

Intersex Overview

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Most people are born either male or female. An intersex person is someone who is born with a body which is in between the two. This can manifest in ambiguous genitalia, a non-standard reproductive system or non-standard chromosomes (for example, XXY rather than XY or XX). There are several conditions which can cause a person to be born intersex, but in simplistic terms it happens because of variations in the biological signals received by different cells in the body of the foetus during gestation. Because these variations in the signals vary in strength, some intersex cases are more extreme than others.

Every foetus starts out with a set of sex chromosomes - usually XX for females or XY for males - and some otherwise undifferentiated cells which will develop into its genitals and reproductive system. As it grows, the foetus develops a rudimentary reproductive system which has the potential to become feminised (ovaries and a womb) or masculinised (testicles). The sex chromosomes trigger signals which tell the reproductive system which way to develop. However, in some cases these are overridden by other hormonal signals, so the system which develops is at odds with what would commonly be expected. This can cause medical complications in some cases. It also causes anxiety for parents who don't know what to make of a child whose physical body is gender ambiguous.

Some intersex people undergo surgery during early childhood to make them more closely resemble ordinary boys or girls. Almost all intersex children are raised as either boys or girls. Often they are not told that they are intersex.

In some cases, it is not obvious at birth that a person has an intersex condition and it is not diagnosed until later life. Some intersex conditions become apparent at puberty, when secondary sex characteristics (breasts, body hair etc.) develop. Other people discover they are intersexed when they seek help because they have been unsuccessful in trying to have a baby. Most (but not all) intersex people are infertile.

One of the issues with assigning a gender to an intersex child is that it is not always possible to tell which they will emotionally identify as. In some cases, intersex people grow up to feel that the wrong choice has been made on their behalf. Most intersex people identify clearly as either men or women, but some identify as a third or in-between gender.

Most intersex people look either male or female. You would be unlikely to notice that a person was intersex when you passed them in the street. Most consider their conditions a private matter. Curious outsiders often ask intersex people to describe their genitals, but this is just as rude and intrusive as asking a non-intersex person to describe theirs.

It is estimated that somewhere between one in two hundred and one in two thousand people have an intersex condition. Despite this, awareness of intersex issues is very limited, even within the medical establishment. This is partly because intersex conditions have traditionally been kept secret due to being perceived as scandalous. Only over the past two decades have people with intersex conditions begun to join together as adults to campaign for better treatment.

Intersex Conditions

The majority of intersex people will have one of the following conditions but there are also some much rarer and less well researched intersex conditions which are not described below.

The majority of births recorded as intersex are cases of hypospadias. This is not considered by everyone to be a 'true' intersex condition because it has only a very localised effect on bodies which are otherwise male. Hypospadias means that the opening of the urethra (the tube which urine and semen pass through) is not at the tip of the penis but is somewhere else along the length of it, sometimes at the base. This does not normally cause medical problems, but some doctors worry that it can lead to social stigmatisation because boys will be unable to urinate standing up in the normal fashion. It is common for children with hypospadias to be operated on to try and make them look more normal. Surgery of this type is notoriously difficult and it is common for such children to require several operations. Complications can leave a

significant number of patients unable to urinate at all without mechanical assistance.

The most common intersex condition to affect people with XX chromosomes is congenital adrenal hyperplasia, or CAH. This is a condition which can be passed down in families. It causes the masculinisation of female foetuses, with varying degrees of severity. CAH babies usually have enlarged clitorises which may look more like penises. These do not cause any medical problems, but are sometimes operated on for cosmetic reasons, in the hope that the reduction will make it easier for the child to grow up as an ordinary girl. However, the evidence suggests that only about fifty percent of CAH people go on to identify as female. In the absence of hormone treatment, CAH people usually develop male secondary sexual characteristics (such as facial hair and deep voices) at puberty. CAH also causes medical problems in most cases, and most CAH people have to take thyroid medication throughout their lives.

A common intersex condition affecting people with XY chromosomes is androgen insensitivity syndrome, or AIS. In AIS cases, the developing foetus fails, either partially or completely, to respond to the presence of testosterone and so does not develop normal male sex characteristics. In fact, many AIS people are assumed to be ordinary girls when they are born, and it's possible that a significant number are never identified as intersex. The vast majority of AIS people (but not all) identify simply as women. They have short vaginas but lack female reproductive systems; instead they have undescended testicles. Sometimes these descend at puberty, often causing great emotional distress. If they do not descend, most doctors advise that they should be removed, as they have a significant chance of becoming cancerous. AIS people are infertile.

AIS people tend to grow tall like men, but develop female secondary sexual characteristics (such as breasts) and a bone structure which is mostly feminine in appearance.

Some people don't have the usual XX or XY chromosome pairings, but have XXY chromosomes instead. This is known as Klinefelter's syndrome. Most people with Klinefelter's have small penises and small testicles, and many develop breasts at puberty. Most (but not all) identify as male. Klinefelter's is also connected with a range of medical problems. It has been linked to language learning disorders, breast cancer, and a tendency to obesity. The life expectancy for people with

Klinefelter's is lower than average; however, the evidence suggests that most are still able to lead fulfilling lives. A few are able to father children.

Another condition in which sex chromosomes are unusual is chimerism. This occurs during gestation when two embryos fuse together at an early stage of development, creating a child who has cells from each of two different genetic combinations. There is increasing evidence that chimerism is in fact quite common, but usually it has little effect on development. However, the fusion of male and female embryos can create a person who has some XX and some XY cells. In some cases, this can lead to the development of intersex characteristics.

Although it is comparatively rare, 5-alpha reductase deficiency syndrome is among the better known intersex conditions. This is partly because it is inherited in such a way that it can be tracked across generations, tending to occur in small clusters in isolated populations; and partly because of the startling way in which it manifests. In Papua New Guinea it is known as kwolu-aatmwol ('female thing changing into male'); in the Dominican Republic, as guevedoche ('balls at twelve'). Babies with this condition appear female although they have male chromosomes. This is because their bodies have not responded normally to testosterone. However, at puberty they develop small penises and male secondary sexual characteristics. In places where this condition is common, it is not treated with the same secrecy as most intersex conditions are in other cultures. Surgical intervention is rare and most affected people live comparatively normal lives.

Intersex physical bodies can also be caused by a number of lesser known conditions. In some cases the cause cannot be clearly established. In other cases, it is caused by exposure to radiation or to particular chemicals during gestation. During the 1950s and 1960s, many American women were treated with a drug called progestin which it was believed would lower their risk of miscarriage. This drug had the effect of masculinising female foetuses, resulting in a condition resembling CAH. Another cluster of intersex births occurred in eastern France in 1986 and 1987. This is thought to be a result of radiation from the Chernobyl disaster, as prevailing winds carried a lot of radioactive clouds over the area in the immediate aftermath of the disaster and government warnings against eating produce which had been exposed to the rain were not issued until several days later. In both these cases, the intersex births were initially hushed-up, but the truth emerged as those affected grew older and began to encounter one another.

Different people have different personal definitions of what constitutes an intersex condition. Some intersex websites and support groups limit themselves to one or more of the most common conditions, sometimes because it is difficult to provide in-depth information about all the different forms of intersex cases and sometimes because the experiences of people with different intersex conditions do not have much in common. In other cases, intersex people with different conditions join together because of shared concerns about how they are treated by wider society.

Intersex Medical Issues

Intersex people are often born with medical complications. Some doctors consider intersex bodies themselves to be an unfortunate medical problem. It is common for intersex people to undergo surgery in early childhood, sometimes just a few days after birth. Frequently, parents of intersex children report that they have difficulty knowing whether the surgery suggested for their children is appropriate or necessary. Having a baby is always a stressful event, especially if that baby turns out to be unusual, and it's difficult for stressed parents to be sure they're making the right decisions.

Surgery carried out on intersex children can be divided into two categories: that which is necessary to treat important health issues, and that which is carried out for cosmetic reasons.

Several of the conditions which cause people to be intersex can also cause health problems which require urgent treatment. Children born with congenital adrenal hyperplasia, for example, often have problems with high blood pressure which must be treated immediately to avoid damage to the kidneys. The formation of intersex genitals can be accompanied by problems with the urinary system, which may not develop in such a way as to let the child pass urine healthily, leading to pain and a high risk of recurrent infections in the absence of early surgical intervention. For these reasons, it's important for parents of intersex children to listen to doctors and accept that some medical intervention may be necessary.

Cosmetic surgery carried out on intersex children is usually aimed at making them look more masculine or more feminine. Doctors who carry out this surgery believe that it will help the children involved to lead

socially normal lives. In most cases, the particular intersex condition involved determines which sex is chosen for the child - for instance, children with androgen insensitivity syndrome look much more like girls than like boys. In some cases, however - especially with CAH - it's hard to decide whether the child looks more like a girl or more like a boy. In these cases, the sex chosen is usually female, because it's easier to surgically construct female genitals than male ones.

Genital surgery carried out on children is not simply the same as the genital surgery carried out on transsexual adults, though many of the procedures involved are similar. Because children are still growing, they often need a series of operations all the way through to adolescence. Some of these operations - particularly those which involve constructing male genitals - have a high rate of complications. Many children find them traumatic. In some cases, parents are required to assist with procedures on a daily basis, for instance by inserting an object into an artificially constructed vagina to keep it from closing up. Further surgery may be necessary in adulthood when the intersex person is ready to become involved in a regular sexual relationship.

Cosmetic surgery on intersex people can cause three major sets of problems. The first is trauma arising from invasive procedures and loss of privacy. The second is loss of sexual sensation, with about a third of adults who have undergone such treatment unable to experience sexual pleasure. The third is the distress which can arise when the sex chosen by surgeons contradicts an individual's own instinctive feelings on the matter. It is possible that some people are entirely happy with the results of surgery of this type, but it's difficult to assess this because historically such surgery has been shrouded in secrecy and happy people are less likely to come forward and identify themselves.

Most organisations of adult intersex people argue that intersex children should be raised without any surgery which is not essential for health reasons. They will then have the option of choosing surgery in later life, when they are able to express how they feel about their own gender. Many intersex children are prescribed hormone treatment to control the feminisation or masculinisation of their bodies when they reach puberty, but by that age most children should be capable of making their own medical decisions.

Social arguments in favour of cosmetic surgery often revolve around very traditionalist notions of what male and female bodies should be able to do. They fail to take into account the natural variety of human behaviours. A traditional aim of surgery to create a vagina is that the

vagina should be capable of accommodating a 'normal sized' penis, but we now know that many heterosexual couples enjoy fulfilling sex lives which don't include this form of penetration. The experiences of transsexual people can also be important in assessing the options for an intersex child - for instance, by providing simple gadgets and techniques which can enable a boy with hypospadias to urinate standing up in such a way that other boys will never notice his difference.

Some intersex people feel that the emphasis on medical issues relating to their conditions is misleading. If they are generally happy with their bodies, they argue, then they don't have a problem - the problem is with a society which doesn't know how to cope with the reality of their existence. Rather than subjecting them to years of surgery so that they won't be bullied at school, schools should deal with the bullies.

It is generally agreed that more information is needed for parents facing difficult decisions about their intersex children. Patients' advocacy groups can help them to assert their views if they feel that doctors aren't listening to them. The increasing online presence of groups representing intersex adults means that, in most cases, they should be able to find and talk to people who have experienced the same proposed surgeries.

Although some intersex people require essential surgery and lifelong medication, most are able to enjoy relatively healthy lives. Intersex conditions may have medical implications, but these don't need to dominate a person's life.

Intersex Language

Considering the difficult medical and social problems which surround intersex people, it might be difficult to see why language is a significant issue, but the language we use defines much of the way we think. Language influences the way we perceive social matters (such as gender) and the way we perceive our own bodies.

If you've studied a language like French or German, you may be aware that some languages have gender markers, sometimes purely grammatical but sometimes used to denote the sex of a particular person. In English we still have some terms like these - 'fireman', for instance - though they are gradually becoming outdated. This is one example of how language perpetuates the idea of a binary gender

system, one in which there is no place for people who fail to identify as male or female. If you were Thai or Japanese, the very words you spoke would be determined, to an extent, by your gender. There was recently a scandal in Japan when it was discovered that some groups of schoolgirls were speaking using word forms normally reserved for men. The girls were breaking a stronger taboo than the use of any swear word in the English language.

It has long been accepted that the lack of a gender neutral second person pronoun (to accompany 'he' or 'she') in English is a problem. The word 'they' has come to be used in this context, but it's clumsy, since it also has another meaning. 'He/she' or 'he or she' tends to be used in formal writing, but can be unwieldy. The internet has increased the popularity of invented pronouns like 'sie' and 'xie', but these have yet to establish themselves in wider circulation. The result is that those intersex people (and other transgender people such as androgyne people) who do not identify as either male or female nevertheless usually have to accept being referred to as 'he' or 'she' (or both). Most intersex people find it extremely offensive to be labelled as 'it', which is sometimes used to demean them by unsympathetic family members.

Aside from the social difficulties caused by language, there can be personal difficulties. Intersex people have no words for their own distinctive body parts. Their genitals are generally referred to in relation to normal male or female

genitals, so we get terms like 'micropenis' and 'pseudo vagina'. The negative associations which these terms convey encourage people to feel that their bodies are inadequate and that they are unsuccessful at being male or female rather than successful at being themselves. This is an example of how intersex people are discouraged from feeling positive about their bodies and hence about their potential as human beings.

The medicalisation of the intersex experience is emphasised every time a particular intersex condition has to be described using an unwieldy medical term. To an extent, this is being eroded as intersex communities increasingly rely on acronyms and abbreviations. Creating more natural alternatives, which fit easily into conversation, is one way in which intersex people can start to determine their own identities.

As intersex people develop a positive sense of their own identity, we need to look at how language can change to accommodate them. It's important for families, friends, and those providing public services (such as health care) to intersex people to respect their choice of terminology in defining their identity. We need to adjust our language habits to make

room for new terms originating within the intersex community. Languages are fluid things which change as society changes, adapting to new social realities, and enabling linguistic change is an important part of accepting intersex people into society.

Intersex Communities

When people discover that they have intersex conditions or first realise that there are others out there in similar situations who're willing to talk about it, often their first concern is how to contact intersex communities. In some rare cases, due to the circumstances of their birth, intersex people are already part of intersex communities living within mainstream society. Either way, communities play an important role in providing support and information and helping people to make their voices heard. They can also provide useful resources for the parents of intersex babies.

Most intersex communities are condition specific - that is, all of their members share the same intersex condition. This can be very useful when it comes to sharing support and advice and collecting information, but it does mean that some groups are quite small and, while they may thrive in an online environment, it's difficult for members to find local support. This means that some intersex people can still feel very isolated in society at large, even if they are members of online or correspondence communities.

Over the past fifteen years, umbrella organisations have emerged to bring together people with different types of intersex condition. The largest and most famous of these is ISNA, the Intersex Society of North America. Consequently, it has led the debate on many of the political issues which face intersex people. It provides an impressive array of resources including lots of medical information, and it has allied itself with several respected medical professionals whose aim is to improve the way intersex people are treated by the medical establishment.

In the UK, The United Kingdom Intersex Association (UKIA) acts as a campaigning group on behalf of intersex people with all kinds of different conditions. It is unable to provide medical information but can refer people to appropriate support groups and specialists. It is primarily concerned with education, both for the public and for intersex people themselves.

There are several online communities where intersex people can meet and talk. Some of these are exclusively for intersex people whilst others also welcome their friends, partners and family members. There are groups which are only for intersex people who have received medical treatment (usually including surgery) for their condition, there are groups which limit membership to people with one of several named conditions, and there are groups which are open to people with borderline conditions.

The intersex community often breaks down into two groups: those who have undergone surgery without their consent, and those who have not. Sometimes people in the latter group complain that they feel excluded or are not considered 'true' intersex people, but there are still several groups out there which aim to cater to their needs. People in the former group share a traumatic experience which it's difficult for other people (even people born with similar anatomies) to relate to, so they need a different kind of support.

In some parts of the world, where there are high rates on intersex births, intersex people form a natural part of the wider community and are able to live openly within a society which respects and understands them. This is true of the guevedoche people of the Dominican Republic and the kwolu-aatmwol people of Papua New Guinea. Because of the way they are affected by their 5-alpha reductase deficiency, these people normally live as girls until puberty, after which point they start living as men. Their societies do not give them special roles because they are intersex (though in the past they were sometimes believed to have magical powers), but neither do they stigmatise them.

In eastern France, where a large number of children were born with intersex conditions after exposure to radioactivity from the Chernobyl disaster, a community of intersex people is beginning to form spontaneously. This will be the first modern instance of wider society suddenly having to get used to the presence of a significant number of people who are open about their intersex conditions. Organisations within this community are campaigning for greater openness from the French government.

For some people, living with an intersex condition is an extremely private matter, but even those people may find intersex communities useful. It is possible to communicate with them anonymously and confidentially. People are also creating new intersex social and campaigning groups all the time in order to cater for the different needs emerging amongst the intersex population. Thanks to groups like these, intersex people no

longer need to feel isolated or feel that nobody understands what they have had to go through.

Intersex Gender

It is commonly assumed by outsiders that intersex people must identify as something in between male and female - as intergendered or third gender. On the contrary, although their bodies don't look like what's expected of male or female bodies, most intersex people identify strongly as either male or female.

Many scientists believe that there may be an overlap between the medical circumstances which cause some types of intersex condition and those which cause transsexualism. However, being intersex is not the same as being transsexual. These different conditions have been included in the Scottish Transgender Alliance's site simply because there is one trait which they do have in common - they both involve having a personal experience of gender which is not always understood or respected by society at large.

Like transsexual people, many intersex people experience the trauma of being raised in a gender role which they do not feel is right for them. This can happen whether or not they have been made subject to surgery in early childhood. Doctors used to believe that such surgery, along with corresponding socialisation, could change a child's instinctive sense of gender identity, but it is increasingly accepted that this is not the case. These days, the planning of surgery usually takes into account the gender identity which most commonly develops in people with each particular type of intersex condition; however, there is no way to be absolutely certain how this will develop.

Intersex people who have been subject to surgery in childhood can face extra complications if they wish to transition between genders as adults. Medical options normally available in this situation may be impossible for them due to the presence of scar tissue from earlier operations and the shortage of healthy, sensitive tissue to use in reconstruction. However, general improvements in genital reconstruction surgery mean that intersex adults who are approaching surgery for the first time and wish to look more male or more female can expect increasingly good results. Other intersex people are happy with their different bodies and don't feel any less male or female as a result.

Although some evidence suggests that homosexuality and bisexuality are more common within the intersex population than in wider society, there has been too little research to draw any serious conclusions. Sometimes what appears to be homosexuality is really just one indication of an inappropriately selected gender assignment. For instance, some people with congenital adrenal hyperplasia who are raised as girls discover they are attracted to other girls as part of a process of acknowledging a feeling that they are really boys (however, about fifty percent of people with this condition are happy with a female identity).

Traditionally, doctors working with intersex patients have used sexual orientation as one of the criteria by which to determine whether or not a gender assignment has been fully successful. This means that, for instance, attraction to women can be considered by medics as an implication that such a patient is not properly female even if that patient is actually comfortable with a lesbian identity.

Often intersex people are encouraged or expected to adopt male or female identities which would seem extreme and unusual to most people, so as to conform to stereotypes. This can be confusing for children who want to please adults and who feel uncertain about how it is appropriate for people of their gender (whether instinctive or chosen by other people) to behave. It can make them feel uncomfortable about their assigned gender even if it would otherwise be the one they would prefer.

Most intersex organisations recommend that parents should raise intersex children as either male or female but be open to the possibility of them changing their gender role as they get older. A relaxed attitude to what constitutes appropriate male or female behaviour can make this process easier and can actually enable intersex children to be more like the other children around them, for whom gender is not always a major concern.

Some intersex people do not identify as either male or female and have campaigned to be recognised as part of a third gender group. So far, Australia is the only country which has given legal recognition to this group. Other intersex people have campaigned to have the category of gender made legally irrelevant by way of things like having it removed from official identification, as they don't believe that their gender should be anybody else's business.

All the major intersex organisations agree that it is important that intersex people should have the legal right to determine their own

gender, rather than having it determined for them by doctors or their parents. Although the law in the UK requires that a legal gender be assigned at birth, it is important that this should be open to change later in life.

Intersex Awareness

Twenty years ago, very few people beyond the medical establishment and those directly affected were really aware of intersex people. Hermaphroditic figures existed in mythology and stories of the human oddities exhibited in Victorian freak shows persisted, but there was little understanding of intersex conditions as something which affect a significant number of people in the modern age. The parents of intersex children were encouraged to keep the condition secret, within a climate of shame, and some doctors even went so far as to erase medical records of the 'corrective' surgery which these children received.

Over the past two decades, intersex campaigning organisations have worked hard to dismantle this culture of secrecy. In the past few years, popular novels and television documentaries have succeeded in bringing intersex conditions to the attention of the general public. The public reaction has, for the most part, been very positive and very much in favour of supporting the right of intersex people to self determination.

Despite these changes, a significant number of intersex children are raised without being made aware of their own conditions. Many report feelings of distress and isolation which stem from being vaguely aware that there's something they're not being told. Many have a sense that they have somehow failed to be what their parents want. Surgery and other medical procedures can be particularly traumatic for children who are not fully certain what the procedures are for. These days, it is generally considered healthy to be open and honest with children when they have other medical complications such as heart defects or childhood cancers, but there is still a powerful stigma which can make people feel that the open discussion of intersex conditions is inappropriate. Some of this doubtless has to do with social taboos against talking about sex, although, for children, sex is not part of the issue.

Despite modern society's treatment of intersex conditions as a primarily medical phenomenon, there is still a lack of awareness about them

within the medical establishment. This means that intersex people can have difficulty obtaining appropriate health services. They may also be reluctant to be open about their

circumstances with new doctors who have not read their notes, due to an expectation of prejudice, especially if they have not conformed to medical expectations by having their bodies altered.

Despite the fact that intersex children may need extra support from school staff, the subject of intersex conditions is never discussed within school curricula and most school counsellors have no training in how to deal with the special problems likely to be faced by intersex children. This means that intersex children often have no-one to talk to about their experiences apart from their parents and doctors, which increases the likelihood of them feeling pressured into accepting treatments which they don't really want. There is no support available within schools for children who wish to change gender roles. The UK government has stated that it does not believe this is an issue for children, an opinion which runs contrary to the documented experience of numerous intersex people who were assigned to the wrong gender role at birth.

2004 saw the first ever Intersex Awareness Day, on which intersex people across North America joined together to try and make governments and the public more aware of their existence and of the issues which they regularly have to face. The following year this was expanded into an international effort.

Intersex conditions affect approximately one in two hundred of the population, which means that there are over three hundred thousand intersex people in the UK alone, with over twenty seven thousand in Scotland. Intersex campaigning groups aim to ensure that these people receive proper representation, protection from discrimination, and equal access to public services.