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Sarah Graham: lesbian, intersex and proud

# BORN THIS WAY

**W**hen my mother talks about her dead twin she says it's as if she can still feel him pressed against her arm, as he was during the time they shared in their mother's womb.

When she told me how a doctor had left her sibling to die I was horrified. Her twin, Paul, was born intersex. The year was 1942. The medical protocol at the time, the legacy of which is still with us today, was brutal: because of his intersex variation – he was born with genitals which looked atypical – he was wrapped in a blanket, left alone in a room for 24 hours, where he starved and cried to death.

The twins were six weeks premature, so keeping them both alive in a private house in rural Wiltshire without an incubator made the survival of one or both infants doubtful and difficult. In fact, my mother recalls, it took three months before they could say she would live.

"It was probably difficult under the circumstances to make a decision of letting one twin go so that the other would survive," she explains. "After all, we weren't in a hospital and I had to be fed for some weeks every two hours with a pipet. I am sure this influenced the decision to save me and let Paul 'go'. I have never thought of this as murder, rather that he was sacrificed so that I had a chance to live. But of course it was the doctor's opinion of his genitalia which meant he didn't survive."

In the 74 years since my mother and her twin were born, the situation for intersex babies is little better. In some cases, intersex babies are terminated pre-natally based on tests that show healthy variable difference. "That's pre-selective infanticide," explains Holly Greenberry, co-founder of human rights organisation IntersexUK. Adding insult to injury, intersex people today are diagnosed with "disorders of sexual development" (DSD), a term coined around 10 years ago which has caused controversy, with its implication that what is naturally occurring should be considered a "disorder".

According to intersex rights campaigners, the current estimate is that one in 200 babies is born with sexual characteristics – genitals, hormones, gonads and/or chromosome patterns – that don't seem to fit typical binary definitions of male or female. Leslie Jaye, of intersex human rights organisation OII-UK tells me, "The plain fact is that nobody really knows because if we're not caught at birth – many intersex people are identified in childhood, adolescence, or much later in life – some never are. Most people born intersex do not have variant external anatomies."

Those born with intersex traits are grouped under the umbrella term intersex. These variations include

INTERSEX PIONEERS SPEAK TO JANE CZYZSELSKA ABOUT LIVING IN A WORLD THAT DOESN'T RECOGNISE THEM

androgen insensitivity syndrome, some forms of congenital adrenal hyperplasia (CAH), ovo-testicular syndrome, Klinefelter syndrome, Turner syndrome, hypospadias and others. That said, 80% of intersex variations have no formal diagnosis at all. And, as Leslie Jaye explains, "these medicalised terms serve to frame intersex as a diagnosis rather than one of embodiment and lends credence to the pathologisation of intersex variation".

Being intersex relates to biological sex characteristics, and is distinct from a person's sexual orientation or gender identity. An intersex person may be straight, gay, lesbian, bisexual or asexual, and may identify as female, male, both or neither.

Because their bodies are seen as different, intersex children and adults are often stigmatised and subjected to multiple human rights violations, including violations of their rights to health and physical integrity, to be free from torture and ill-treatment, and to equality and non-discrimination.

Leslie Jaye outlines some of the ways that doctors abuse the rights of those with intersex variations: "They enforce irreversible sterilising procedures and gender mis-assignments; intersex individuals are not given access to their paediatric records and running through all the clinical papers and medical protocol is a very strong theme of homophobia. Clinical interventions on intersex children are predicated on producing heterosexuals."

"Clinical papers often focus on parental responses to a child with a phallo-clit larger than deemed acceptable, and prenatal procedures are used to change the bodies and orientation of those with CAH and who have XX ('female') chromosomes. This practice has now been stopped in Sweden because of the deep concerns about the unacceptable side effects".

Lesbian therapist and addictions counsellor Sarah Graham found out that she was intersex aged 25, after years of abuse and mutilation at the hands of doctors who misinformed and lied to her and her parents.

It all began when she was seven, and doctors told her mother and father that

she had a clitoris that was "larger than it should be". In their quest to find out why, doctors subjected Sarah to invasive examinations, often holding her down against her will, and discovered she had internal testes.

Without informed consent from either Sarah or her parents, the doctors decided to remove her testes, telling her she was a "special little girl" and that her ovaries must be excised to prevent them from becoming cancerous. They lied.

"The chance of me getting cancer was less than the chance of getting breast cancer," Sarah explains. "And they don't automatically cut women's breasts off, do they?"

Four years after her operation, Sarah was put on female hormones to ensure that she developed "normally" but life would never be the same. At school, while her female peers were fretting about periods, she felt different and alone. Fearing that others would judge her a "freak" she felt unable to confide in anyone. She made two attempts at suicide when she was just 14 years old.

Sarah's experience, like countless other intersex people who have suffered at the hands of the surgeon's scalpel, is proof of the paternalistic ideology that drives much medical practice today and which robs those with intersex conditions of bodily integrity and more.

It wasn't until a gynecologist revealed to Sarah, aged 25, that she was intersex and told her doctors had known since she was eight that she learned the ovaries she'd been told had been cut out were in fact testes.

Sarah was born with androgen insensitivity syndrome or AIS and had XY ("male") chromosomes instead of XX but she was born a girl and had a birth certificate to prove it. "I had never questioned my sex, and suddenly with this new information, my lesbian identity that had previously felt cool and rebellious became a source of shame. Would other lesbians reject me?"

Artist Del LaGrace Volcano is a polysexual non-binary intersex person who tells me he feels both female and male. Del suspected he might be inter- ▶

**"Most people born intersex do not have variant external anatomies"**



MaPa Del LaGrace Volcano with children Mika and Nico

sex based on his own physiology and a family history of an intersex variation called ovo-testicular “syndrome”. Del is one of many people to only discover they were intersex later in life when their body diverges from typical sex development at puberty. He began a medical investigation in the mid 90s which is on-going. At the same time he stopped plucking his facial hair for a few weeks and developed a dashing goatee and tried at the same time to come out as intersex.

“[My coming out] was widely interpreted, including by DIVA magazine, as me transitioning from female to male,” he remembers. “I felt like it was time to stop hiding and feeling ashamed of the masculine characteristics of my

body. I felt scared I would be cast out of the lesbian nation and by many I was. Luckily, I did find some community with trans men for a while before I discovered the intersex community.”

Thankfully, community and activism are on the rise, riding on the shoulders of the first wave of intersex activists who started to address the injustices committed against intersex people in the 1990s. Leslie Jaye explains that prior to 2005 clinicians never openly admitted to parents or publicly that intersex existed at all – “they simply traded our records amongst themselves. And lied. A lot. It isn’t nearly so easy for them now, and don’t they know it”.

In the UK the campaigning group

IntersexUK is one of a few groups worldwide calling for a raft of changes to UK and international law. Along with various colleagues worldwide, the organisations often work together to deliver international consensus statements and are driving change in international law.

Here in Britain, activists such as IntersexUK co-directors Holly Greenberry and Dawn Vago, who along with Sarah Graham made history last year in the Independent On Sunday’s Rainbow List, are increasingly raising awareness. And thanks to this work, and much work carried out by international colleagues, the UN is now committed to taking action through a new body, the Commission for the Rights of

PHOTO DEL LAGRACE VOLCANO

the Child (CRC), which is investigating the countries which continue to abuse and torture children and which has publicly critiqued numerous countries for abuse against healthy bodied intersex children; this includes criticism of France, Scotland and others. The UN’s Special Rapporteur on torture and over six UN bodies recognise the magnitude of the harmful practices committed against intersex children.

As the first intersex-bodied woman to speak at the UN, Holly Greenberry, who identifies as pansexual, spoke about the big buzzword in intersex circles, coercive medical treatment. “Numerous medical professionals coercively encourage parents and carers to agree to irreversible genital and gonadal surgeries and they can do this because the parents aren’t given support or information and because doctors talk about cancers. We hear many doctors still use frighteningly presumptuous terminology about risks of ‘gonadal cancers,’” says Holly.

Holly speaks from personal experience. Her parents were informed of variations of her anatomy at birth. Her secondary sex development was complex and atypical. In her teens matters again came to the attention of doctors who operated on her body with disastrous consequences. “I have had four different ‘diagnoses’ in life, and neither I nor my family had any meaningful emotional support; what the doctors did when operating on me was to cause life-long issues of pain, scarring, complex hormonal issues, and ongoing urological issues which also continue.”

After over 20 hospitalisations and many operations Holly still lives with problems caused by neglectful diagnosis, horrific medical errors and terrible surgical interventions. “Children really should never have to live with this,” she says.

There are further consequences of the failure of true recognition for Holly. Stuck with an “M” on her birth certificate, she cannot marry or have a civil partnership. “I’m female, a legal mother, but the value and equality that the Gender Recognition Act offers only applies to transgender people, not

all biologically intersex people, so I’m faced with many other inequalities. I’m a daughter, a sister, a woman. It’s an utter mess. After surgeries a right to our true legal identity is essential also.”

And while female genital mutilation is now illegal in the UK, current legislation permits doctors and surgeons to cut and “correct” the genitals of babies who don’t “fit” conventional notions of male and female. Thankfully, however, a growing body of clinical professionals in the UK are bringing awareness and change to this shameful practice that has resulted in children being misassigned and subjected to surgery throughout their lives from birth.

Speaking to Sarah, she tells me about the psychological toll of her experiences with medical professionals who forced on her a series of medical interventions, surgical and hormonal, throughout her childhood. The way doctors have treated her makes her feel as if she’s been seen as “sub-human”. It is not uncommon to hear this word from intersex survivors of medical abuse. And those who have escaped the surgeon’s knife also suffer. The stigma of being intersex in a world that at best doesn’t recognise you and at worst labels you a freak causes untold mental and spiritual distress.

“If they’d left my body intact,” Sarah says, “I would have produced hormones naturally and after years of lies and deceit I wondered if anyone would want me if they knew the truth.” After suicide attempts and descent into drug and alcohol addiction, Sarah went to rehab and has spent the last 15 years getting comfortable with who she is. “Now I’m honest about who I am and no one has judged me as harshly as I have but I still sometimes feel very alone in the world and can question my ability to heal the trauma I’ve experienced.”

Since deciding to live openly as intersex Del has found the response from family and friends has been mixed. “One of my sisters and my mother were unable to cope when I let my beard grow and it wasn’t until I took extraneous testosterone a year later and my voice dropped that they accepted me again, no doubt because

at least then I was passing as a something – a man – rather than a freak. My husband at the time, Johnny Volcano, was very supportive but I lost other friends, some lesbian, lots of white gay men and most of the straight female journalists I was hanging out with around that time.”

Understandably Del and many intersex-bodied people like him are angry that those within the LGBT communities have taken so long to acknowledge the existence and plight of intersex people. But he feels there is hope. “I feel extremely positive about now and the increasing amount of visibility intersex is achieving, both on a political level but also on the broader cultural canvas. In the small town I live in I am out and proud and just in case someone doesn’t ‘get it’, I have a four-year-old who calls me MaPa about 100 times a day, loudly, in public. The day care my kids go to not only know that my being a ‘MaPa’ is related to my being intersex, all the parents are aware of this too and the kids call me MaPa Del.”

The biggest change, in Del’s opinion, needs to happen in the hearts and minds of the general public. He says “they need to be aware that sex, gender and sex traits exist on a spectrum and that what we have been told in school and by society harms us all, sometimes in subtle ways and other times with tragic consequences. Not being able to answer the primal question: ‘Is it a boy or a girl?’ must stop being treated as a social emergency.”

The activists at IntersexUK have a raft of demands aimed both at the government and on an international scale. Their vision is to ensure irreversible genital mutilations, sterilisations and other non-consensual abuses against healthy intersex bodied children is stopped. “A child’s body is theirs for the whole of their life and the right of that person’s autonomy must be respected above the right of others to ease social discomfort. Scalpels without consent don’t sculpt gender, they sever children’s futures,” says Holly. “When irreversible surgical and hormonal procedures are performed on a child or young person in an attempt to ►

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Holly Greenberry: Proud mum and co-founder of Intersex UK

surgery would help him be a man and improve his own sense of masculinity, and that the surgery was reversible. The parents didn't seem fully aware of the severity of side effects and had no peer support to help them make their decisions; no one wants a child to suffer but these surgeries are often horrific and always irreversible in many of the effects."

Last year Malta became the first country to outlaw surgery on intersex babies following work by intersex advocates who convinced officials that trying to "fix" intersex infants with surgery is damaging and unnecessary, and that intersex individuals should be allowed to determine their own identity and whether they desire surgery as they grow up. Maltese officials will now work with medical professionals to draw up best practice guidelines to ensure any surgery or medical interventions that do take place are medically necessary and not "driven by social factors without the consent of the minor".

Sarah, who is currently working hard in LA to be the world's first out intersex comedian, is also hopeful. "This visibility is so important to help others not feel so alone. It's a cliché but laughter is the best medicine."

"Aside from surgery being stopped," she adds, "I really want to have the option to be intersex on passports by the time I die. Symbolically that's so important because it proves we exist as whole, acceptable humans. I just got a new 'female' passport and it feels like a lie. My maleness is being denied. I am both."

Leslie Jaye believes that raising awareness of the widespread lack of knowledge about the spectrum of variation in embodiment that men and women can and do naturally encompass is a key factor in changing societal values.

If only my uncle had been allowed to live as he was born, perhaps he too would be glad to know of the intersex pioneers who are fighting for the right simply to be as they are. **D**

Find out how to be an intersex ally at [tinyurl.com/IntersexAlly](http://tinyurl.com/IntersexAlly). [@IntersexUK](https://www.instagram.com/IntersexUK)

cosmetically 'normalise' their bodies to ease social discomfort, [they] cause life-long sterilisation, mass scar tissue, urological issues, not to mention sexual function and insensitivity; the side effects here are a non-exhaustive list. It's simple – wait, peer support, and ask the person."

With recent high-profile interventions in the British media and meetings with political ministers, IntersexUK's outreach is significant and growing.

Says Holly: "We work by educating within universities, engaging with mainstream media and consulting with NGO and government bodies. Intersex-

**"I want the option to be intersex on passports by the time I die"**

UK aims to develop a cross-party intersex equality committee to ensure families and society recognise that intersex bodied children are not uncommon and that enforcing gender through 'normalising' archaic and irreversible medical procedures is not acceptable. That said, we recognise that it's ok to give a child a gender without damaging them irreversibly; children will clearly define their own gender. Surgery without fully informed consent will never forge a child's gender. We recently heard of another UK parent who was told that if they agreed to the surgeon operating on the child's genitals, the