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THINGS YOU ONLY KNOW IF YOU ARE BORN INTERSEX

THE DEBRIEF: 1 IN EVERY 200 PEOPLE IN THE WORLD ARE BORN INTERSEX - SO WHY DON'T WE TALK ABOUT IT? WHAT'S IT ACTUALLY LIKE TO GROW UP INTERSEX?

ILLUSTRATION BY KELSEY WROTEN

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1 in 200 people, 0.5% of the world's population.

What springs to mind? That's a greater number than the world's Jewish population. That's nearly as common as red hair or twins.

Those numbers refer to a population of people known today under the umbrella term of intersex. (http://www.ilga-europe.org/sites/default/files/how_to_be_a_great_intersex_ally_a_toolkit_for_ngos_and_decision_makers_december_2015_updated.pdf%20)I am one of them.



Let's knock some definitions out first. So – what is intersex?

'Intersex' is used as an umbrella term to denote a number of variations in a person's bodily characteristics that do not match strict medical definitions of male or female. Intersex is NOT a medical condition but stands for the spectrum of variations of sex characteristics that naturally occur within the human species. These characteristics may be chromosomal, hormonal and/or anatomical and may be present to differing degrees. Many of these characteristics are immediately detected at birth and sometimes these variants become evident only at later stages in life, often during puberty. Most intersex people are healthy, and only a very small percentage may have medical conditions, which might be life-threatening, if not treated.

So far, so simple – if challenging. So how is it different from being transgender? Is it anything to do with your gender or sexuality?

Gender is one's expression and identity of being male, female, or the many other gender expressions we have come to be more aware of. Sexuality is whom you are attracted to. Sex refers to your biology, the body you are born into, which is where the term intersex fits. So intersex is distinct from one's gender identity or sexuality as it relates to one's anatomy or biology.

But what does it mean to be intersex? Or rather, what is it like? I am intersex so I could tell you what it's like for me but as with everything else in this world, while there are patterns in the experiences of intersex people, it would be wrong to make generalizations based on my life alone. The experiences and lives of intersex people are as diverse as everyone else in this world. But here are some lessons I have learned...

1. Intersex is a natural variation. Sex is not binary, it's a spectrum.

Like gender and sexuality, sex itself is a spectrum. Is your head spinning? Intersex is a natural variation. It is not 'abnormal'. It is not a 'defect'. As with everything else in the world, variation is beautiful and a great part of life. There is nothing wrong with being intersex. There is a lot right with it.

We, as intersex people, are acutely aware of the constricted understanding of sex, gender, and sexuality. These narrow definitions affect everyone and it is in everyone's benefit that they expand to represent reality. As intersex advocates, we work very hard to raise our voices and visibility in a positive way to educate and advance the equality of all intersex people. This starts with people recognising that intersex is not the issue, but society's response to it.

2. Like everyone else in the world, intersex people are diverse

Everyone's story is different. I was born in 1991 under the assumption that I was a 'typical' baby girl. When I turned 16 I was told that this assumption was false. I have been born with Frasier's Syndrome, which means I have XY gonadal dysgenesis or, put more simply, 'typically' male chromosomes and gonads in the place where ovaries might otherwise be. I identify as an intersex female. I am also healthy and happy (apart from my undiagnosed obsession with Peanut Butter).

3. Ignorance is not a solid state

When I was told about my intersex body I panicked. Not because I was ashamed but because I knew nothing about what being intersex meant and no one to provide me with the answers. Eventually I developed shame and came to know the stigma of being intersex from a variety of sources, mostly medical. It was challenging to feel alone and to feel that my body was 'unacceptable', but that all changed when I came to know the activism and resources provided by intersex activists. All it took for me was a video of an amazing woman on YouTube and an article in the Independent to make realise I wasn't alone and there was nothing wrong with me. And I began to think maybe I could work with these people to change society's mind too.

Today, though I still receive some shock or unsavoury initial reactions from friends and co-workers when they hear the word 'intersex', with a little patience and information people at worst realise the offence they've caused and at best they become an ally.

4. Intersex human rights are threatened and ignored every day

There are many challenges for people born with intersex traits. Governments generally only accept and are aware of two sexes and ignore the existence of intersex people. We face discrimination, trauma, and do not enjoy equality or human rights protection we need. The right to your own body is undermined. Intersex children and new-borns are regularly subjected to mutilating surgical and medical interventions to make their bodies 'conform'. They are performed without the consent of the child, are medically unnecessary and have traumatic consequences in later life. These surgeries are carried out all over the world, even here in the UK.

5. There is support, advocacy, and information out there

Across the world, intersex activists and educators work incredibly hard to change the current state of affairs. They are changing laws and developing policy, they are sitting at the table – be it at the United Nations, their national Parliaments, or their local community centres. Intersex activists face a great challenge, which they are rising to.

One such organisation is IntersexUK (<http://www.ukia.co.uk/>). They work with activists around the world at the UN, EU and national level to educate, inform policy, and raise awareness of intersex people and their human rights issues. In the last six years they have worked with human rights commissions, contributed to protective legislation, and lectured at leading universities.

6. You can't be what you can't see

Intersex people are very rarely a topic of mainstream discussion, and when we are it often results in sensational and stigmatising portrayals. When you are told you are intersex, society can give the impression that you do not have a place or that you have to hide. People don't realise how often intersex variations can be a subject of ridicule or a punch line amongst friends or in the media.

It took me nearly a decade to be open with being born intersex. In that time I lived with severe depression, anorexia, and anxiety stemming from ideas that I wasn't worth anything as an intersex person. Despite their protestations, I believed that I would never be worthy of my friends or partners.

It wasn't being intersex that made me feel so terrible, it was the misguided notion that sex is binary and that anything outside the (hetero)norm is 'wrong'. I've realised, through talking to other intersex people, that intersex is beautiful and that we shouldn't have to hide.

7. Nothing about us, without us

Legislative change has to happen for intersex people to be protected and enjoy full equality. That will not happen unless intersex people are given the microphone (as the Debrief has done here). We can't expect legislative change if intersex issues aren't publicly discussed, but this depends on intersex people not only having a seat at the table but that they lead the discussion.

As luck would have it, there are numerous intersex academics, policy experts, activists, and organisers who are so qualified and hard working it can make one feel incredibly lazy. These people have accomplished a great deal in recent years, with Intersex people creating change and sitting at the head of the table.

8. Finding out that you are intersex is hard, it may challenge you and many things you thought you knew but...

There are so many ways to be in this world. That is a great thing.

My intersex variation has given me one of the greatest gifts in my life - an appreciation of diversity and of the struggles outside my own experience.

Being intersex I have learnt to listen, to empathise, to keep my mind open, to be compassionate, and to realise what preconceptions I have and then try to dismantle them.

I wouldn't swap my body for anyone else's. I'm proud to be intersex and I hope you are proud to know we exist.

Find out more about what it's like to be Intersex here:

XY Suz (<http://www.xysuz.com/home/>)

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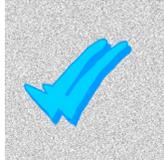
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