

Promoting Health and Social Progress by Accepting and Depathologizing Benign Intersex Traits

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Narrative Inquiry in Bioethics, Volume 5, Number 2, Summer 2015, pp. 114-117

Published by Johns Hopkins University Press

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I was born with ambiguous genitalia and it was a doctor who, by honoring my bodily integrity and not “fixing” me, gave me the greatest gift I’ve ever received. Because my body and its sexual traits are a positive, fundamental part of my experience and identity as a human being, I know that having my genitals removed or altered according to someone else’s vision would have deeply damaged me, both physically and psychologically.

The doctor who protected my autonomy was, unsurprisingly, my father. I say “unsurprisingly” because in my experience parents are typically more protective of their children than doctors are of their patients. Also, doctors do not discuss cases with other doctors in the same way they do with laypeople, as doctors know more about medical issues such as the risks involved in infant genital surgery.

Other than having clitoromegaly (a large clitoris), my reproductive anatomy is typically female, and so I was assigned female and raised as such without incident. My parents didn’t discuss my intersex traits with me, and I grew up thinking of myself and being accepted as, a girl.

When I began menstruating, my father told me I’d need to take pills to “grow taller.” I thought this unusual, as I wasn’t short, and later overheard my mother arguing with him, saying that the pills were “experimental”. I was reminded of this discussion years later, when she told me that the pills had actually been hormones to make my breasts grow. I never took them though as she convinced my father not to make me.

Article 7 of The International Covenant on Civil and Political Rights states that, “No one shall be subjected without his free consent to medical or scientific experimentation,” and I’m grateful to both my parents for protecting my civil rights as they protected my health.

Due to my Catholic upbringing and schooling, I had no opportunity to compare my genitals to other girls’, and it wasn’t until the age of twelve that I realized, while perusing magazines with friends, that I have atypical sex anatomy. Contrary to common speculation however, this awareness

didn't make me question being female. I simply assumed there must be some genital variation in humans.

I feel my parents made the wisest decision possible by registering me as one of the two accepted, available genders but allowing me to live, physically and behaviorally, as who I am. Despite not having developed a stereotypically curvaceous female figure, I was popular and excelled in typically feminine social activities, as well as sports and academics. For example, I was one of four girls selected out of one hundred twenty-five that competed for a spot on my high school cheerleading squad when I tried out to help a friend who needed a tryout partner.

Other than escaping IGM (Intersex Genital Mutilation) and estrogen therapy, I've had only a few experiences pertaining to my medical care around being intersex. These experiences fall into two categories: seeing medical doctors who treated me the same after discovering that I have ambiguous genitalia, and seeing ones who didn't. I feel incredibly blessed that my experiences in the former category vastly outweigh the latter.

My first experience came at the age of twenty, when a gynecologist asked me if my clitoris had always been as large as it is. I responded that it had, and she said, while looking at me disapprovingly, that she'd like to do some tests. When I asked her what they were for though, she wouldn't respond directly. She said I'd reported having some upper lip hair, and acne, on my intake forms. I replied that neither were above average, and asked if there were health issues I should be concerned about. She reluctantly said no. I asked what reason there was then for undergoing tests because of the size of my clitoris.

She finally responded, "It's just not normal."

Fortunately, I'd had positive reactions to my sex traits from the people I'd dated. For example, the first man I was intimate with told me my body was beautiful and proposed marriage several months later. Positive experiences such as these, alongside the doctor's uncaring attitude, made me question her and decline having tests done.

However, the doctor's assertion that my clitoris was "not normal" had a negative psychological impact. It made me question—for the first time—whether there might be something problematic about my difference.

I decided to seek a second opinion at the medical clinic at N.Y.C.'s LGBT resource center. I recounted my experience with the first doctor to the physician and asked if there was anything for me to be concerned about. She examined me, concluding that my ovaries felt fine, that clitorises come in all shapes and sizes, and that she thought mine was beautiful. By affirming the natural diversity in genital size, and referring positively to mine, this doctor undid the psychological damage done by the one who had deemed my genitals abnormal.

I first saw the word "intersex" in a newspaper article at the age of twenty-six, and confirmed via research that I'm intersex by twenty-eight. It was extremely helpful to have a word to describe this aspect of myself, and to know that others like me existed.

I was shocked and saddened however, that almost all the intersex adults I met had been subjected, at a young age, to "normalizing" genital surgery, also known as IGM. Ironically, although the interventions were performed in order to help them fit in, they'd had the opposite effect, resulting in physical and psychological trauma that made feeling normal difficult. However, the common response from their doctors had been that, bad as these results might be, they'd have been worse off without "normalization".

The fact that my lived experience completely contradicts the claims made to justify IGM motivated me to become an advocate. I wanted to help future generations experience the joy I have because I was allowed to keep the healthy genitals I was born with. I wanted all intersex people to have the right to make their own decisions about their sex anatomies; and I still do.

However, being an advocate has made me vulnerable to a pathologizing gaze that I had hardly experienced in my medical care. For example, a doctor advocating for IGM during a television interview, in which I'd just revealed having clitoromegaly, once said, in an alarming tone,

“Sometimes the clitoris is so grossly enlarged that it resembles a baby boy’s penis!” Although I was applauded for confronting him on trying to depict us as physically repulsive, experiencing such palpable prejudice was extremely unpleasant.

Despite these challenges, the pain I have witnessed in those subjected to IGM is so profound that I felt, and continue to feel, compelled to continue my advocacy. I viewed, and continue to view, IGM as enforced social prejudice.

This view was confirmed when Dr. Kenneth Glassberg, a pediatric urologist who appeared on the television program “20/20” with me (April, 2001) said, as justification for IGM, “Society can’t accept people of different colors, and now we’re supposed to accept somebody whose genitalia don’t match what their gender is? I do not believe this society is ready for it.”

His statement revealed that doctors are participants in a cultural legacy that deems those who challenge dominant values unacceptable. It reminded me of European cases from the 1500-1800’s that I’d read while studying sex and gender at U.C. Berkeley, in which individuals were tried for “gender fraud” if discovered to be intersex. Today, medical doctors are the ones expected to act when the “boy or girl?” question cannot be readily answered.

The doctor’s assertion that IGM is performed because society is not ready to accept intersex people also confirmed what I’d long suspected: that IGM exists to benefit non-intersex people—such as our parents—rather than those subjected to it. It seemed similar to when homosexuality was a disorder (until 1973), and doctors assisted parents who’d discovered that their children were gay and sought medical treatments (commonly electroshock therapy) to “cure them”.

Being intersex was pathologized in 2006, as a “Disorder of Sex Development/DSD”. Just imagine waking up to find that being what you are has suddenly been deemed a disorder! It was extremely upsetting, triggering a deep depression. The main thing that helped me out of it was witnessing the dissent by my intersex peers.

Like many of us, I reject the term “DSD”, which I find as insulting as when my father referred to my lesbianism as a “psychosexual disorder”. He was just using the label he’d been taught in medical school, he wasn’t trying to hurt me, and similarly, while I don’t think doctors intend to offend and/or hurt me when they use “DSD”, that’s the effect it has. I use “intersex” exclusively, and ask others to use it to refer to me, because I find being described solely as an acronym depicting sexual difference dehumanizing, stigmatizing, and hurtful.

Some have been substituting “differences” for “disorders” in “DSD”, and while I welcome a de-pathologized diagnostic label, I think it’s hurtful to our already marginalized community to be referred to as people with medical conditions when this is not how other communities are labeled. For example, the diagnostic term for being transgender is “gender dysphoria”, but transgender people are not called “individuals with gender dysphoria.”

I prefer “intersex traits” as a diagnostic term because, as I explored in *The Advocate* (“What’s in a Name: Intersex and Identity”), the history of civil rights movements demonstrates that communities seeking equality don’t define themselves solely as being different from the norm or the dominant population. Rather, they use terms that positively describe their unique identities.

This is why I recently found the Association of American Medical Colleges’ (AAMC) report, “Implementing Curricular and Institutional Climate Changes to Improve Health Care for Individuals Who Are LGBT, Gender Nonconforming, or Born with DSD”, so alarming. I was upset to see that, while the other members of the LGBTI community are identified with their self-chosen identity labels, “intersex” people – the “I” in “LGBTI”—have instead been identified with our diagnostic term. It was even more upsetting given the countless stories I’ve heard first hand about how the term DSD has hurt my peers, and the awareness of one of the editors of the report of these experiences, as she is the non-intersex female co-author of the paper that originally called for the change to DSD, and was informed of the dissent against the term.

I was also concerned to read, “The use of the term [“intersex”] as an identity label is currently in flux...”, because its use amongst those diagnosed with DSD is actually increasing. Even Facebook noticed, including us as “intersex” when it expanded its gender categories beyond “male” and “female” early last year.

I think it’s crucial for medical professionals to be aware that the community of people that have connected around being born with variations of reproductive and/or sexual anatomy was originally, and continues to be, the “intersex” community. For example, I have participated in our global gathering of community advocacy leaders, the International Intersex Forum. We work for bodily integrity, self-determination and other human rights for “intersex people”, as do institutions we work with such as the U.N. Office of the High Commissioner of Human Rights, which invited me to speak at the U.N. in 2013. Also, the following year, some of my colleagues attended the U.S. State Department’s “LGBTI” event, the Conference to Advance the Human Rights of and Promote the Inclusive Development for Lesbian, Gay, Bisexual, Transgender and Intersex Persons.

It’s thrilling that institutions like the U.N. and the U.S. government are starting to address intersex people’s human rights, but consequentially very concerning to see the AAMC identifying us as people “Born with DSD”, as doing so risks excluding the medical treatment we’re subjected to from public policy and protections for “intersex people”. I thus urge all medical professionals to describe us, when an umbrella term is needed, as they do lesbians, gays, bisexuals, and transgender people—our fellow LGBTI community members—with the identity label that defines us as uniquely equal individuals: intersex. Although this may seem challenging, as noted, it has already happened with transgender individuals.

In contrast to those forced to undergo “normalization”, being intersex has not been traumatic or a hindrance to me precisely because my doctors employed a, “if it ain’t broke don’t fix it,” approach towards my atypical, yet healthy, sex traits. In addition, my experiences demonstrate that presenting intersex traits in a non-stigmatizing manner promotes psychological health and self-

acceptance. I attribute my fulfilling life as a homeowner with a career, friends, and committed partner I love, to the non-invasive medical care and non-stigmatizing rhetoric towards my intersex traits that I was exposed to during my formative years.

If medical professionals are truly interested in promoting our health and well being, they should begin by leaving intersex infants' and minors' healthy sex organs intact, describing intersex traits as the naturally occurring variations they are, and de-pathologizing being intersex. While many have historically treated those who are different as disordered, or otherwise inferior, doctors are in a unique position to learn from these mistakes and facilitate acceptance of, rather than prejudice towards, intersex people, as the many doctors who did not stigmatize my body did. I thus encourage medical professionals to put aside any negative preconceptions they may have inherited from society's historically stigmatized portrayal of intersex people, in order to treat us with the same respect for bodily integrity, sexual sensation, reproductive capacity, and self-determination that all people deserve.