who did just that, dressing and living as men in order to serve in the military, 15 although this does not appear to be the case for Pulaski. Records show he was baptized a boy, which would not have been the case if he presented as female at birth. 13 Was he baptized a boy because he "looked" like one?

If Pulaski was born with CAH, then the excess testosterone his body made could have left him with external genitalia that looked typically male. This conclusion would align with Pulaski's known external characteristics such as facial hair and male-pattern baldness—both an outcome of testosterone production atypical for a female.

Without a definitive DNA test there is no way to conclusively prove Pulaski was born intersex. Although DNA testing was done to determine that the skeletal remains matched a Pulaski relative, the DNA needed to verify biological sex and an intersex variance is typically not available, due to degradation, from skeletal remains. However, the evidence amassed to date makes a compelling case that Pulaski was born with XX chromosomes and CAH, and lived his life, very successfully, as a man.

#### Non-classical CAH

In non-classical CAH, the most common yet mild form of CAH, the functionality of the 21-alpha-hydroxylase enzyme is modestly impacted in those with either XX or XY chromosomes. Usually characteristics found in those with non-classical CAH occur later in childhood, and can include acne and premature body hair. For adolescents with XX chromosomes specifically, characteristics can also include an atypical amount of body hair and irregular menstrual cycle.<sup>7,8</sup> Children born with non-classical CAH most times have typical genitalia. For example, a child with XX chromosomes would have a clitoris that is typical in size, a vagina, and separate urethral opening (pee hole).

# The genetics of CAH

CAH is a genetically inherited trait passed onto the child from a father and a mother. In cases where CAH is caused by an inability to make functional 21-alpha-hydroxylase, each parent possesses one non-functional 21-alpha-hydroxylase gene (see figure below). The gene that provides the instructions to make 21-alpha-hydroxylase is found on chromosome #6.

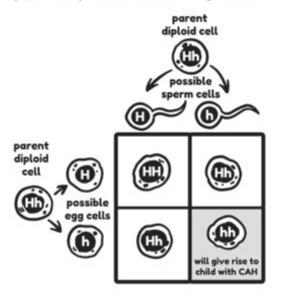
During the process of making sperm in the testes and egg cells in the ovaries the chromosome content is halved from 46 to 23 through the process of meiosis (see Chapter 4). As each parent has two #6 chromosomes, one carrying a functional (designated with a capitalized H) and one carrying a nonfunctional 21-alpha-hydroxylase gene (designated with a lowercase h), 50 per cent of the sperm and 50 per cent of the egg cells produced by the prospective parents will each contain a #6 chromosome bearing the non-functional gene form.

In the generation of an embryo that gives rise to a fetus, and ultimately, a newborn child, a sperm with its 23 chromosomes must make contact with an egg cell and all of its 23 chromosomes. If each of the original parents is a carrier of the non-functional gene, there is a 25 per cent chance that a child will be born with CAH due to the child's possession of two #6 chromosomes, each carrying a non-functional 21-alpha-hyroxylase gene (hh). <sup>16</sup>

#### meiosis and the punnett square

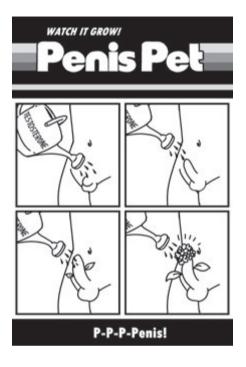
A punnett square is used to determine the probability of an offspring having particular gene types.

In this example each prospective parent has one non-mutated gene form (H) and one mutated gene form (h) present in their specialized diploid cells used to make gametes.



#### The penis chia pet

Remember chia pets, the toy figurines that look bald or furless until you add water to make their hair or fur grow? The grooves of the chia pet terracotta figurine are covered with chia (*Salvia hispanica*) seeds, and when watered, sprout. The figurine's tagline reads, "Just add water and watch them grow." Penises, similarly, require something to activate their growth—in this case, high levels of functional androgens such as testosterone.



The key to the natural range in the size and function of human genitals depends on the concentration of androgens produced. Most humans, including those born male, female, or intersex, produce both androgens and estrogens to some degree. The amount of androgens, and one's sensitivity to them, determines whether we are born with a clitoris, a penis, or something that is similar to, but different from, either of these.

In the case of most males with XY chromosomes and testes, the phallus grows much larger, externally, than a clitoris, developing a penal shaft that is typically at least several inches long. The organ also distinguishes itself from the clitoris by developing a urinary tract. One exception, as discussed in Chapter 4, is CAIS (complete androgen insensitivity syndrome), where the phallus in individuals with XY chromosomes will develop into a clitoris because there is no sensitivity to the androgens present.

#### The Spectrum of Sex

Essentially, one could say that human beings' default sex is female. It's what we all end up looking like—regardless of our chromosomal patterns or reproductive organs—unless we have enough androgens present and enough sensitivity to them to signal our body to change our genitals to something else—typically, a penis.

#### **HOW BEING INTERSEX BECAME NO BIG DEAL**

#### Thea Hillman

# Part 1: Medic alert bracelet/"My body was wrong"

Her eyes told me my body was wrong. Pubic hair on my fouryear-old body. The look on my mom's face made it clear to me my body was cause for concern. I was worrying her. And so, in the most intimate ways, along with my mom and doctors, we sought together to correct my body.

My mom told me I had a medical condition, an enzyme imbalance. I learned to swallow pills, submit to blood tests, let authoritative men inspect my clitoris and vulva, probe my vagina and anus, searching for signs of abnormalcy and incorrectness. I learned I was a freak and the origin of this freakishness was my body, the private parts of my body.

At the same time, my mother's words taught me to be proud. She told me the hair I had on my vagina was hair everyone gets, but I just got mine early. That made me feel special. So when she asked if I wanted to get my pubic hair removed, I refused: "That's my special hair!" My enzyme imbalance was a source of uniqueness.

After they diagnosed me with congenital adrenal hyperplasia, I started taking medication to postpone puberty

and help me grow. I wore a medic alert bracelet for the remainder of my childhood, which, as it's designed to do, attracted a lot of attention and questions. It was my badge. A curved silver oval, red snake on one side and my name on the other.

# Part 2: Freak belt buckle/"My body was wronged"

And they did correct it. Me. Mostly. According to them, I was very lucky. My treatment was a complete success: I was over five feet tall and got my period at 13. Where they may have "failed," though no one said as much, was the facial hair...and the queerness. And if they'd been paying attention, the shame and the fact that I considered myself a freak.

In my late teens and early twenties, as I tried to figure out who I was, it would seem I was trying to convince anyone paying attention that I was anything but normal. Sure, by day I did what was expected of me: I was in college, then grad school, then later full-time career-track jobs. But while in New York on a college field study, I frequented S/M leather bars by myself. In grad school while on a family reunion in Montreal, I left my cousins, went into a dyke bar that didn't allow men, and spent the night at the home of a glorious butch I'd picked up on the dance floor. While working as a managing editor at a publishing company by day, at night I'd walk down my block to the weekly bisexual sex party at the Fairy House.

In my late twenties I began to meet intersex people. I learned that my condition wasn't just something I had; it was something that had been done to me or something that happened to me. I learned that many intersex infants and children are treated as if their bodies are an emergency. And that many of the medical decisions made by their

#### The Spectrum of Sex

doctors and parents aren't medically necessary, but rather driven by a desire that the child someday be able to perform heterosexual sex. Not to have genitalia that function, not orgasm, not reproduce, not be themselves, not be happy, not be able to make these irreversible decisions themselves. And while there were important medically necessary aspects of my treatment, I learned the normalizing, heteronormative implications behind the decisions my mom made about me, and all she had consented to on my behalf.

In addition to my fevered search for sex and connection, I channeled my passion, shame, and anger into writing, performing, and claiming my intersex experiences. I took a leading role at the time to end unnecessary nonconsensual intersex surgeries and to make the world safer for difference of all kinds. The title of one of my Intersex 101 talks was "Intersex Makes Great Dinner Table Conversation."

I took a jewelry-making class at San Francisco City College. I made a silver belt buckle. In the center was a brass six-pointed star, a sherrif's badge. On top of the star was a single word, cut out of silver, in a font so intricate it had taken me hours to cut by hand: freak. My mom hated that freak belt buckle. "Why do you need to call yourself a freak, after everything we did to make you normal?" Normal was a gift my mom had fought so hard to give me, and I handed it back to her without even opening it. "Normal is a weapon of mass destruction," I wrote at the time. Normal, and everything done in its name, was the enemy.

### Part 3: Engagement ring/ "My body really isn't the issue"

I'm in my late forties now. I spent more than a decade passing as normal half the time, and then being a professional freak, speaking at colleges and festivals, being interviewed by national media, and testifying in front of doctors and at the San Francisco Human Rights Commission about being intersex. I also published two books, the second specifically about being intersex. And the majority of people who came up to thank me for my work or who identified with the book weren't intersex.

They were everyone who had ever had an experience of otherness—they were abuse survivors, trans, fat, disabled, ill, had surgery as a child, had been bullied. It was unexpectedly and incredibly affirming, because I wasn't alone: everyone has felt like a freak at some point in their lives. It was also a shock to my sense of self, because if everyone's a freak, then am I really one? And if I kept insisting I was a freak, who was I trying to convince, and why? Sometimes it felt like bringing up intersex, my otherness, rather than creating a sense of commonality or connection, was actually creating a divide where none existed.

What I've learned, from life and just listening to other people's stories, is everyone is shaped by responses to their bodies. It's become clear to me that bringing up intersex where there is no mention of it beforehand can be exactly like talking about my genitals in the middle of dinner. Which may be appropriate, but more likely not. Not so much because it would be impolite, but more because it just isn't relevant. It isn't that big of a deal. And in some ways, maybe it never was.

I did get lucky. I had a loving mom who talked to me about my body and my treatment. I had expert healthcare. I came out as queer and then intersex in the San Francisco Bay Area.

#### The Spectrum of Sex

I was surrounded by a supportive progressive community where I could envision and then have a baby on my own.

I found a partner. Someone I didn't meet at the time but who'd been at those sex parties 20 years ago and had read my writing. Someone who recognized me, and my love of jewelry, who had a custom engagement ring made for me with recycled gold and an antique, conflict-free diamond. Me, engaged to marry someone, and a man at that! Me, who could never have imagined doing something so normal. Because I thought it wasn't me and because I thought I couldn't have it. Because I didn't know that even white men from tiny farm towns in Wisconsin feel like freaks too. And are looking for people like me.

My mother has had her own coming out process around me claiming intersex. But over the years she became a fierce advocate and has been in her share of films about intersex. She says if she had to do it all again, she wouldn't have worked so hard to make me normal—she says I always was who I was.

I'm trying it on now, a new umbrella term "normal," big enough to embrace me and all my experiences. Us. I'm thinking maybe normal is a journey—sometimes life-long and sometimes requiring tremendous effort and luck—to feel at home in your body.

# Chapter 6

# To Be or Not to Be

## The Androgynous Phallus

As previously discussed, most of us "quickly assign one of only two sexes" to our fellow humans based on their outward physical appearance. This can lead to mistaken assumptions not only about which chromosome patterns and/or reproductive organs someone possesses, but also about which types of genitals. The appearance of one's genitals is largely dependent on the development pattern of what is known as the primordial phallus, the sex-neutral organ that develops into the clitoris or the penis.

We have already seen cases (e.g. congenital adrenal hyperplasia, CAH) where the external size of a clitoris can be enlarged beyond what is typical. In such cases, the organ is still a clitoris by definition as it does not have a urinary tract or urinary and ejaculatory capacity, but it may be large enough to resemble a small penis. Conversely, there are distinct cases where a phallus develops into a penis, by definition, with a urinary tract and urinary and ejaculatory function, but one that society may deem "too small" to be considered adequate for a male.

Cases of what are known in medicine as ambiguous genitalia beg several questions. Is it the size or the function of a phallus that resolves its ambiguity, or is it a combination of these factors? For example, if a phallus is large enough to be considered a penis, might not the person who possesses it want to call it one, even if it lacks urinary and ejaculatory function? Or, on the other hand, is every phallus with urinary function a penis even if it doesn't resemble one due to its small size?

These examples beg another question: what is the most important factor to consider when making decisions about how sex organs are gendered? While these decisions are usually simple and dictated by biology, is a different approach needed when the answer to the question "clitoris or penis?" is not obvious?

It is typical for a child born with female XX sex chromosomes, a vaginal opening, ovaries, and an external sex organ that cannot function in urination or ejaculation to be assigned the female sex. However, we have seen cases where children born with all of the aforementioned traits were assigned and raised male because their external sex organ was large enough to "look" like a penis.¹ These cases demonstrate that the sex a person is perceived to be, rather than how the person may or may not fit into a scientific definition, often carries the most weight in our society.

The importance given to appearance is due to the fact that our culture responds to the visual aspects of sex more than scientific ones. In most interactions, for example, we don't know for sure what chromosomal patterns or internal biological functions someone has—yet we feel comfortable viewing and treating them as a certain sex.

In turn, people perceived as a certain sex, and living as it, usually prefer to use the labels and language associated with that sex. For example, someone who looks male and is living as a man would, in most cases, want their phallus to be called a penis. How would it impact this person to be told they should call it a clitoris because it lacks a urinary tract? Conversely, if an individual has a small phallus that this person doesn't think of as a penis, should it be called one because it has urinary function?

How would this impact the person if they looked female and were living as a woman?

While the examples above are based on individuals born and living with intersex traits, they could also apply to transgender individuals. We note that many people hold negative beliefs about trans people, known as transphobia, often based on the idea that being trans is not "natural," or that trans people are not accepting of who and what they "really are." These views are unfairly applied to trans people when you consider that the same could be said about many, perhaps even most, non-trans individuals.

For example, how many female-born individuals, who live as women, do "unnatural" things to their bodies in order to create the ideal version of their womanhood? Things like hair removal, breast implants, and even, simply, makeup, are all examples of the many ways in which non-trans women frequently and consistently alter their natural appearance in order to look more "womanly," so to speak. It is also very common for male-born men to alter their bodies—often from a young age with weight lifting or even steroids, or more recently, as adults, with modern procedures like pectoral implants—to appear more "manly."

All of these practices exist because of the strong social relevance our society gives to gender and gender expression. Some female-born women feel their breasts are "too small" to embody the women they feel themselves to be. Many trans women feel similarly and get breast implants for the same reason. Whether transgender or not, many people choose to change things about their natural sex traits to better embody their internal gender identity.

There is a deep relationship between the gender someone is perceived as, and/or feel themselves, and how we view and refer to their sex parts. Simply put, we don't live in a world where biological sex traits are viewed neutrally and given no social significance or impact. If we did, the birth of intersex infants

would be treated and celebrated just like that of male and female babies. But this is far from the case, as we will explore later in this chapter.

Even the term "ambiguous genitalia," although medical in use and origin, is more socially than scientifically informed. If a phallus isn't a penis or a clitoris, then isn't it, scientifically speaking, something else? The fact that we do not acknowledge natural variation even at the level of our external genitalia demonstrates that social norms and customs outweigh scientific fact when making decisions about defining sex. If we acknowledge the fact that some people are born intersex, and that sex organs exist that are not exactly clitorises or penises but a blend of the two, such organs are not ambiguous at all. If anything, they could be more accurately deemed androgynous or genital variant.

Despite our social norms, some people are comfortable with their androgynous phalluses. Indeed, the intersex co-author of this book falls under this description and has met others who feel similarly. Some live and identify as men, some as women, and some as neither or both, known as non-binary.

We have been taught to think that sex is always defined as an either/or between two possibilities: XX + ovaries + clitoris = female, or XY + testes + penis = male. However, as the cases explored in previous chapters demonstrate, not all human beings are born this way. It is important to realize that when we look at someone and make an assumption about their "sex," usually within a split second, we do it without knowledge of their chromosome pattern, internal reproductive organs, or even their external genitalia.

As Chapter 7 will explore, there are cultures that have acknowledged for centuries that sex exists beyond the two possibilities of male and female. However, Western society often repressed sex and gender-diverse people found in certain indigenous cultures they encountered.<sup>2</sup> When there are

exceptions and a person doesn't fit neatly into a male or female "box," the Western response has been to assign and raise these babies either male or female regardless. In this process, physical appearance has always been the primary factor for determining if someone is assigned "male" or "female."

Once medical advancements permitted, infants and children born with genital variance began to also be subjected to nonconsensual, "medically unnecessary" genital surgeries to create genitalia akin to what is present among typical males or females. These surgeries, entirely cosmetic in nature, were performed, and continue to be at the time of this writing, in an effort to enforce the chosen sex assignment. In addition, hormone therapy was often recommended and administered by medical providers, at a later age, to assist the development of the assigned sex.

The process of surgically altering genitals and other sex traits in order to change one's natal sex was originally known as sex reassignment surgery. Subjecting babies to this practice could be accurately described as *infant* sex reassignment surgery, and would be considered deplorable by most. Indeed, allowing even *teenagers* who want to undergo these procedures is viewed as problematic because many people's sense of self is still evolving during adolescence.<sup>3</sup>

However, when performed on *intersex* babies, until quite recently infant sex reassignment surgery has been considered acceptable. Historically, these surgeries have been performed to reassign intersex babies' sex to either male or female, a practice often referred to as "normalizing surgery," or "corrective surgery," by the medical community. These terms illustrate how being intersex is often stigmatized as a birth defect in need of correction by the medical community, rather than accepted as a naturally occurring sex variation.

We note that, today, the term "sex reassignment surgery" has been replaced by the term "gender affirming or confirming

surgery" by the transgender community, and we support this.<sup>4</sup> However, in contrast to transgender adults who voluntarily choose to undergo procedures to affirm their gender identities, intersex infants are subjected to these procedures involuntarily, with no awareness of their future gender identity. So "gender affirming or confirming surgery" cannot be accurately used in these cases.

Nobody likes being stigmatized, and it is thus not surprising that intersex individuals and allies reject the terms "normalizing surgery" and "corrective surgery" to refer to infant sex reassignment surgery. Instead, the practice is most commonly referred to by community members and allies as "medically unnecessary, nonconsensual genital surgeries," or sometimes as "intersex genital mutilation" (IGM). The latter term is used due to the practice's similarity to female genital mutilation (FGM).

Some cultures practice FGM, which can involve partial or complete removal of the external portion of the clitoris.<sup>5</sup> According to practitioners and critics alike, the reasons for cutting clitoral tissue are to enforce cultural norms of female "femininity" and "sexuality." As of 2019 in the United States a majority of states have banned the practice of FGM.<sup>6</sup> One could argue, as highlighted in a *Harvard Law Review* article, that the removal of clitoral tissue from a female baby born with an enlarged clitoris is performed for similar reasons as FGM.<sup>7</sup>

IGM has been criticized as a human rights violation of physical integrity, bodily autonomy, and self-determination. In addition, an increasing number of medical and human rights associations have found the practice of IGM to be not only psychologically harmful but also irreversibly harmful to the physical body, for reasons explored below.<sup>8</sup> However, at the time of writing, only one state, California, is considering legislation to ban the practice.

IGM can result in physical pain, urine leakage, bladder infections, loss of sexual sensation, pain with intercourse, hot

flashes, osteoporosis, and/or absence of sexual desire, arousal and orgasm. One may wonder why producing an absence of sexual desire in females who are born with large clitorises has not been criticized in the same manner it has been for victims of FGM. Is it possible IGM has been justified as a means to ensure that those assigned female adhere to social norms for women—the same rationale used to justify the practice of FGM within some cultures?

The clitoris is not the only sex organ affected by IGM. It is not unusual for atypically small penises to be characterized as defective or insufficient. Rather than allow those born male but with small penises to be assigned male and raised as boys, it has often been considered preferable in the West for these individuals to be subjected to sex reassignment surgeries as infants to make them "female." This is often the case with male children born with 5-alpha reductase deficiency (5-ARD).

# 5-alpha reductase deficiency (5-ARD), a.k.a. Güevedoce

In the absence of the enzyme 5-alpha reductase (called 5-ARD) the developing fetus with XY chromosomes does not make a form of testosterone known as dihydrotestosterone (DHT), and without this type of androgen their external sex organs develop differently than usual. Sometimes their external genitalia appear typically female, sometimes "androgynous," and sometimes male but with small penises that oftentimes have a urethral opening on the underside of the penis (hypospadias).<sup>10</sup>

In cases where babies with 5-ARD appear typically female, they are often assigned female and raised as such. In all cases, however, at puberty an increase in the level of testosterone leads to the development of secondary sex characteristics that are not directly involved in reproduction, such as deepening of the

voice, development of pubic hair, and increased muscle mass. In addition, the increased testosterone will compensate—albeit modestly for the lack in DHT—to spur the phallus and scrotum (the body fold that holds the testes) to grow larger.

This pubertal development is responsible for the term "Güevedoce" in the Dominican Republic, where 5-ARD is more common.<sup>11</sup> In Spanish, the governing language of the Dominican Republic, *huevos* means eggs, and is also slang for "balls" or testicles. Güevedoce is a contraction in the local dialect of the Spanish phrase, *huevos a los doce*, meaning, "balls at 12," or more formally, "testicles at 12."

Statistics have shown that when children with 5-ARD are left alone and not surgically altered, most, but not all, grow up to have the gender identity of a man—even if they were raised female. Indeed, in the villages in the Dominican Republic where 5-ARD is more prevalent, it is sometimes celebrated when a child they believed to be female naturally transforms into a male and assumes a gender role as a man.<sup>11</sup>

Why do we subject male babies with 5-ARD to IGM in nations that follow Western medical protocols? Is it because male happiness and well-being have often been equated with having a large penis?<sup>12</sup>

## Partial androgen insensitivity syndrome (PAIS)

IGM is also performed without any regard for a child's gender identity in cases of partial androgen insensitivity syndrome (PAIS).<sup>13</sup> Children born with PAIS have XY chromosomes and partially working androgen receptors (see Chapter 4) that can also lead to the development of a small phallus. As in cases of 5-ARD, these children are sometimes surgically outfitted with female genitalia in nations that practice Western medical protocols.<sup>9</sup> Hence, it is not unusual to find individuals physically

altered to look like females who will grow up to identify as boys—boys who will wait in vain for their penises to develop. The physical and psychological trauma these children sustain cannot be overstated.

What if a child with PAIS or 5-ARD, who has been subjected to sex reassignment surgery to create a "female" body, grows up to identify as a boy who is sexually attracted to girls? The person would likely be labeled a lesbian, but in reality the individual's sex was originally that of an intersex male. If the child had not been subjected to medically unnecessary cosmetic surgeries the child would have maintained a body more akin to a typical male, albeit with some genital variance, and would have been viewed as heterosexual. Moreover, as several cases demonstrate, the individual might reject their forced female sex reassignment and want to live their life as a boy/man to reach a place of "wholeness," psychologically, physically, and socially.

An infinitely more respectful and psychologically healthy alternative would be to support individuals' self-determination. Shouldn't everyone have the right to grow into their true gender identity and sexual orientation without having to endure interfering surgeries that attempt to force certain outcomes?

Sex reassignment of a male baby to female requires castration, and like clitoral reduction surgery, castration of a small penis results in an impairment of the individual's capacity for sexual desire, arousal, and orgasm. But similar to females who have had their clitorises reduced, their sexual capacity is deemed unimportant. Is this because maintaining the illusion of the sex binary is paramount and believed to necessitate the possession of "normal"-looking genitals, no matter the physical or psychological cost?

Despite a long-standing debate over the ethicacy of IGM,<sup>14</sup> and the multitude of reports from former patients about resulting psychological and physical harms,<sup>15,16</sup> proponents of

IGM have maintained that the appearance of an individual as clearly male or female is paramount.

Society can't accept people of different colors, and now we're supposed to accept somebody with genitalia that don't match what their gender is? I do not believe this society is ready for it.<sup>14</sup>

People from time immemorial have had accidents of nature and presented kids with partially formed genitals that they didn't understand.<sup>17</sup>

In 2019, doctors with a stakehold in cosmetic genital surgeries on intersex infants and minors opposed proposed bans on these practices in California and Connecticut (State Bill (SB) 201 and SB 388, respectively). California's SB 201 states, "The bill would authorize a physician and surgeon to perform the medical procedure without the minor's consent if it is medically necessary and the physician and surgeon provides the written and oral disclosure to the parent or guardian and obtains their informed consent, as specified." Despite the fact that SB 201 would only prohibit cosmetic procedures on infants and minors too young to consent, the California Medical Association, an influential lobbying arm of doctors in the Capitol, and the Societies for Pediatric Urology, both opposed it. 19

#### Intersex genetic testing

Although screening embryonic or fetal DNA for the presence of chromosomal variances and/or gene mutations has become routine, the bioethical issues surrounding this type of testing are fraught with controversy. Depending on test revelations, a decision can be made to: destroy or implant an embryo created via *in vitro* fertilization or terminate or maintain a pregnancy.

In the case of diagnosing CAH, the question of whether to treat a fetus *in utero* (during pregnancy), in an attempt to avoid the development of an enlarged clitoris, can arise. This often happens after a mother gives birth to a child diagnosed with CAH and becomes pregnant again. The chance her second child will have CAH and be female (see Chapter 5) is 12.5 per cent (a 25 per cent chance the child will have CAH multiplied by a 50 per cent chance of having an XX child = 12.5 per cent).

However, the virilization that causes the development of an enlarged clitoris happens early, before ten weeks into a pregnancy. This is before CAH can be detected in the fetus via tests such as chorionic villus testing or amniocentesis.<sup>20</sup> Thus, those trying to prevent the development of an enlarged clitoris would have to subject the fetus to unnecessary chemical treatment before knowing if CAH is present.

The chemical treatment of choice is dexamethasone (Dex).<sup>21</sup> In Sweden, the only country where long-term studies of the drug have been performed, prenatal use of Dex was banned due to findings that linked it to birth defects and to a decreased ability to process and manipulate verbal information.<sup>22</sup> In other words, the use of Dex has been found to adversely impact the cognitive abilities of future females.

Some medical practitioners have argued that the ability to dampen virilization in female fetuses is beneficial for the ultimate sociological and psychological well-being of the child. They cite studies that have found female children virilized by CAH are more "tomboyish" and less likely to be interested in typical gender roles, such as heterosexual marriage, as adults.<sup>23,24</sup>

However, academics, intersex advocates, and American LGBTQIA+ community leaders have critiqued the prenatal use of Dex to secure development of females with typical genitalia and heterosexual gender role expression. They argue that the practice is sexist and homophobic because it risks harming

#### The Spectrum of Sex

the intellectual abilities of females in an attempt to ensure they adhere to sex and gender norms. <sup>25,26,27</sup>

Indeed, biological systems operate freely, without the ideological constraints that religious beliefs, politics, and social constructs impose. The genetic and physiological mechanisms that underpin life on this planet are elegantly complicated, affording unbridled variation. It seems only sound and natural that our social mechanisms be equally complicated and varied as well.

#### FINDING ME: IT'S A HERM!

#### Dana Zzyym

When I think about what my mother's doctor might have thought when I was born, I laugh. Boy, girl... WTF? I wasn't what anyone expected. The doctor declared a medical emergency because no one knew what to do.

Ultimately, I was assigned male, but as I realized later, with multiple surgeries performed to "assist" in the assignment. However, I never felt that I was the boy/man everyone said I was. It took me 50 years to start to figure that out, despite the hints I'd had all along.

I joined the Navy as a young adult, in part to prove my maleness to the world. When I compared myself to other men while there, I noticed that my penis was very small. No one had one that looked like mine. My scrotum looked different too; it didn't hang like the others. These issues were combined with the fact that I'd always had urine leakage, and that both my penis and scrotum hurt all the time.

Despite this, I got to marry a wonderful woman. But when the relationship ended I was forced to do some deep soul searching. I realized that my many issues had interfered with my marriage, and that they stemmed from the surgeries that were performed on me when I was very young. Not just the resulting pain issues I had, which were worse during sex, but also severe trust and intimacy issues due to the way I've been treated by everyone involved in "caring" for me as an intersex person.

I decided to get counseling and contacted Veterans Affairs (VA), as I was a Navy veteran having served three tours of duty in Beirut. I also searched the internet to see if I could find any information about penises like mine. I couldn't, but my search did yield a word: intersex. It exposed a whole new world to me, but I wasn't really clear about what it meant.

I began speaking to both a psychiatrist and a therapist about all the unusual incidents during my childhood, as well as the emotional issues created by these events that still persist to this day. The "hints" that I was different from my brothers included things like waking up in hospitals and not knowing how I got there, and of course the multiple surgeries I underwent between three and six years of age. Also, from the age of six through eleven, every time I'd needed to see a doctor, for whatever reason, I was put up in stirrups, tied down, and a parade of doctors looked at me and touched me. I hated men for that.

Later, starting at the age of 15, I'd been forced to take "special vitamins" every day. I suspect they were hormones and/or puberty blockers, but whatever they were they changed my body. I started to gain weight and no longer had the stamina to ride my bicycle for miles, as I previously had.

My therapist encouraged me to see a urologist, who told me I was born with "ambiguous genitalia." He said the surgeries I'd been put through had been done in response to that fact. I was angry, but I finally had an answer, or rather an explanation, for my childhood trauma.

The urologist helped me confirm that I was not born a typical boy or girl—but what did that really mean? I didn't know what else I could be because I thought of sex and gender as only binary in those days. The only thought that I could muster was that if I wasn't one of the sexes, male, I must be the other.

In anger, I called my mother and told her that she and my dad had cut me to look male, but I was born intersex and was a woman—a trans woman at this point since I'd have to transition from my assigned male sex. I wanted surgery on my male genitals anyway, to try to alleviate the pain I always felt. My mother cut me off when I told her these things, but my father apologized for the surgeries and everything else that had happened to me because I'm intersex. This began the process of healing the life-long rift that we'd had between us.

I was euphoric to think I finally knew who I was, but it didn't last long. I soon realized that I was not a trans woman either. Despite having surgeries to remove my constructed penis and scrotum, and to construct a vagina—which I did because my surgeon said it might provide sensations of pleasure or orgasm—I didn't feel like a woman. The physical pain also still persists to this day, from internal scarring; but much of it is gone and I'm happy to have the part of my body that was someone else's idea of who I should be gone as well.

The urologist hadn't used the word "intersex" when informing me that I have "ambiguous genitalia." As I tried to figure out who I am, however, I realized that if I wasn't male or female, intersex—also known as being a "hermaphrodite," or "herm" for short—was the only thing left.

I became depressed, having never heard of anyone being any of these things. I went back to the internet and found intersex people, organizations, and every book I could on the subject. After several months, my depression lifted when I finally acknowledged the truth.

It was hard to admit I was intersex because I'd been raised to think that sex was binary—only male or female—and I didn't want to be outside a system our whole society is based upon. But I eventually recognized that everybody has something unique in their makeup that makes them different from everybody else. This allowed me to accept that being intersex is just one of the many different ways of being human.

Once I did, I experienced a calm and peace about myself. I realized it was okay to be intersex, or a herm, as I call myself, and that I was normal. That in fact, I was born and was perfect—until I was cut.

I realized I needed to do what I could to stop other children from being subjected to the horrific surgeries and traumatic events I was forced to deal with. I thought about the civil rights movement and how Black people in this country had to fight to be recognized as fully human. I decided that if I could get a government entity to recognize me as an intersex person, then maybe I could help to achieve civil rights for all intersex people.

I started in 2011 at Colorado's Division of Motor Vehicles. Even though I followed the same procedure required for transgender people at the time, they wouldn't accept my request to amend my sex on my driver's license to intersex. They said if I had a passport with intersex as my sex marker then they would give me a driver's license with the same. I went to the Colorado Department of Regulatory Agencies and filed a complaint, but lost. The lesson I learned is something I've often been quoted saying, "If you're not written specifically into the law, you are specifically excluded from the law."

In 2012 I met a former Judge Advocate General's Corps (JAG) lawyer at a VA hospital who taught constitutional law. What I learned from him helped me figure out a plan to get an intersex passport. I tried to do so in 2014 because I was asked to represent the intersex organization I was volunteering

with, OII-USA (today the Intersex Campaign for Equality) at an international intersex conference in Mexico City. I was denied, appealed the decision, and was turned down again.

After reaching out to several pro-bono law firms, Lambda Legal stepped in to help. On October 26, 2015 we filed my lawsuit in the 10th District Court (Federal) in Denver to seek an intersex/non-binary passport with an "X" marked for sex. We chose that date because October 26th is recognized as Intersex Awareness Day. My lawsuit aims not only to bring awareness, but also federal legal recognition for all intersex citizens.

My case inspired others, such as my intersex colleague Sara Kelly Keenan, who became the nation's first non-binary Californian. To date, ten states now offer third gender recognition on IDs in the form of an "X." The X was originally selected by an intersex person in a passport case in Australia in 2003, and is the third gender marker commonly used in Western nations and states today. It was selected because the organization that governs international passports already had an X marker available, representing "Sex Unknown."<sup>28</sup>

On September 19, 2018, the Colorado Federal District Court judge ruled in my favor, stating,

This Court has already given the Department an opportunity to shore up the record and show that its decision to deny Dana Zzyym a passport was the result of rational decision making. For the reasons explained above, the Department failed to do so. Dana has been pursuing a passport for close to four years now. I grant Dana's request for injunctive relief and enjoin the Department from relying upon its binary-only gender marker policy to withhold the requested passport from Dana.<sup>29</sup>

However, the State Department still refused to issue me a passport, so my case has gone to the Court of Appeals. As of this writing I'm waiting for a date for oral augments in the appellate court.

Many people don't realize that we are not just being cut and/or subjected to medically unnecessary hormone therapy as children; we are also being forced into and raised in a binary society. Even though we are born with non-binary bodies, this society makes us choose between being boys/men and girls/women. It erases us with its binary viewpoints and structures. While not all intersex people identify as non-binary, we're all at risk of being cut up as babies or young children to fit into the male/female binary system.

This is why I continue my battle for sex and gender recognition. I can't undo my own suffering, or change its terrible impact on my life, but the depth of it pushes me to fight for an end to medically unnecessary surgeries on the genitals of children. It's the bureaucratic structures that need to be fixed to accurately include our existence, not the other way around.

# Chapter 7

# Which Came First, the Chicken or the Egg?

#### Sex and Gender

What did come first, the chicken or the egg? To know this, we first need to understand that sexual reproduction involves two individuals who provide genetic information to form a novel individual. We can now see that sexual reproduction between a proto-rooster (male) and a proto-hen (female) could have given rise to a chicken egg. In other words, the egg came first, as Astrophysicist Neil deGrasse Tyson described in a succinct Tweet, "The egg—laid by a bird that was not a chicken." When it comes to sex and gender, however, the relationship between the two cannot be chronologically ordered in the same way as this age-old question.

The term "sex" is defined as: "Either of the two main categories (male and female) into which humans and most other living things are divided on the basis of their reproductive functions." As this definition reveals, reproductive function is the very basis for the category of sex.

Given that reproductive function is the basis for sex classification, the fact that intersex is often not acknowledged equally along with male and female is due, in part, to the uncertain role intersex individuals play in reproduction. As explored in previous chapters, many intersex individuals are infertile, and in cases where they are not, there may be sociocultural factors limiting their ability to engage in reproduction, as we explore in this book. Yet the fact that the existence of intersex individuals *has* been historically acknowledged, despite this, is a testament to the demonstrable nature of human sexual anatomy. It exists, regardless of how we name or categorize it.

However, our ideas surrounding the term *sex* do not solely center on sexual reproduction and the creation of novel offspring. When many of us think of someone's sex we also take into account that person's "gender." Long before the intricacies of internal reproductive organs or chromosomes were understood, humans created terms to describe different members of the species, and it's significant to note that these terms were created to address different types of behavior—which is often defined today as gender role—as well as particular sex parts.

Many are aware that although "sex" and "gender" are often defined and used similarly, they are historically distinct terms. *Gender* was originally used to refer to a "kind" of person or thing, but this use was discontinued by the beginning of the 20th century.<sup>3</sup> After that, it was used to refer solely to "grammatical gender" in languages such as Spanish and French that assign masculine or feminine traits to nouns.<sup>4,5</sup> The meaning of *gender* shifted to refer to humans beginning in the 1950s, to describe how individuals express and perceive themselves as men, women, or something else.<sup>6</sup> This meaning is expressed in the second part of the definition shared below.<sup>2</sup>

*Gender*. Noun. Either of the two sexes (male and female), especially when considered with reference to social and cultural differences rather than biological ones.

The term is also used more broadly to denote a range of identities that do not correspond specifically to one's sex. Binary terms used to describe one's gender or gender-based

characteristics are woman/girl, man/boy, and feminine/masculine.<sup>7</sup>

Sexual anatomy defines individuals as male, female, or intersex, but these categories are also thought, in most societies, to give one a certain *gender* as man, woman, or non-binary, respectively. This connection between sex and gender has deeply informed most societies, determining social activities, customs, employment, and law. In essence, the connection between sex and gender has often determined the type of life one could lead, and continues to do so in many cases and in many countries.

Even though the term "sex" has a distinct meaning from the term "gender," as it references the collection of characteristics involved in reproduction, as outlined previously, conflating the terms has been commonplace for nearly half a century. However, drawing a simple division between sex and gender is also inaccurate because biological sex itself is a gendered category, rather than a scientifically determined one, as the remainder of this chapter will examine.

# Was it really about biology? The gendering of sex

What do we mean by the phrase, "sex is a gendered category," particularly given the scientific definition of the term *sex*? One need only acknowledge one example of intersex, complete androgen insensitivity syndrome (CAIS), to understand. Before doing so, a review of the scientific definitions of all sexes is useful.

*Male*. Adjective. Of or denoting the sex that produces gametes, especially spermatozoa, with which a female may be fertilized or inseminated to produce offspring.

Noun. A male person, plant, or animal.<sup>2</sup>

*Female*. Adjective. Of or denoting the sex that can bear offspring or produce eggs, distinguished biologically by the production of gametes (ova) which can be fertilized by male gametes.

Noun. A female person, animal, or plant.2

*Intersex.* Adjective. Relating to or denoting a person or animal that has both male and female sex organs or other sexual characteristics.<sup>2</sup>

As reviewed above and covered in Chapters 2 and 3, a typical male possesses testes that are able to produce gametes known as sperm. However, as explored in depth in Chapter 4, people with CAIS are born with testes but are assigned female at birth, today and always. How could this be, if sex is determined on a purely scientific basis? The answer, in short, is that science is complicated and cannot be constrained and limited by two categories of sex.

As explored in Chapter 4, individuals with CAIS have historically been assigned female at birth, and continue to be, for very good reason: they *look* female, at birth and through adulthood. In addition, incorrect sex assignment has not been an issue for CAIS individuals because in the vast majority of cases they grow up to identify as women.

Given that appearance is historically all we had to go on when sexing babies, and often still is, it makes sense for babies that look female to be assigned female. Conversely, as we have seen in Chapter 5, there have been cases where individuals with ovaries that produce eggs—a trait that would make one female by definition—were assigned male at birth and reared as such because they appear male. To do otherwise, and assign babies to grow up as a sex that they belong to, by definition, but do not appear to be, would create numerous social complications.

The cases cited above are evidence of the fact that sex is not the simple, straightforward category that many assume it to be. In fact, in Western society, the category of sex itself is determined most significantly by our attitudes regarding what is known as gender. This has been explored by numerous scholars, and can be witnessed most readily by the way Western society has responded to the birth of babies who are neither male nor female, but rather, intersex.

In Sexing the Body: Gender Politics and the Construction of Sexuality, biologist and scholar Anne Fausto-Sterling examines early research on the intersex population by sexologist John Money, noting:

...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.<sup>8</sup>

Later, doctors who encountered intersex babies at birth followed this paradigm, telling parents that they simply needed a little more time to determine whether the infants were "actually" male or female.

How could it take time to figure out a baby's sex, if sex is determined simply by one's physical status at birth? The situation reveals that the "actuality" of intersex babies' bodies and sex has been denied and hidden in order to construct and uphold a culturally based system of sex that is exclusively male and female.

Fausto-Sterling further explores the cultural basis of sex determination by examining how intersex babies might be assigned male or female depending on the location of their birth:

A group of physicians from Saudi Arabia recently reported on several cases of XX intersex children with congenital adrenal hyperplasia (CAH)... In the United States and Europe, such children, because they have the potential to bear children later in life, are usually raised as females. Saudi doctors trained in this European tradition recommended such a course of action to the Saudi parents of CAH XX children. A number of parents, however, refused to accept the recommendation that their child, initially identified as a son, be raised instead as a daughter. Nor would they accept feminizing surgery for their child... This was essentially an expression of local community attitudes with...the preference for male offspring.<sup>9</sup>

Today, many societies have chosen to limit the categories of sex from those that naturally occur—male, female, and intersex—to only those that support societal beliefs and customs, that is, male and female. This limited construction of sex in turn creates either a "difficulty" in assigning sex to intersex babies, or the assignment of a sex that is not, by definition, accurate.

As gender theorist Judith Butler notes,

...perhaps this construct called 'sex' is as culturally constructed as gender; indeed, perhaps it was always already gender, with the consequence that the distinction between sex and gender turns out to be no distinction at all.<sup>10</sup>

Butler is referencing the fact that sex and gender have been historically conflated whenever necessary to uphold our culturally constructed notions of each. This is evidenced most easily in the case of CAIS described earlier in this chapter.

#### Butler continues,

It would make no sense, then to define gender as the cultural interpretation of sex, if sex is itself a gender-centered category. Gender should not be conceived merely as the cultural inscription of meaning based on a given sex (a juridical conception); gender must also designate the very apparatus of production whereby the sexes themselves are established.<sup>11</sup>

The statement references something that was introduced earlier in this chapter: the male and female sex categories were created to describe one's potential to embody the socio-cultural roles of mothers or fathers. Contrary to the popular assumption that gender is an offshoot of sex, the male and female categories of sex are based on our cultural notions that all humans are either men or women in terms of their gender.

# Was it always binary? Historic acknowledgement of sex diversity

Biologists and other scientists have long known that sex is expressed in a multitude of ways too complicated to be accurately encompassed in only two categories. Nevertheless, there has been a concerted effort in many societies to limit the recognition of biological sex to the two categories of male and female. However, there are examples where other cultures have recognized the diverse expression of biological sex, such as many of the indigenous tribes of the Americas. As explained in the personal story, "On Being Native and Intersex" in Chapter 3, the Navajo traditionally recognized four genders, within which intersex people were included.

Similarly, ancient Jewish texts acknowledge the existence of six different sexes. 13 These include:

- Zachar: what we define as "males" who identify and live as men.
- *Nekevah:* what we define as "females" who identify and live as women.
- Androgynos: a person who has both "male" and "female" sexual characteristics. There are 149 references to the androgynos sex in the ancient Jewish texts of the Mishnah

and Talmud (1st-8th centuries CE); 350 in classical Midrash and Jewish law codes (2nd-16th centuries CE).

- *Tumtum*: a person whose sexual characteristics are indeterminate or obscured; 181 references in Mishnah and Talmud; 335 in classical Midrash and Jewish law codes.
- Ay'lonit: a person who is identified as "female" at birth but develops "male" characteristics at puberty and is infertile;
   80 references in Mishnah and Talmud; 40 in classical Midrash and Jewish law codes.
- Saris: a person who is identified as "male" at birth but develops "female" characteristics at puberty and/or is lacking a penis. A saris can be "naturally" a saris (saris hamah), or become one through human intervention (saris adam); 156 references in Mishnah and Talmud; 379 in classical Midrash and Jewish law codes.

The descriptions for these different sexes mirror what we know today about different intersex populations. <sup>14,15,16</sup> For example, a tumtum would describe an intersex person with genital variance and other characteristics that make identifying the person as either male or female difficult. Also, as explored in Chapter 6, individuals with an intersex variation known as 5-alpha reductase deficiency (5-ARD) would be referred to as Ay'lonit within the ancient Jewish definitions. These individuals often appear female at birth and throughout early childhood, but in puberty their bodies begin to masculinize to the point of appearing male due to an increase in testosterone production.

Additionally, these categories include variations that are not limited to sex characteristics, as seen in intersex people, but also provide for variations in gender identity, as seen in transgender people. As outlined by the text, a *saris* could refer to either intersex or trans individuals. This is because a

saris—one identified as male at birth but who develops female characteristics at puberty and/or is lacking a penis—can be "naturally" a saris (saris hamah) or become one through human intervention (saris adam). This "becoming" definition would apply to trans women born with male sex characteristics who live their life as women with regard to gender identity, regardless of whether they undergo gender reassignment surgery to become more female-bodied or not.

The Bugis of Indonesia are another culture with a complex system of sex and gender classifications. They are the largest of the three ethnic groups found in Southern Sulawesi, the third largest island in Indonesia. According to the Bugis, humans are comprised of the following five categories:

- *Oroané*: "manly men," those born with male sex characteristics who grow up to be men.
- *Makkunrai*: "womanly women," those born with female sex characteristics who grow up to be women.
- *Bissu*: imagined to be hermaphroditic beings who embody female and male elements. While it is enough that one's body is imagined hermaphroditic, while often being anatomically male, *bissu* consciously dress in ways that highlight male and female characteristics.
- *Calabai*: those born with male sex characteristics who take on the role of heterosexual females as adults.
- *Calalai*: those born with female sex characteristics who take on the roles of heterosexual males as adults.

The groups are defined according to the physical traits they are born with, defined in the West as "sex," and also by the social roles and behaviors they take on as adults, defined in the West as "gender role," "gender expression," "gender identity," or often simply, "gender." Accordingly, anthropologist Dr. Sharyn Graham noted in 2001, that,

The Bugis acknowledge three sexes (female, male, hermaphrodite), four genders (women, men, calabai, and calalai), and a fifth meta-gender group, the bissu.<sup>17</sup>

As outlined in a National Geographic documentary about the Bugis:

...all five genders must co-exist for there to be universal harmony. 'There are five genders,' Bissu high priest Pooang Matoa explains, 'and we don't need to separate people based on their gender because everything must live in harmony. If one of the genders is separated, then the world would become unbalanced.'18

During 15 months of extensive ethnographic research in Indonesia, Graham learned that *bissu* "...are a combination of all genders. To become a *bissu*, one must be born both female and male, or hermaphroditic. (To be precise, the Bugis believe that a *bissu* who appears externally male is internally female, and vice versa.) This combination of sexes enables a 'metagender' identity to emerge."<sup>17</sup>

Interestingly, the Bugis' acknowledgement of the *bissu* population incorporates an understanding of non-binary sex (intersex) as well as gender identities that have recently emerged in the West. Given Western society's focus on being an "advanced civilization" based on superior scientific knowledge rather than on ancient and unscientific outdated beliefs, one would think that it would have a classification system of sex and gender at least as sophisticated as the Bugis. Instead, it has adopted and vigilantly enforced a simplistic binary system that rejects both scientific evidence and citizens' lived experience.

Examining how the awareness of sex and gender diversity has been negotiated within Jewish culture provides a lens as to why a binary sex/gender system is often favored.

The Talmud, the central text of Rabbinic Judaism and the primary source of Jewish religious law and theology, acknowledges the "androgynos." In *Gender in Judaism and Islam*, religious studies scholar Charlotte Elisheva Fonrobert examines early, canonized rabbinic legal texts that provide an extensive list of laws for Jewish people.<sup>19</sup>

Specifically, Fonrobert evaluates how these laws are organized purposefully and explicitly according to gender categories, and the positioning of the *androgynos* within these categories reveals much about gender duality in Jewish culture.

Most basically, norms and laws apply to people as either men or as women... Further...there are laws that apply to people irrespective of whether they are men or women, grouped together as the 'ways of both men and women.' The referential categories 'men' and 'women' remain in place... it is the reality of the person who is both man and woman, and therefore something else (and androginos) that puts the rabbinic logic of gender duality to a test.<sup>20</sup>

Within these laws, *androgynos* are categorized in four ways: as similar to men, as similar to women, as similar to both men and women, and as similar to neither men nor women.

Consider for a moment the last two groups... Under the first heading we find the laws of capital crimes, where what seems to matter is that the victim is human: 'people are held responsible for any damage caused to him'..., just as when the victim were a man or woman. After all, it is not gender that establishes victimhood. But the framing: 'like both men and women' does not translate into 'gender does not matter.' On the contrary, it makes gender duality the referential framework.<sup>21</sup>

Why were the authors of rabbinic Jewish law interested in establishing a binary system of gender duality within daily observational Judaism? As explored, "...rabbinic halakhic discourse institutes a functional gender duality, anchored in the need of reproduction of the Jewish collective body. As such, it aims to enforce and normalize a congruence between sexed bodies and gendered identities..."<sup>22</sup> The focus on reproduction—which, as discussed earlier, is the basis for sex classification—in turn necessitates a focus on sexual behavior as well as gender expression.

Although the texts on these laws include the minority opinion of "Rabbi Yossi who insists that '...an *androgynos* is a *creature* in his own right and the sages could not decide whether he is man or woman" within the majority of opinions, *androginos* are positioned entirely within the binary man/woman framework. The impact, as Fonrobert explores, is a cultural enforcement of gender duality, even while examining those who fall outside of it.

That is, we can read the emphatic insistence on gender duality...as calling into question the logic of duality at the very moment of justifying it, following a Shakespearian hermeneutic principle: 'The lady doth protest too much, methinks.' The more emphatic the justification, the less self evident is the logic of duality.<sup>24</sup>

More recently, political and religious developments in Indonesia have had a similar, binary enforcing impact on sex and gender classification within the Bugis culture examined earlier. Originally, the *bissu*—those with characteristics of both genders—were highly valued as priests and spiritually gifted members of society, often given positions in the royal palace as well as land and fields of their own. After Indonesia gained independence from Dutch rule in 1949, however, Islamic fundamentalist regimes that came to power persecuted those who expressed sex and/or gender diversity.

"They were banished," explains anthropologist Halilintar Lathief, in an article chronicling his efforts to revive *bissu* presence in Bugis society. In the 1950s, the Islamic group Muhammadiyah banned the *bissu*, and an Islamic mob decapitated the city of Bone's *bissu* leader and paraded her head around town. "All of that trauma lasted several generations," Lathief explains. "It is amazing there are actually any Bissu these days." <sup>25</sup>

Similarly to the ways in which Jewish tradition favored typical males and females in their legal traditions and daily life practices, the new Islamic leaders in Indonesia also favored civic presence and participation by traditional males and females. Worse, while Jewish law acknowledged and allowed for those with sex variance to be socially positioned as women or men in order to participate in Jewish culture, Islamic law in Indonesia sought to eliminate any acknowledgement of sex diversity, and to limit civic participation only to men born male and women born female.

This left no place for *bissu*, *calabai*, and *calalai*—those known as intersex and transgender people in our society—to live openly. Thus, many went into hiding. As the article chronicles, "One bissu from a village near Sigeri learned to dress so convincingly as a woman that to this day no one in the village knows she was born male."<sup>25</sup>

It is interesting to note that this state of living in hiding is remarkably similar to what many intersex and transgender people have experienced in Western nations for centuries. While many view intersex, transgender, and gender-nonconforming (behavior or gender expression by an individual that does not match masculine or feminine gender norms) communities as a new social development, history tells us this is not the case. Transgender, gender-nonconforming, and intersex people have always walked the Earth, albeit often in "the shadows" and undetected.<sup>26</sup>

Just as Judeo-Christian customs and beliefs informed the suppression of sex and gender-diverse communities within Jewish and Indonesian culture, they have also had this impact in many nations around the world, including the United States. In *Bodies in Doubt: An American History of Intersex*, scholar Elisabeth Reis chronicles the role religion has played in the marginalization of the intersex community within the United States.<sup>27</sup>

Simply put, religious beliefs have limited our cultural acceptance of sex to the categories of male and female, resulting in the suppression of sex and gender-diverse people as well as a constrained understanding of how sex and gender are actually interrelated in many people's lives. Once sex is framed as consisting exclusively of two "opposite" male and female categories, then gender identity can be framed as being naturally limited to the two "opposite" categories of "man" and "woman."

This positions everyone who does not fit into the male/man or female/woman framework as deviant citizens, with the level of deviance determined by how much one's identity or behavior differs from cultural norms. For example, while female children known as "tomboys" deviate from traditionally feminine modes of dress and behavior considered appropriate for those gendered as girls, it is now acceptable for girls/women to wear clothing originally restricted to boys/men, and to behave in a manner considered masculine. Thus, female children who are "tomboys" are generally accepted within modern society.

If, however, female children grow up to deviate from cultural expectations for women—as lesbians, queer, gender-nonconforming and/or transgender adults—they will be marginalized for not satisfying traditional expectations for women. Such marginalization can range from peer and/or familial estrangement or rejection, to discrimination in the workplace, to vulnerability to extreme violence such as rape or murder.

The same is true for male children who do not grow up to satisfy cultural expectations for men, who often have more restrictions placed on them. For example, it is less acceptable for males to behave in ways deemed "feminine" than it is for females to behave in ways deemed "masculine." In addition, wearing women's clothing would make most male children immediately vulnerable to social scrutiny and in many cases, marginalization, unlike their tomboy peers.

As this book has explored in depth, an exclusively binary system of sex classification is scientifically inaccurate. The enforced sex binary has negative repercussions not just for scientific awareness, or for intersex people, but ultimately, due to the inherent connection between sex and gender, for all people who digress from cultural gender norms.

#### FORTUNE COOKIE WISDOM

#### Jonni Pettit with Angela Pettit

A fortune cookie I received while we were dating read: "You and Your Wife will be Very Happy." David said, "Keep it; it's funny." Now, it's in a scrapbook. We couldn't have known, then, it foretold our future.

David and I subsequently married in 1966 and spent the first 28 years as husband and wife. It may be difficult for some to accept, or understand, but for us, David's transition to Angela literally saved our marriage. (Note: David is used before the transition, S/he during, and Angela afterwards.)

The first five years were honeymoon-like, and then the Vietnam War intervened. David was a navigator in the Air Force and was involved in 16-hour-long bombing missions every third day. He would spend most of his off-time sleeping.

One day, his plane didn't return, and the Air Force couldn't find them. I wouldn't give up hope he would turn up safe. I stood at the runway and waited for him. I realized, then, he could be taken away in an instant, and I said aloud, "I can't live without him." I promised myself that when he came home nothing would separate us. After more than 24 hours we were finally told that David and his crew had landed safely in Thailand. Three days later, they came home, and all David could say was, "We ran out of fuel."

After the cease-fire we returned home to South Dakota—but life was not the same. David was unhappy. He became closed-off, uncommunicative, and compulsive. He was a wonderful father for our daughter, but as a husband he was distant, controlling and critical of everything—what I wore, what I did around the house, and of my career in journalism. I blamed his behavior on PTSD [post-traumatic stress disorder], but eventually learned it wasn't that at all. David was not a man, but had been pretending, for a large part of his life, to be one.

As Angela explains,

I'd known since I was a three-year-old I was in a body that wasn't right. I looked at myself and I didn't see me. When I was a child I dreamt of being changed into a girl. When I entered puberty I realized I was eroticized differently from other boys, who liked looking at *Playboy* and *Hustler* while masturbating. I preferred looking at a high-class fashion magazine. I would imagine how wonderful it felt to wear form-fitting dresses, nylons, and high heels. I was sure the fabrics were soft and silky.

I did everything imaginable to try and live as a man. I joined the Air Force and served my country in wartime as a much-decorated officer. No matter how masculine I acted, I longed to be a woman. I had a penis between my legs, but I didn't want it; I had no emotional connection to it.

The one good thing my life as a man gave me, though, was my wife Jonni. I loved her deeply when we married and still do. But trying to navigate an intimate relationship as a man was proving impossible as each year of marriage passed. I had no choice but to spend all my mental energy to make myself fit the expected male mold. But doing so left me no time for small things, like interacting with people more than necessary. This proved to be disastrous for my life with Jonni.

I grew up in the '50s, a time when our language didn't include the concept of transgender. A noted philosopher said, 'If the words to describe something don't exist, then you can't think the thought.'

After years of secretly wearing Jonni's clothes and even using a secret PO Box where I could have clothes and shoes delivered in my size, I finally told Jonni the truth: I needed to dress as a woman because I should have been born female. It was the scariest thing I ever did, scarier than any flight mission I engaged in during the war. Jonni looked at me and without missing a beat said, 'Yeah, so what, and what do we do now?' Jonni later told me that our life, all the bad and wonderful times, flashed through her mind in that moment. And there was no question, she still wanted a life with me. But the difference, she saw a real possibility at happiness, now that the truth was out in the open. She cried tears of joy.

I had spent so many years thinking Jonni would leave me and ask for a divorce. That fear was never realized. Telling Jonni the truth literally saved my life and marriage. The day after I spoke my truth, we shopped together, for women's clothing for me.

Eventually it became clear to both of us that David needed more than dressing in women's clothing. We sought help and found an outstanding therapist who guided us toward David's transition. We followed the Harry Benjamin Standards, where the requirement was for David to live as a woman for at least a year before having surgery. S/he did and together we found that going out in public felt scary, exhilarating, and wonderful, all at the same time.

S/he had beard removal and worked on changing her voice, and started taking anti-androgens, and estrogen—which forced her into puberty. The genitals shrank, and s/he grew small breasts and became overtly feminine. I found myself with a 57-year-old teenager, who wanted to wear short skirts, lots of makeup and perfume, and five-inch heels. It wasn't unusual for me to say, "You're not going out like that, and, if you do, I won't be going with you."

After three years of therapy and s/he living as a woman we traveled to Montreal, Canada for the sex reassignment surgery (now more appropriately called gender affirming surgery). A group filmed us through the process, for what was to become a Discovery Channel documentary: "Changing Sexes: Male to Female." When the swelling subsided and the healing process was complete, Angela's body had become aligned with her gender as a woman. The penis was gone. The "balls" were gone, and for the first time Angela was complete. She could finally look in the mirror and see the woman she should have been her whole life.

We are proof a good marriage can survive when there is a foundation of love and commitment. I am not sexually attracted to women, but I am attracted to my spouse who now happens to be a woman. I've always been a supporter of the LGBTQIA+ community, so being seen as a lesbian doesn't bother me. It makes me happy to be a part of an additional family of outstanding people. Angela, on the other hand, prefers to be seen as transgender and says, "being a lesbian negates the first 50+ years of my life as a man."

I had to learn to make love to a woman, and the learning was lots of fun. The twinkle in Angela's eyes is everything

to me. Angela is 97.9 per cent the opposite of David, and she's just as delightful as she was 23 years ago when she first started her transition.

#### NOTES FROM THE FRONT LINE

#### Les Hamanaka

When I was *in utero*, in the days before ultrasound was available, my mother and her obstetrician thought I was a boy. I was told they were quite sure of it, but I was born a "girl." My mother and her doctor's inkling about me has always seemed entirely plausible because I have never not given off a boy vibe. I'm pretty sure "vibe" is not a biological term, but it's something people have always managed to read about me at any age, even at a hundred paces.

I'm proud, and actually relieved, that I managed to find my authentic self early in life, even in the absolute Dark Ages of the LGBTQIA+ movement. I was about three years old, in my ubiquitous cowboy hat and boots. My mother knew I was happiest in boyish clothes and she just let me be, much to her credit, given that it was long before most people ever had a fleeting thought that gender and sex might possibly be non-binary. But my butch self was already discernible before I was born, when no one had any way to see or "know," or presume to have an opinion, about what sex or gender I was.

Of course, not everything goes swimmingly for those of us who are gender-ambiguous. For instance, the English language fails me. There are no nouns or pronouns that exist in English that represent me accurately. She/her or he/him? None of the above, please. And no salutation, either: no Mr. and no Ms. I suppose I am a woman but I'm really not like most other women. I feel like an imposter in any women's

locker room. I'm not a man either, but when I hang out with my straight male friends it's pretty obvious that we have the same interests and energy—the same vibe, if you will. They're comfortable with me because I'm comfortable with myself.

When a restaurant server approaches my wife and me, gives us a quick glance, and asks, "How are you ladies tonight?" I know she or he is trying to be polite but I actually feel uncomfortable and annoyed when referred to as a lady. My wife is fine being identified as a lady because that is what she is and how people read her. When a store clerk asks me, "Find everything you were looking for, sir?" I am far less annoyed but also wish my voice didn't usually give me away when I answer. When people realize I'm probably not a man, most responses include profuse apologies and some kind of an excuse, such as the clerk wasn't wearing his glasses or she only saw me from the back.

I honestly don't expect someone who is making a splitsecond determination of a stranger's sex or gender to have any idea about someone who purposefully expresses an ambiguous or opposite gender. I give zero clues that I am a female person so I certainly don't fault people for reading me as masculine. I am masculine. I only shop in men's departments (it's much easier online). But I wish people didn't feel compelled to make an immediate assessment at all about a person's sex or gender. How about we allow just a little more room for ambiguity?

Gender identity and expression can be subtle and nuanced. And don't even get me started on the racial aspect of gender expression as an Asian-American person in a majority white culture who has crossed the borderland between feminine and masculine. Suffice to say that there is a world of difference between being perceived as one versus the other, and neither is very flattering to the majority white culture.

The front line of gender ambiguity often emerges in public restrooms. I have been known to cause varying levels of

confusion, concern and/or outright alarm when I use public restrooms. I would use men's rooms more often if they weren't so gross. (Okay, so I'm gender-ambiguous with a teensy bit of OCD.) Most women mind their own business but sometimes I can sense those who have been overly indoctrinated into the rules of binary gender.

The most frequent experience I have when I walk into or out of a public women's restroom is that the next woman walking in or out thinks she's made a terrible mistake. She will typically check the signage on the door and then, convinced that she hasn't made a mistake after all, will go on with her life. Occasionally, a woman in the restroom will actually inform me, indignantly, as if I'm the most clueless dude in the world, that "This is the women's restroom!"

For some reason, these encounters are more frequent in airport restrooms and I can only assume it's because the people passing through airports are traveling to or from places in the world that are very unlike the Bay Area. I've lived in other regions of the US and have visited other parts of the world and it's clear to me that the general populace in the Bay Area simply does not pay as much attention to people who don't fall into binary gender classifications. That is worth a lot to me. Maybe the rest of the world will eventually head in the same direction.

I think the real strength of a gender outlier develops not in the wider world but in ourselves, and in the people who love and appreciate us. I discovered a long time ago that I really didn't care what anyone else thought about me as a gendernonconforming butch when a girlfriend thought I was fine just the way I was. And with no girlfriend I was still fine.

I remember reading Kate Bornstein's *Gender Outlaw* in the 1980s and agreeing with her, long before it seemed possible the day would ever come, that gender-nonconforming people can set everyone else free from socially imposed sex and

#### The Spectrum of Sex

gender dictates. What if these prisons exist only in your mind and you can actually be whoever you are?

I've lived in a gray zone of gender all my life. It means that I have to create my own space and educate random people any day and any time, sometimes just by walking down the street or showing up for a job interview. But that's okay—because, if not me, who will do it? I don't want to change myself. I want the whole world to change instead.

### Chapter 8

# Sex and Gender Terms

### Linguistic Collateral Damage

In not acknowledging the spectrum of sex expression, our ability to discuss the issues of sex and gender accurately and consistently is limited. For example, although it has become popular to point out the difference between "sex" and "gender," the language used by many belies a distinct understanding of the terms.

During the debate surrounding California's Proposition 8 court case, opponents of same-sex marriage invoked the phrase, "Marriage is between a man and a woman." The usage of the words "man" and "woman" was inaccurate because those terms refer to gender—as in gender identity, role, and expression—rather than natal sex. For example, while trans men not only identify as, but are often perceived to be and accepted as "men," they are not the people who marriage equality's opponents were referring to when utilizing the term "man." They were referring to those born with certain sex characteristics possessed by "males." This is highlighted in the case, *Kantaras v. Kantaras*.

In 2004 the Florida Court of Appeal invalidated the marriage between a post-operative trans man, Michael Kantaras, and a female person named Linda. Represented by her attorney, Matthew Staver of Liberty Counsel, Linda argued that the marriage was invalid because both individuals possessed the same XX sex chromosomes. Linda wanted the marriage invalidated as a strategy to win full custody rights of the children the couple had raised together. Staver argued that sex is an immutable characteristic that is fixed at birth, and because husband Michael Kantaras possessed XX chromosomes it meant this person had to be female. "What you're born with is what you are," Staver stated, and the court agreed.<sup>3</sup>

The conflation of sex and gender terms seen in the Proposition 8 case is nothing new, as the terms male/man and female/woman have been and are still regularly used synonymously. In fact, prior to the 1950s anyone born male was automatically defined as a man, and anyone born female as a woman. The transgender community had yet to become socially visible, and there was no public awareness that someone might have an internal identity that differed from the one associated with their birth sex.

The conflation of the terms male/female with man/woman began to erode in the 1950s due to sexologist, John Money, who worked with the intersex population. Unlike typical males and females, who were defined as men or women, respectively, this was not possible with intersex individuals whose sex as male or female was unclear. This created the awareness that an individual's identification as a man or woman did not always correspond with their biology.

In response, John Money introduced the concept of "gender role" to refer to the self-identification as men or women by intersex individuals whose sex as male or female was unclear due to genital variance. Critical to his work and the term's usage was the concept that an individual's gender role could differ from various biological definitions of an individual's sex. Money developed the idea that gender was mutable,<sup>5</sup> which informed his creation of guidelines that recommended surgical intervention to conform intersex infants' genitals to fit a male/man or female/woman "norm." The use of "gender role" grew

steadily, often shortened to "gender," among social scientists, and feminists in particular, as it enabled analysis of the cultural roles given to females.

By the 1980s, however, *gender* began to be used in place of the term *sex*. As outlined by biologist David Haig, "Among the reasons that working scientists have given me for choosing gender rather than sex in biological contexts are desires to signal sympathy with feminist goals, to use a more academic term, or to avoid the connotation of copulation." For his 2004 paper, he surveyed more than 30 million titles of academic articles, from the years 1945–2001, for occurrences of the words "sex" and "gender," noting that, "the use of gender has tended to expand to encompass the biological, and a sex/gender distinction is now only fitfully observed."

However, as explored in an amicus brief submitted when the Proposition 8 case reached the Supreme Court of the United States, even utilizing the biological terms does not support the definition of marriage between, in such cases, a "male" and a "female." This is because there are intersex people who are, scientifically speaking, male, but who are legally female, live as women, and are legally married to males, and vice versa. While these marriages are legally valid, they draw attention to the fact that trying to constrict marriage based on binary "man" and "woman" parameters is inaccurate and misguided.

Opponents of the LGBTQIA+ community aren't the only ones conflating sex and gender, however. How often, for example, have we heard phrases such as, "I was assigned male at birth, but I always knew I was really female," or conversely, "I was assigned female at birth but knew I was really male," from members of the transgender community? As we can see, the biological sex terms "male" and "female" are employed in the statements above, although what is actually being referred to in the phrase, "I always knew I was really..." is gender as "men" or "women."

The cited statements above have become commonplace. This is perhaps due in part to the fact that on most forms in the United States when one is asked to check one's "gender" the choices given are "male" or "female." Transgender citizens are thus encouraged to use sex terms when speaking about their gender, as witnessed in the statement: "I just applied for my gender reassignment from female to male."

In addition, it makes sense that trans individuals would eventually begin conflating sex and gender terms. It would be awkward, at best, to always have to separate one's born sex from one's gender/gender identity in everyday discussions. For example, if you are a trans woman whom someone calls "female," this could entail correcting the person and explaining that, "I am a woman, but I'm not female," or, "I'm a woman who was born male."

Specifying the difference between one's sex and gender—which most people do not have to do—requires drawing attention to the fact that one's sex characteristics are, to some degree, different from what the person we are speaking with assumes. This can be uncomfortable for all parties, given how squeamish our society can be when speaking about sex anatomy, and particularly so for the person revealing themselves to be different. For many, it may not even be safe to reveal this information as it could elicit violence.

This is evidence to the fact that, while it is easy to say that sex and gender are entirely distinct factors, it is far from easy to maintain this distinction in our everyday lives because of the ways in which sex and gender terms and their usage impact people's lived experience. Nevertheless, it is important to recognize that the frequent use of sex terms to refer to gender identity not only blurs the distinction between sex and gender, but also our awareness that sex diversity exists.

For example, if the terms "male" and "female" were used strictly to refer to biological sex, then it would be understood—

even if one had never heard the word "intersex"— that someone who says they are both, or neither, "male" nor "female" is referring to their sex characteristics at birth. However, it has become commonplace for non-binary people who are not intersex to describe themselves as both, or neither "male" nor "female." Given the context wherein many are familiar with the existence of trans but not with intersex, it's easy for people who hear such statements to assume that only *gender identity* is being referenced to fall outside the binary system.

### The failings of a binary gender term

The term *cisgender* originated in the 1990s and gained popularity within transgender discourse after appearing in *Whipping Girl* in 2007. While the term is a useful means for distinguishing the different experiences between trans and non-trans people, its linguistic failures provide a lens into the problems inherent with upholding a two-sex model. As such, further examination of the term "cisgender" and how its use can inadvertently erase the lived experiences and identities of many, warrants further exploration throughout this chapter.

The issue of intersex exclusion can be easily observed by examining the different ways in which the term *cisgender* is defined. We note that in addition to the definitions below, the term has also been defined as being the opposite of transgender, or referring to, "those who have a gender identity or perform a gender role society considers appropriate for one's sex."

Cisgender 1: denoting or relating to a person whose sense of personal identity and gender corresponds with their birth sex. 12

*Cisgender 2*: an adjective for someone whose gender corresponds to their assigned sex.<sup>13</sup>

The first definition listed above, which elicited headlines when added to the *New Oxford Urban Dictionary* in 2015, is the original. Under this definition, all humans, regardless of birth sex (intersex, female, or male) are deemed capable of being cisgender, that is, of having what is often posed in gender identity discussions as a mind-body "match" between their birth sex and gender identity. For example, a person who was born intersex and feels neither male nor female, but rather grows up to have a non-binary gender identity that "matches" their non-binary birth sex would be considered cisgender under this original definition of the term.

However, the term *cisgender* was created to draw a distinction between trans people and non-trans people, and people with non-binary gender identities—a.k.a. non-binary people—are considered a sub-set of the transgender community. Thus, while it may be accurate for intersex people with non-binary gender identities (whom we will refer to as "non-binary intersex people") to be defined as cisgender by others or themselves, it distorts the intended use of the term. For example, how can someone be transgender and cisgender at the same time if the terms are antithetical?

In addition, *cisgender* is meant to correlate with the experience of "cisgender privilege." *Cisgender privilege* appeared in academic literature in 2010, defined as the "set of unearned advantages that individuals who identify as the gender they were assigned at birth accrue solely due to having a cisgender identity." However, a look at some of the different cisgender privileges quickly establishes that intersex people, regardless of gender identity, often do *not* experience them. <sup>15</sup>

As outlined in, "30+ Examples of Cisgender Privilege," some of these privileges are:

• Use public restrooms without fear of verbal abuse, physical intimidation, or arrest.

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- Use public facilities such as gym locker rooms and store changing rooms without stares, fear, or anxiety.
- Strangers don't assume they can ask you what your genitals look like and how you have sex.
- Your validity as a man/woman/human is not based on how much surgery you've had or how well you "pass" as non-transgender.

One need only look at these four examples to realize that intersex people do not experience these privileges. If an individual has an intersex variation that results in an androgynous or atypical physical appearance, the first and second examples do not apply. In addition, if an individual "comes out" as intersex, one of the first things that is called into question—and into public curiosity—is what their genitals look like, thus leaving intersex people exempt from experiencing the third privilege unless they live in hiding and secrecy regarding their intersex status.

Most notable is the fourth example, the exact opposite of what most intersex people experience. As examined in the previous chapter, intersex people are routinely deemed in need of surgeries to validate them as men/women/human, often from the moment they are born.

Perhaps due to the incongruence between intersex people's lived experience and the intended meaning of *cisgender* and *cisgender privilege*, a second definition of cisgender arose, listed above as *Cisgender 2*. The second definition replaces the phrase "birth sex" with "sex assigned at birth."

Under the assigned sex at birth definition, non-binary intersex people are no longer defined as cisgender. While this resolves the conflict of defining non-binary people as cisgender, it creates other significant problems. These are: (1) the obfuscation of intersex biological sex variation; (2) the obfuscation of intersex genital mutilation (IGM); and (3)

the linguistic erasure of a natural intersex "mind-body match." In addition, like the first definition, its use incorrectly assigns gender identity, a.k.a "misgenders," various populations.

### Obfuscation of intersex biological sex variation

By replacing the words "birth sex" in the original definition with "sex assigned at birth," intersex bodies, and thus people, are linguistically disappeared, replaced by the male or female labels "assigned" to them. As we explored while examining Jewish rabbinic law and its treatment of intersex people, known as *androginos*, language can and is used to construct and support certain belief systems (see Chapter 7). Rabbinic texts construct a system of gender duality.

Today, defining cisgender as someone whose gender identity corresponds with their sex at birth constructs and upholds a binary two-sex system. This is due to the fact that, although one's birth sex can be male, female, or intersex, at the time the definition was created, babies were exclusively assigned only male or female. Even now, at the time of writing, only a small number of countries and states allow a birth assignment that is not male or female.<sup>16</sup>

While *cisgender* is also defined as having "a gender identity or gender role society considers appropriate for one's sex," if you are born intersex this doesn't apply because there are no gender norms attributed to your biological sex, as society doesn't acknowledge that intersex exists. Indeed, as "cis" means "on this side of," and "trans" means "on the other side of," those who are not born on either side of this binary framework of sex are inherently excluded, although these terms are presumed to apply to all humans. Thus, intersex people are excluded from linguistic social inclusion through the usage of cisgender terminology.

# Obfuscation of forced infant sex reassignment surgery and other forms of interphobia

The grave disadvantage and risk of irreversible harm that intersex people experience, via forced sex reassignment surgeries as infants, a.k.a. IGM, and violent forms of discrimination, is obfuscated by placing them in the same category as those *born* and assigned male or female. Categorizing those born male or female together with those born intersex and *assigned* male or female implies that their experiences are similar—particularly as many are not even aware that the practice of IGM exists—when typically, nothing could be further from the truth.

Numerous reports exist from intersex people who identify as the male or female sex they were assigned at birth, but who were subjected to IGM as infants. Their narratives share difficult childhood memories of medical procedures—"procedures" because infant genital surgeries typically require follow-up surgeries as tissue grows and expands—and office visits consisting of invasive genital exams and questions about their sense of gender identity and sexuality. The overwhelming majority of those subjected to IGM report that these experiences made them feel there was something deeply wrong with their gender and/or sexuality.<sup>17,18</sup>

In addition, there have been reports of infanticide, abandonment, and even attempts at murder of intersex children by parents from African countries where IGM is unavailable. <sup>19,20</sup> Likening the experience of people born intersex who grow up to identify as men or women to that of typical males and females who experience certain privileges if they grow up to identify with their male or female assignment is wildly inaccurate.

### Erasure of the non-binary "body-mind match"

Under the "assigned sex at birth" definition, non-binary intersex people are defined as transgender rather than cisgender. However, this linguistically erases the fact that gender non-conforming and non-binary gender identities can be natally congruent. This definition also implies that if an intersex person grows up to feel intersex and identify as non-binary, it is not a socially beneficial experience, as being cisgender is defined to be. We note that this is the same claim made by those who recommend sex reassignment surgery on intersex infants.

Proponents of IGM have argued that growing up with a non-binary body left as-is might result in a non-binary gender identity, and used the belief that this outcome is negative as a means to recommend IGM. However, these assumptions are contradicted by intersex adults who have shared that having a non-binary gender identity that matches their non-binary intersex body is a positive experience.<sup>21</sup>

Studies have shown that not all intersex people grow up to have a non-binary gender identity, and some clinicians have used these findings as a reason for recommending IGM. However, for those who do grow up to be non-binary, the challenges of living in a dually gendered world should not be used to justify IGM. Many children have difficulties to overcome as members of marginalized communities, but are not subjected to medically unnecessary procedures to erase the traits that *might* cause them social challenges.

Creating a framework in which only those born male or female are capable of experiencing a positive "cisgender" match between their natural bodies and gender identity positions intersex people, their natural bodies, and their potential gender identities as innately inferior. This, in turn, supports oppression and violence against intersex people.

### Misgendering

As an examination of *cisgender* definitions reveals, cisgender rhetoric positions intersex individuals where it pleases, without concern for their lived experiences or gender identity. This opposes the term's intended goal of creating more understanding and acceptance of sex and gender variant communities.

In addition, intersex people are not the only ones misgendered by *cisgender*. As writer and author J. Nelson Aviance explains:

Don't tell me that I am somehow normatively gendered for my body when my life experience has led me through periods of deep confusion about my gender identity...you don't get to make a reductive statement about my gender identity or how I embody my gender while trying to argue for recognition of the diversity of other peoples' [sic] embodied genders. If you are going to argue for a less simplistic reading of others' embodied genders, than [sic] you have to do so with mine too. That includes recognizing that as a queer person, I'm automatically not inhabiting the normative roles society has constructed for those with a penis... By imposing the label 'cisgendered' onto me... You are silencing my voice and rejecting my right to determine my own identity.<sup>22</sup>

As this quote elucidates, many people who face severe discrimination for expressing their gender in an atypical way nevertheless identify with their birth sex. However, they, too, are labeled with a cisgender gender identity that erases this experience by lumping them together with those who are not gender variant.

While the intentions behind cisgender terminology are good, we agree with the author of the text above that there are ethical inconsistencies with arguing for the right to self-determine one's gender identity while denying this right to others by assigning them gender identities they did not choose—particularly when these assignments are inaccurate. This is why, for example, we refer

to infants and young children not as "boys or girls" throughout this text, but as female, male, or intersex infants/children.

We strongly support trans people's rights, such as the right to self-determination. We also support these rights for *all* people, which is why our critique of cisgender terminology is so extensive. It provides a means for examining the pitfalls of creating terms based on the erroneous binary sex model.

The linguistic failures of the term cisgender illustrate the problems inherent in employing an erroneously binary sex model to describe gender diversity. Under an inclusive, equanimous framework, however, the question should not be how do we fit intersex people into cisgender rhetoric, but rather, why are we we linguistically erasing the existence of biological sex variation and gender non-conforming gender identity with new binary terms for sex and gender?

Some have suggested the terms "trans" and "non-trans" as a means of distinguishing between people who grow up with a gender identity that matches their birth sex from those who do not.<sup>20</sup> This appears, for now at least, to be the most ethical and sound solution, as these terms are accurate and don't misgender various populations.

### Collateral damage

Whether one cares about the fate of intersex people or not, perpetuating the lie that sex is only male or female strengthens the foundation of binary thinking upon which sex and gender discrimination is built. It enforces the false view that all humans naturally fall into "opposite" sex categories with "opposite" gender identities and expression, which places all those whose gender identities or expression fall outside these poles in a marginalized position.<sup>23</sup> This framework has informed discrimination for centuries, and continues to do so.

Not recognizing the existence of sex diversity harms more than just the intersex community. As recent attacks on the transgender community have demonstrated, excluding the natural existence of sex and gender diversity supports interphobic and transphobic beliefs and policies. For example, in 2016 the state of North Carolina signed into legislation House Bill 2.<sup>24</sup> The law applied to bathrooms in government buildings and stated that a person had to use the bathroom corresponding with the sex listed on their birth certificate. In the months that followed over two dozen states introduced similar bills.<sup>25</sup>

If we had recognized and accepted sex diversity early on, this type of legislation would likely never have been introduced, as society would account for diverse expression and identity. For example, some people born with the intersex variance, 5-alpha reductase deficiency (5-ARD), may appear female at birth, be listed as female on their birth certificate, and be raised and live legally as such. However, as explored in Chapter 6, these people may naturally masculinize during puberty so much that they appear male. Which bathroom should they use? Numerous examples like this one demonstrate how sex diversity can impact the situations that House Bill 2—which was eventually repealed—did not address.

A more recent example of non-acceptance of sex and gender diversity is inscribed in an unpublished (leaked) memo from the Department of Health and Human Services (HHS).<sup>26</sup> In the October 2018 memo the Trump Administration appeared focused on narrowly defining sex under Title IX. Title IX states,

No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance.<sup>27</sup>

Based on the memo's verbiage, HHS would define sex as... "a person's status as male or female based on immutable biological traits identifiable by or before birth... The sex listed on a person's

birth certificate, as originally issued, shall constitute definitive proof of a person's sex unless rebutted by reliable genetic evidence."<sup>28</sup>

As we have explored in depth, there are people whose "immutable biological traits identifiable by or before birth" are neither male nor female. One of them, in fact, made headlines in early 2017 as the recipient of the first birth certificate in the United States to list "intersex," rather than male or female, under the field for "sex." The HHS' narrow definition literally erases this person's, as well as all intersex people's, existence.

In June 2019, the Vatican published, "Male and Female He Created Them," a 31-page guide to "support those who work in the education of young people," thereby joining in the attempts to erase trans and non-binary people via the attempted erasure of intersex people.<sup>30</sup> This erasure appears intentional, because acknowledging that sex consists of the three categories of male, female, and intersex makes it harder to insist that transgender and non-binary people's sex/gender should be defined as male or female only, based on their biological traits at birth. The HHS' definition and the Vatican document intend to force all transgender people to live as the wrong gender, and all intersex people to live as the wrong sex, and, in some cases, the wrong gender as well.

As many know, it is useful for trans people, particularly those who have had their bodies medically reassigned, to be able to change their legal sex/gender status to reflect their lived gender. This possibility is denied under the narrow definition cited in the HHS memo, which would take the transgender community back to the era when they were unable to have their true gender legally recognized on identification documents.

As one of the last remaining *bissu* high priests informs us, if any one of the genders is excluded, the world will fall out of balance. At the very least, as we explore above, not recognizing all sexes can negatively impact many.<sup>31</sup> Perhaps the lesson is that achieving harmony within our species and equality for all people is only possible when we accept the human species in its entirety: including the entirety of our biological sex expression.

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# Diversity is Healthy

# Tips for Creating An Intersex-Friendly Environment

Intersex people live among us in every facet of society, comprising an estimated 1.7% of the population. Yet they have often been described using words with innately negative connotations, which can impact self esteem, body image, the ability to live

Creating a safe setting requires the use of affirming or neutral language to describe people. This handout provides tips on how to make intersex commun-ity members feel safe and

#### Inclusion Matters

Communities forced to hide due to discrimination benefit from visual cues that are welcoming. Display community pamphlets or signs to convey that it's safe for intersex people to be open about who they are.

#### Support diversity

Intersex is just a natural, healthy variation of sex, like male and female. Remind intersex people or their loved ones of this if they are struggling with stigma due to society's binary views on sex and gender, and direct them to educational and/or support resources.

Be scientific, not subjective Comments like, "Their genitals don't look right," or, "They have the wrong sex organs," convey negative messages and are subjective, not medical, opinions. Yet they're often made about intersex traits in health care settings and beyond. Stick with factual descriptions such as "genital variance," or the name of a body part, without gendering it, to avoid inadvertently insulting intersex people.

#### How would I feel if \_\_\_\_\_?

When in doubt, use this simple rule: If you wouldn't want it said about yourself, a loved one, or their/your sexual characteristics, don't say it about an intersex person.

#### AVOID: "Disorders" or "Differences

#### "Disorders" or "Differences of Sex Development"/DSD

This term is opposed by intersex people because it demeans healthy intersex variations. "Differences," while better, still otherizes.

#### Adjectives w/Negative Connotations, such as:

"abnormal," "defective,"
"deformed," "lacking," "wrong"
These descriptions are harmful
because, unlike other body parts,
sex traits are linked to our sense of
self as sexual human beings.

#### Assumptions About:

#### Bodies

Intersex bodies can look exactly like, or different from, those of typical males or females.

#### Gender identity or sexual orientation

Like all people, we don't know an intersex person's gender identity or sexual orientation unless/until they tell us. Respect intersex people's identity. Don't assume to know what they want, should want, or will want.

#### Future Outcomes

People often assume being intersex is/will be a difficult "peoblem," but such predictions are unsubstantiated as intersex people can and have/do lead happy, thriving, healthy lives without medical treatments to "fix" them.

#### \* Labels of choice

Just like those born male or female, some people born with variations of sex characteristics

#### USE:

#### Variation(s) of Sex Characteristics (VSC)

The preferred community term to describe the many different types of intersex. "They have a variation of sex characteristics called

#### Objective Descriptions:

- "small penis" rather than "micropenis"
- "enlarged" or "large clitoris," rather than "grossly enlarged," or the clinical, "clitoromegaly"
- "genital variance" rather than "ambiguous genitalia"
- "testes" not "male gonads";
  "ovaries" not "female gonads"
  (Why potentially insult
  someone's gender identity
  when it's unnecessary and
  avoidable?)
- "didn't develop" rather than "failed to develop"
- "has" or "doesn't have" rather than, "has the wrong...," "is incomplete," or, "is lacking"

#### Gender Neutral Terms

Due to the non-binary nature of intersex bodies, gendering is sometimes confusing. If unsure, use gender neutral terms until you are able to ask/the gender is known.

- \* "they" rather than "he" / "she"
- "phallus" rather than "clitoris" or 'penis"

prefer to be described with gender terms such as, "man," "woman," or 
"non-binary" (aka "enby") rather than the biological term "intersex." 
Many also use "intersex men, "intersex women," or "herms" (short for 
the reclaimed "hermaphrodite," referring to non-binary identified 
intersex persons). Be respectful: ask, don't assume.

# Glossary

- 5-alpha reductase deficiency (5-ARD) Inability to make 5-alpha reductase, an enzyme required for the conversion of testosterone into dihydrotestosterone (DHT).
- **Androgen insensitivity syndrome (AIS)** A variance that results in total or partial loss of androgen receptor function.
- Androgens A family of steroid hormones that play roles in male sexual and reproductive development, and in the production of estrogens. An example of an androgen is testosterone.
- Autosome A numbered non-sex chromosome.
- **Chromatid (sister chromatid pair)** A chromosome attached to its chromosome duplicate (sister).
- **Chromosome** Comprised of protein and nucleic acid (DNA). Some of the DNA sequence within a chromosome is organized into regions called genes.
- Cisgender A term created to replace "non-trans" which has been criticized for misgendering queer and gender non-conforming people who identify as their birth sex, and intersex people.
- **Clitoris** Erogenous, erectile tissue associated with typical female genitalia. **Clitoromegaly** Enlarged clitoris.
- Congenital adrenal hyperplasia (CAH) Variances that result from enzyme mutations and can lead to over-production of testosterone, and a lack in production of cortisol and aldosterone, in some cases.
- **Diploid** Two complete sets of chromosomes.
- **DNA** Deoxyribonucleic acid comprised of linked nucleotides associated with one of four base types (adenine, guanine, cytosine, and thymine).
- **Enzyme** A molecule, typically a protein, that functions as a catalyst in a chemical reaction.

**Estrogens** A family of steroid hormones that play roles in female sexual and reproductive development, maintenance of bone density, cardiovascular health, etc. An example of an estrogen is estradiol.

Gametes Sperm and egg cells used for sexual reproduction.

Gender (gender identity) The psychological and mental perception of one's self. Gender related terms include woman/man, girl/boy, feminine/masculine.

**Gender nonconforming** Adjective. Refers to people whose behavior or gender expression does not match masculine or feminine gender norms.

**Gender nonconformity** Noun. Behavior or gender expression by an individual that does not match masculine or feminine gender norms.

**Gender variance** Noun. Behavior or gender expression by an individual that does not match masculine or feminine gender norms.

**Gender variant** Adjective. Refers to people whose behavior or gender expression does not match masculine or feminine gender norms.

**Gendercide** Also known as intersex genital mutilation (IGM); the subjugation of a person to nonconsensual gender-conforming surgery.

**Gene** Comprised of DNA and embedded with the instructions needed to generate a protein or a portion of a protein.

Gonad Gamete-producing organ; ovaries and testes (testicles).

Gonadal dysgenesis Undeveloped gonads.

Gonadal intersex Intersex variance that results in the possession of ovarian and testicular tissue. Gonadal intersex is synonymous with "true hermaphrodite."

Haploid A single set of chromosomes found in gametes.

**Herm** A term used by some intersex people whose gender identity is non-binary.

Hermaphrodite A term used by some in lieu of intersex.

**Hermaphrodite** ("true" hermaphrodite) Intersex variance that results in the possession of ovarian and testicular tissue.

**Homolog** One chromosome of a pair (homologous pair) that was inherited from the egg cell or sperm and used to create the diploid zygote.

**Hormone** A molecule that is released by a hormone-producing cell and is capable of interacting with a receptor to effect a change in cell function/activity.

**Hypospadias** The presence of a urethral opening that is not at the top of the penis glans. In some cases of hypospadias variant genitalia can occur.

Interphobia Bias and prejudice against intersex people.

### Glossary

**Intersex** An individual with internal and/or external sexual and reproductive characteristics that are not tipically male or female.

**Intersex genital mutilation (IGM)** Also known as **gendercide**; the subjugation of intersex people to nonconsensualsex reassignementsurgery.

**Klinefleter syndrome** An individual with three sex chromosomes (trisomy, XXY).

**Meiosis** A process that occurs in the gonads and results in reduced chromosome number to create haploid gametes from diploid cells.

**Mitosis** Cell duplication that results in the production of two cells with an equal, diploid chromosome number (23 pairs or 46).

**Monosomy** The absence of one chromosome of a particular type.

**Mutant** Arises when a change within the sequence of DNA results in a trait change.

Mutation Alteration or change within the sequence of DNA.

Ovary Gonads found in typical females. Site of egg cell development.

Ovo-testis Gonadal tissue that is a mix of testicular and ovarian tissue.

Phallus A penis, or structure, or tissue that resembles a penis.

**Protein** A molecule that has a particular function and was made from gene(s) instructions.

Sex chromosome The chromosomes designated X or Y.

**Sexual orientation** The sex/gender one is sexually attracted to in relation to one's own sex/gender.

**SRY gene** Provides the instructions to make TDF (testis-determining factor).

**Swyer syndrome** An individual who is XY and possesses undeveloped testes (gonadal dysgenesis).

**Testis** Also known as testicle. Gonads found in typical males. Site of sperm development.

**Testis-determining factor** (TDF) A protein encoded (codes for or provides instructions) by the SRY gene that initiates male development within the embryo.

Trans man Individual born with female sex characteristics who is a man with regard to gender identity. A trans man may or may not opt to change their physical body via gender reassignment surgery and/or through hormone treatments.

Trans woman Individual born with male sex characteristics who is a woman with regard to gender identity. A trans woman may or may not opt to change their physical body via gender reassignment surgery and/or through hormone treatments.

- **Transgender** Used to describe someone who feels that they are not the same gender (= sex) as the gender (= sex) they were said to have when they were born.
- **Trisomy** The possession of three chromosomes of the same type (e.g. three sex chromosomes, XXY).
- **Turner syndrome** A variance that results from the possession of a single X chromosome (monosomy, XO).
- **Zygote** The diploid cell created after a sperm fertilizes an egg cell. Also known as a fertilized egg.

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Hida Viloria is a writer and pioneering intersex and non-binary educator. As chairperson elect of the Organization Intersex International (OII) and founding director of The Intersex Campaign for Equality, s/he has been a frequent consultant (United Nations, Lambda Legal, Williams Institute...) and radio and television guest (Oprah, Aljazeera, 20/20, NPR, BBC...), and one of the most highly published persons in the field (Washington Post, NYT, Daily Beast, Ms., Huffington Post, OUT, The Advocate...). He/r groundbreaking memoir *Born Both: An Intersex Life* (Hachette Books) received critical acclaim and a 2018 Lambda Literary Award nomination.

Maria Nieto is a Professor in the Department of Biological Sciences at California State University, East Bay and an award—winning novelist. Her current scientific interests have centered on the subject of sex and gender. In 2013 she submitted the first biology—based amicus brief submitted to the Supreme Court of the United States in support of marriage equality. Her two fiction novels (Floricanto/Berkeley Press), *The Water of Life Remains in the Dead* (2015) and *Pig Behind The Bear* (2012), have collectively been awarded a Next Generation Indie Book Award (2016), an Independent Publisher Award (2015) and International Latino Book Awards (2015, 2016).

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