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Special report: Intersex women speak out to protect the next generation



One in 2,000 babies does not fit neatly into male or female categories. Sarah Morrison meets four members of a new group that's campaigning to change attitudes and to help others feel less alone

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It has taken Holly Greenberry, Sarah Graham, Dawn Vago and Elizabeth Jo Roberts years to go public with their stories. Born into a world that insists on dividing people into two sexes, they did not always know how they fitted in. They were born to typical families in typical areas of Britain, but none of them developed into typical male or females. They are intersex.

An estimated one in 2,000 babies is born with an intersex condition or a (controversially named) disorder of sex development (DSD), which means that they are born with a reproductive or sexual anatomy that does not fit the typical definitions of female or male. This can include atypical genitalia, chromosomes or internal sex organs.

The women argue that their very existence has been “eradicated” by British society. Generations of children have been operated upon to “normalise” their genitals or sexual anatomy, while official documentation, from birth certificates to passports, requires a male or female box to be ticked. They argue it’s one of the last “human rights taboos” in the western world.

The women have a type of androgen insensitivity syndrome (AIS), which means they have XY chromosomes, but are partially or completely insensitive to testosterone – they are all infertile.

The group has come together to launch a campaign, calling for the Government to urgently review the way intersex people are treated. Following on from Germany’s decision to allow newborn babies to be registered as neither male nor female, their recommendations include the option to leave the sex on British birth certificates blank, measures to protect babies or young people from irreversible and non-consensual treatment and surgery, better emotional support and increased education.

“We are at a tipping point,” said Greenberry, co-founder of Intersex UK. “Most intelligent human beings would be completely surprised and utterly dismayed at the civil inequality and human rights abuses that healthy intersex children and young adults are facing.”

She added: “We need to sit around the table with the Government because we have lived through it. We are positive role models, and professional and intelligent women, who want to represent the needs of children so that the problems we experienced aren’t replicated.”

In the 1960s, it became the norm to operate on children with atypical sexual anatomy at a young age. Doctors assigned the child’s gender and operated to reinforce it. Although attitudes started to change around the turn of the millennium, and clinicians say they have moved to a more “multi-disciplinary” approach, there is still no record of the number of operations carried out, according to Professor Sarah Creighton, consultant gynaecologist at University College London Hospitals.

This year, the UN Special Rapporteur on Torture condemned non-consensual surgery on children to “fix their sex”, saying it could cause “permanent, irreversible infertility and severe mental suffering”.

XXXora, a 33-year-old intersex artist from London, who supports the women’s campaign, refused an operation. She was born with ambiguous sex organs and raised as a boy, but describes herself as “super-feminised from the beginning”. She said: “I never had surgery or hormones. We talked about it, but then I wouldn’t be me. I don’t want to morph into a blue or pink box; I want to stay in my silver box.”

But the campaign is not all about surgery. Certain intersex people, such as Greenberry, are struggling to correct the sex marked on their birth certificates, which makes it impossible to marry and more difficult to adopt children.

Lord Wilf Stevenson, opposition whip and former special adviser to Gordon Brown – who has a more common DSD called hypospadias – supports the campaign and has raised concerns with ministers. “The issue is that the current law has been overtaken by medical technology,” he said.

There is also a need to provide long-term emotional support for intersex people. Ellie Magritte (not her real name), the mother of a girl with AIS and a member of the support group DSD Families, said adults “need and deserve much greater investment in adult DSD care, focusing not on gender, genitals and genetics, but on health, wellbeing and happiness”. She said not all people with a DSD define themselves as intersex, but added: “The main challenges for families and kids is the social context in which we live with these conditions.”

Pia Clinton-Tarestad, head of specialised commissioning at NHS England, said that the NHS is “working to assess the services we commission for intersex people”, and that it understood that “issues surrounding the timing of, and consent to surgery, are controversial”. She added that best practice involves “co-operation and agreement” between child, parents and a multidisciplinary clinical team.

Holly Greenbury

When Holly Greenbury was born, almost four decades ago, doctors spotted a degree of sexual ambiguity. She has XY chromosomes, but also partial androgen insensitivity syndrome, leaving her partly insensitive to testosterone. She was assigned a male sex on her birth certificate, but she did not develop secondary male characteristics during puberty. She knew her gender was female and underwent treatment and surgery throughout her teens. Now, the businesswoman, from south-west England, is in the process of adopting a child. Because she is unable to change her name or sex on her birth certificate, adoption is harder and marriage impossible.

“I’ve never been completely male nor completely female in my genetics. I didn’t masculinise the way a male was expected to, and my body feminised in certain areas. I didn’t have the words to express myself; I didn’t know how I fitted in. It left me feeling really isolated and, while I tried to identify as male, I couldn’t do it. It was like having a series of repetitive panic attacks. Surgery was horrifically damaging and led to huge number of follow-up surgeries. It all could have been prevented if there had been more medical understanding and if there had been less haste in trying to guess which label best fitted. I should have been allowed to be an ambiguous teenager with the freedom to express my natural gender.”

Dawn Vago

Thirty-three years ago, when Dawn Vago was born, she looked like a typical baby girl. But when she was a young child, doctors told her parents that she had testes which would have to be removed. The married singer and programme director from Warrington, Cheshire, is genetically XY and has complete androgen insensitivity syndrome, which means she is totally insensitive to testosterone. She has been on oestrogen replacement therapy since she was 11.

“The doctors told my parents there was no one else in the UK with this condition. I felt alienated from all of my classmates. I always identified very much as female, but had issues accepting myself. When I first read my file and saw my diagnosis, my world completely exploded. I found a support group and all of a sudden, felt like I wasn’t alone. The moment of joy turned into anger. I was in my early twenties and had spent my whole life and childhood feeling alienated. I realised that it doesn’t have to be this way.

“The doctors told my parents that they should push me into a career and make me become a busy woman, so maybe I wouldn’t have time to settle down and have a family. They said I would find it very difficult to find a partner. Two and half years ago, when I walked down the aisle to my incredibly handsome husband, deep inside I was sticking a middle finger up to the entire medical establishment. I am very proud of who I am and I love my body, but I hate the journey that I’ve been on.”

Elizabeth Jo Roberts

Elizabeth Jo, a 29-year-old freelance journalist from Edinburgh, was brought up as a girl. At three years old, when doctors discovered undescended testes, they removed them without her parents’ consent. She was told at the age of 10 that she was infertile and, in her mid-teens, that she had androgen insensitivity syndrome, having been born with XY chromosomes. She met other people with intersex conditions for the first time only a few weeks ago.

“My parents told me I couldn’t have children at 10 years old. I took it pretty badly. It’s like when you’re winded and all the air is sucked out of you. It destroyed my adolescence. I got bullied quite a lot. When I was 10 or 11, I was first given oestrogen pills, but I used to forget to take them, so I never really developed significantly.

“I struggled with identity issues throughout my adolescence and even in my twenties. I’ve left it late on in life to meet others like myself. It has been one of the best things I’ve done; emotionally cathartic. I suffered quite heavily from depression. I want to help others to not feel the same way. They don’t have to feel bad about themselves. Social change takes years to happen, but we should be living in a society where people don’t feel bad about their identity because they have chromosomes that are variations on the norm. They should have freedom to express themselves.”

Sarah Graham

Sarah, 44, did not find out the truth about her diagnosis until her early twenties. The counsellor from Surrey has complete androgen insensitivity syndrome. She presented at birth as a baby girl and was raised as one, but she has XY chromosomes and was born with internal testes, instead of ovaries. When doctors removed them, at the age of eight, they told her they were removing her ovaries to protect her from cancer and imminent death.

“They should have told my parents the truth about my diagnosis. The lies were enormously damaging to me and affected my life. They put me on oestrogen replacement therapy when I was 12 years old but, if they had left my body intact, I would have produced hormones naturally. Every six months, I was prodded and poked by an army of medical students.

“Once I saw my diagnosis, I felt like a total freak, like I didn’t belong, and was offered no support. I felt like the only person in the world with the condition and that no one would love me. I went into a massive period of self-hatred and self-destruction, which fuelled a drug and alcohol addiction. Children need to be able grow up intersex if they want and parents shouldn’t be so pressured to make a decision. We must be given the space to exist.”

To find out more visit:

[Intersex UK](#)

[The Androgen Insensitivity Syndrome Support Group](#)

[DSD Families](#)

[Hypospadias UK](#)