



Esther Morris (/author/Esther+Morris)

The self I will never know

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[Equality \(/topic/Equality\)](#)

Esther Morris, born with an intersex condition, writes about the scandal of ‘corrective surgery’ whereby thousands of children are mutilated without consent.

There are times when I wish I didn't know so much. And I realize that what I know, I learned too late. Reclaiming a childhood of medicalization can be challenging at best, but key to my survival. The challenge is not that I was born with atypical reproductive anatomy – but the power of others to question and correct my natural anatomy.

My treatment became white-coat violence the moment I lost my choice. The reason for ‘corrective treatment’ is to prevent emotional trauma associated with diverse anatomy. Yet quality of life and emotional support were never part of my care. Living in a body that raised all these questions left answers beyond my reach. Medical treatment is focused on correcting intersex variations, not advice for living with them.

I was not told of the frequency of intersex – it's actually more common than cystic fibrosis. At the age of 13, I was scheduled for surgery. I was not allowed to accept myself; I was told what is normal and how I should be. I was never told that I was viable; or that who I was is all I had to be.

Once deemed a ‘medical success’ I was left to feel that I had drastically failed, because corrective surgery did not make me feel normal. My feelings became irrelevant and I have feared success from that moment on. I survived by denying I had any feelings at all. My body was altered to meet social values, but my values were never discussed. My puberty was focused on vaginal function before I had a chance to care.

Children who don't conform

Every day throughout the world children are born who challenge social values. And every day the response has been to make those children conform. This is not about children in medical crisis, but about children who are intimately invaded because their genitals aren't ‘up to standard’. These kids are called intersex. Their genital or reproductive anatomy is treated as an emergency that must be corrected immediately. Genital variation is not medically threatening, but cosmetic surgery is the medical standard in most ‘civilized’ societies. In the United States alone, genital surgeries are performed on at least five children every day, probably more. Many will have to have surgery repeated several times throughout their lives.

In the year 2000 the American Academy of Pediatrics issued a statement that ‘ambiguous genitals’, the global term for intersex, constitutes an emergency. In fact, intersex includes anyone born with atypical genital or reproductive anatomy. Treating an emergency does not require parental consent even when cosmetically derived. This brings to light some curious questions about what is atypical, and who has the right to decide what acceptable genitals are. Are medical professionals standing by with rulers and stamps of approval? To some extent they are, and we are all subject to their judgement. The majority who pass are sent on their way; but, for the sacred few who don't measure up, the silent nightmare begins.

I think of intersex as a civil rights movement still in the stage of breaking the silence

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Intersex occurs as often as once in every 1,000 to 1,500 live births. Incidence is unusual, but not rare.

Treatment refers to medical intervention to make atypical genital or reproductive anatomy normal.

Normal is defined by medical standards determined by anatomical dimensions. The medical criteria for genital and reproductive anatomy are: a clitoris cannot be larger than 3/8 of an inch at birth? Or? visible? The recommendation is that an 'enlarged' clitoris be surgically reduced to match the medical standard. A penis is 'too small' if it cannot be stretched longer than one inch at birth. The recommendation for a child with a penis considered too small is to reassign the child female, and then create typical female anatomy. An 'adequate' vagina is one that will accept an average size penis. When a vagina is 'inadequate' various treatments are recommended to promote heterosexual intercourse. Medical treatment is deemed successful once these intimate dimensions are met.

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Elusive data

The data surrounding intersex is difficult to determine for many reasons.

Doctors disagree amongst themselves regarding what conditions are considered intersex. Treatment for their 'intersex' patients could easily match treatment for patients with a different diagnosis. Many former patients avoid medical care because their medical histories are painful to explain to new doctors, or they have lost their trust in providers. These people are 'lost to follow-up' and data is unavailable.

Even as an insider, performing follow-up research has been difficult because many people cannot discuss their medical histories, do not know their medical histories, or have been used as research subjects during their intersex treatment. I suspect the incidence of intersex treatment is much higher than we imagine. Statistics on various diagnoses include:

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- People whose bodies will not categorize them as male or female: 1 in every 1,000
- People with chromosome types that are NOT 'normal' XX (female) or XY (male): 1 in every 1,666
- Male-defined bodies with XXY chromosomes: 1 in every 1,600
- Female-defined bodies with XXY chromosomes: 1 in every 10,000
- Vaginal agenesis (or absence): 1 in every 4,000
- Number of people who have some form of genital surgery: 1 or 2 in every 1,000

There are dozens of intersex conditions that are medically corrected. Though techniques vary, the treatment goals remain the same:

- • Enlarged clitorises are surgically removed or 'reduced'
- • Treatment for vaginal agenesis includes a variety of vaginal reconstruction techniques to increase vaginal size and depth for penile vaginal intercourse
- • Treatment for hormone differentiation involves lifelong hormone therapy and/or genital surgery
- • Treatment for urethras that are not at the tip of a penis involves multiple surgeries to lengthen the urethra to allow urination while standing up
- • Treatment for 'gender ambiguity' usually entails infant genital surgery and surgical sex assignment at birth.

Compiled by **Esther Morris**

Information from the website of the Intersex Society of North America:

Losing sensation

The caveat of current protocols is that adults who have received successful treatments claim a loss to their quality of life. Others lose sexual sensation as a result of removed, reduced, enlarged or scarred genitals, in addition to loss of self. People are generally too young or traumatized to make the immediate decisions required upon discovery, so parents and providers are left in charge. Treatment histories are not always disclosed, so children grow up in confusion. Since treatment is irreversible and permanent, discerning what is important to the child is essential for the parents or physicians who wish to do no harm. How can we ascertain what is best for the child when they are still too young to speak?

The medical community believes people will be traumatized by their atypical anatomy and need corrective treatment to lead happy and healthy, or normal, lives. Many adults argue that correction creates its own stigma that leaves them struggling with identities and loss of self. The growing

number of support groups and patient advocacy groups (currently 3,012 appear in an internet search) endorse the position that corrective treatment does not resolve the issue of psychosocial adjustment.

Many people believe that corrective treatment created problems they didn't have before. Others believe that the foundation of their discontent is the treatment itself; and the values that overlook medical needs in the rush to correct intimate anatomy. Although doctors have produced a number of studies that support the current protocols, the reports contain limited definitions of physical normalcy. There is currently no data collected that includes quality of life for intersex outcomes. The intimate nature of intersex is complicated by the stigma around genital anatomy. We are not so quick to judge other parts of anatomy. We teach our children to respect diversity, yet adults create a 'state of emergency' over the size and shape of genitals. The real phenomenon is that the prevalence of genital and reproductive variation is kept such a secret. Intersex variations are so quickly 'disappeared' that we don't get a chance to know about them, or how they might mature.

Break the cycle

The panic of discovery is real, and based in a perpetual cycle of ignorance. Discovery invites panic because intersex is unheard of. Panic invites correction to make it go away. Correction invites a conclusion that out of sight is out of mind. Doctors will admit to the wide range of variation, but the standard for what is acceptable has been determined by social and medical values rather than human nature. Removing intersex variation tips the scale to override diversity. By normalizing genital and reproductive anatomy, we lose awareness. With each altered child, another will be born into the panic of ignorance.

The truth is that we need to move intersex away from the medical context and into our social consciousness. I think of intersex as a civil rights movement still in the stage of breaking the silence. I compare intersex awareness to other movements that have earned their place in the world. You cannot remove our existence by removing our anatomy. The panic that people feel at discovery comes from silence and isolation. Inclusion of diversity could prevent emotional trauma without physical or emotional scars. Educating families would provide time for children to decide what they want for themselves.

When I talk to people about intersex they are stunned by what they did not know. Their ignorance is genuine and their concerns hopeful. They see the benefit that intersex awareness can liberate everyone from rigid standards. History reminds us that social values can change with awareness. Just like homosexuality, which has finally been removed from the Diagnostic and Statistical Manual for mental disorders, intersex cannot be cured. Corrective treatment will never change who we really are: it only prevents others from knowing us.

The invasion I feel now is the need to feel my past and the fallen hope that I would find my 'self' in a medical diagnosis. Nary a day goes by that something doesn't remind me that I am a misfit in a normal world. When I am strong, I revel at being a misfit, and know that normal is no-one's reality. When I am strong I challenge ignorance and educate those who care to know. But I feel invaded when my strength dwindles, and I return to a solitary world. I feel invaded by pain and health concerns that never were addressed during treatment. I feel invaded by the ignorance of experts. I feel invaded by depression that takes too long to wane. I feel invaded by the theft of my former self whom I will never get to know.

Esther Morris is a US-based writer, health worker and intersex activist, serving on the Board of the Intersex Society of North America. Shocked at how little knowledge there was among women with her condition – MRKH (which involves congenital absence of vagina) – she founded .



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