

What is Intersex?

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I have been asked to provide some material from different sources, but these are requests I find hard to engage with. One is for me to provide a primer on intersex for undergraduate students. The other is to give a personal biography. I have been considering why at this stage of my life and research I am finding it so difficult to comply with these requests. This writing also comes out of a request to OII for material on intersex for a non-academic audience in a medical context.

I am very interested in writing phenomenologically, because writing from an existential position seems more illuminating and less prone to misinterpretation than writing about 'facts.' Facts are not always what they seem. In writing about intersex, the first thing that has to be understood is that the definition of intersex has changed and has become increasingly policed by people with medical, activist and academic careers.

When I first learned about intersex, I understood it was about being born somewhere between the sexes. That could be to do with having mixed genital or gonadal structures, genital appearance that did not match to phenotype, appearance that did not match up with sex chromosomes, and so on. The wisdom of experts was that intersex was extremely rare. As time went on, it emerged that people who were intersex had a set of medical conditions, mostly genetically based, and that most intersex people were not intersex at all. Many intersex people did not see themselves as intersex, had no experience of medical intervention in childhood, were happy with their

assigned gender, and had heterosexual orientation. Because of the vagueness that had become associated with the term 'intersex', a new term began to be used – 'disorder of sex development' (DSD).

What was interesting about this shift in understanding about intersex was that it included people who would not tend to think of themselves as intersex, and excluded others who did appear to have intersex histories. The process appeared to be based on whether somebody had a diagnosable condition, or persistent symptoms that could not be modified in a way to make them 'disappear.'

Historically, intersex had been a much broader and inclusive category, and included many people who would

now be considered transsexual, as well as many homosexuals. This was an idea that can be traced back to Magnus Hirschfeld, and up until the 1960s was still current – anybody not part of the binary-sexed heterosexual normality was in some way intersex. There were assumed to be reasons for this that were grounded in biology. With John Money, the emancipation of gay and lesbian people,

and surgery for transsexuals, the focus on

biological causes became restricted; being gay or lesbian was no longer seen as a sickness, gender identity was developed to explain the sense of sex one identified as, and gender behaviour was seen as rooted in social development. Transsexuals were increasingly identified as biological men or women with a gender identity in conflict with their physiology. This left only those with issues that had clear biological markers as being subject to biological causes.

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The prevailing trend with regard to people with biological manifestations of intersex was to regard this as an illness, a deformity, and something in need of medical treatment. The theories about the social basis of gender meant that young children would be operated on to make them appear to conform more closely to the gender they most closely represented, and socialise them accordingly. In the USA, for those who were seen as requiring treatment, many were assigned female. In the UK, some were assigned female, but others assigned male. The development of new learning and techniques entailed research into the causes of the conditions which gave rise to intersex states.

These conditions did not always have intersex effects, but were causative of many of the presentations of intersex:

- Congenital Adrenal Hyperplasia (CAH)
- Androgen Insensitivity Syndrome (AIS)
- 5-alpha Reductase Deficiency
- Klinefelter's Syndrome
- Turner Syndrome
- Mosaicism
- Etc.

As well as these, there was the exposure to androgens prenatally, known as Progestin Induced Virilization (PIV).

These tended to be about having some mixture of chromosomes, having XY chromosomes and appearing female, having XX chromosomes and being virilized. What happened in this process was that surgical interventions were carried out to make people appear more female, and have this reinforced through social conditioning. The

term 'intersex' became expanded to include people with a variety of medical conditions, even if there was no atypical sexual features. At the same time, those who had XY chromosomes but could be assigned male were not included in the same way. So, the idea that there could be a similar process

to PIV in an XY foetus exposed to oestrogens prenatally was disregarded, and is still contested. That

is despite the levels exposure of women to diethylstilbestrol (DES) from the late 1940s to late 1960s, and subsequent exposure to environmental disruptors; these have been posited as underlying a range of intersex-like manifestations in XY males.

The assignment of the term intersex has tended to be applied to people assigned and reinforced as female, while those assigned male have been discounted. This has tended to be because those assigned male have been seen as less severely affected by their manifestations of these issues than those assigned female. The way this has worked has been that intersex has been thought of predominantly affecting people assigned female, rather than male, and thus a problem for women and feminists.

Historically, people who experienced interventions for intersex were not told what these interventions were for; in many cases neither were the parents. There is documentary as well as anecdotal evidence

for this. With the de-coupling of intersex from physiology, through DSD,

to a predominantly genetic-based set of 'disorders,' people who have intersex histories are not necessarily seen as being intersex at all. Instead, people with genetic 'disorders' are now seen as intersex, even though only some of them will have

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had intersex features or experiences.

A proportion of people who did have experience of medical intervention and intersex features have gone on to have issues about their gender. Even among those with what became accepted as intersex conditions the proportion who are dissatisfied

with their gender assignment is high at 6-7%. Of those who had intersex-like histories but

not identified as having a specific condition causing this, it is hard to establish, because there has never been any attempt to investigate this beyond qualitative studies (such as my own). Many are regarded as transsexuals, and this may be for them an optimum outcome and resolution to their issues. Others find it difficult to relate to any specific gender role or identity.

I personally do not subscribe to the disorder model for intersex. I consider intersex to be a part of human variation. I do appreciate that there are people with a range of medical conditions which may or may not have effects that produce the phenomena of intersex in a multiplicity of manifestations.

I also argue that such phenomena arise independently of chromosomal/genetic-based issues. Intersex (or variations of sex development – vsd, according to Milton Diamond) may arise because of genetic, chromosomal or endrocrinological factors, and that underlying condition may require treatment for health, survival and well-being. However, that is not the same as an approach to intersex itself as being in some way disordered, and in need of treatment, or individuals as needing modification. I would argue that the use of the term ‘intersex’ be restricted to those with clear manifestations of signs of intersex, and extended to those people with those signs who have no

underlying condition to account for this.

From this perspective, a term such as ‘DSD’ appears to be entirely inappropriate – because it is developed out of a misidentification of intersex with conditions which may cause intersex. Some of those affected by these ‘disorders’ may

not have their sex development affected, and others may have their sex development

affected, but not have an identifiable ‘DSD’. Going back a step or two in re-cycling the term ‘intersex’ would be helpful to be clear what is being included is about sex presentation and development. Jettisoning the term ‘DSD’ for a set of disorders that may or may not result in intersex features would seem to make sense, and find some other term based around their true commonality – which is their being conditions with a genetic and/or sex chromosome basis.

This conflation of intersex features with conditions connected to sex chromosomes and genetics has made it increasingly difficult to discuss and explain intersex, especially to a lay audience. The problem is that one can either

focus on genital/gonadal presentations, or talk about a catalogue of medical conditions. I have dealt with the latter in some depth. Now I will talk about the problems with the other approach.

In almost no social interaction, are we expected to discuss our ‘private’ parts. Transsexuals are expected to play this game – where they talk about this, but aren’t allowed to mention it either. People want to know if they have had the surgery – but as soon as they actually talk about it, this is often seen as problematic. However, if one is intersex, people seem to assume they have a right to know all about their genitals. People wish to know all about the medical

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procedures they had, their upbringing. It is hard not to open up to this, because without describing how it was/is, how else will people learn? But, if I am at dinner, I would never ask the host whether his cock was big enough for his wife, and does he find his penis improved by circumcision (or does he wish he had been circumcised); I would not ask her about whether she has ever thought of labial reduction and vaginal

tightening (not over dinner anyway).

Medical meetings are often peppered with pictures of before-and-after photos. These are pretty overwhelming at conferences on transsexuality – but those are about adults. In an age when people are trying to tackle child pornography, public images of children’s genitals seems totally inappropriate. I rarely attend medical meetings on intersex, despite the knowledge to be gained, precisely because I do not wish to see these pictures. They have an innocence about them, yet they reveal a disturbing truth – that a child’s genitalia can be cosmetically altered to appear more pleasing as sexual organs long before they will ever make use of them as such. The question has to be asked, pleasing to whom?

Presumably the people who saw their genitals as displeasing – doctors, surgeons, nurses,

parents, etc. What their potential future sexual partners might have thought about their original genitalia can only be hypothetical – because they will never know what they would have been like.

I refuse to engage with these pictures, neither to look at, promote, use to disturb, nor to illustrate. I know that Del LaGrace Volcano has used these images in an artistic context; that too I have

found problematic (and said so). I think that for a campaign to promote intersex awareness to use images of children before/ during/after genital surgery makes as much sense as if a lesbian-feminist group opposed to pornography were to distribute images of lesbian porn to lesbians.

So, what does that leave us to discuss? I have ruled out a model that defines intersex pathologically,

ruled out the generation of lists of conditions, ruled out personal disclosure, ruled out the use of images to give examples. Producing some line drawings showing the different stages of genital development, and what can ‘go wrong’ only serves to reinforce that there is something wrong in having other-than-‘perfect’ genitals.

It does not leave very much to say at all. But hopefully, in the process of eliminating what I feel unable to say, an insight has been gained into what it is I am talking about here. Intersex is an experience, it is an experience of being different; that difference is in part to do with having genitals that are different, of having a sex that is not quite the same as other men and women. It may

be that involves wishing to be more like other men or women – even when one was not assigned as the

man or woman one wishes to be more like. It may be about not really being able to fit in with being either a man or a woman. It may be about wishing one’s genitals and reproductive system were like other men’s or women’s – it may be wishing they could be/could have been left alone to be what they are. It may be about wishing one could meet another man or woman and appear ‘normal’ to them; it may be about wishing

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one could meet another man or woman who can accept one as they are. It may involve surgery in childhood, but never being told about it; or, if aware of it, not being told why this is happening – simply that it is ‘normal’ for some people. It may be about not having had surgery; it may be about having had surgery and having it all explained.

It may mean people identify as gay, lesbian, straight, or have no interest in sexual relationships at all.

Just as the reasons that give rise to intersex in any individual are varied, and the expressions so varied within and between the different ‘conditions’ (or non-conditions), so too the outcomes and manifestations in people’s lives, and their responses to them are as varied as the numbers who experience this. Few intersex people I have come across are alike. From this perspective, what seems off is not that there is such a variety of ways of being intersex, but that there are such limited ways of not being intersex – and yet that is the reality that seems to face the majority of human beings.

Where does this lead? Children may be different from other children, and develop differently. Some may be just like other boys and girls, some may start puberty early, and some may start puberty late or not at all. There

are medical options that will be offered to help them, but it is important to see what is best for the child, and that they be consulted. Drugs that delay precocious puberty, affect growth, bring about puberty will all have effects and side-effects; for example, some drugs will make a child more male or more female – it is important that the child is aware of what will happen, and is happy with it.

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Intersex people are like anybody else, many will grow up and want relationships with members of the opposite sex, some will not. Some may want relationships with people who are the same sex; some may not feel happy staying the sex they were assigned as. There may be a higher chance

of their not being happy with the sex they were assigned, and so it is important to be open and

flexible about this as they grow up. If they do not feel comfortable in their assigned gender, there is nothing wrong in this, it is just how they are; the same goes for who they are attracted to when they get older.

Surgery should be avoided until children are of an age they can make their own decisions – unless for serious health issues. This is because any surgery reduces the options open to children when they grow up. If a child has ambiguous genitalia, they may wish to find love and companionship with someone who will appreciate them that way; or if they decide to change the sex that they were assigned, their options are better than if they have had surgery to confirm the original assignment.

Intersex is not part of LGBT, but LGBT people can be allies; being intersex does

not exclude being trans in some way, but trans issues are not intersex issues. Some intersex people

will be regarded as trans, others as lesbian, and they may come to understand intersex in that context; some will be gay, and some straight. This is why, when I write, I try not talk about theory or ideology as applied to other people’s experience, but how my experience informs my theory or ideology. What is difficult about this is that in saying my thinking is wrong in some way, it amounts to saying I am wrong

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about my experience – but often that is the only certainty I have in my life. It is this certainty, when it contradicts the other ideologies of intersex, or trans, or LGBT, or religious fundamentalisms, or politics, or medicine that can lead to exclusion. The last thing a group that is driven by ideology wants is for somebody to step up and say ‘but that is not my experience’; the way that is dealt with is often by saying I did not have my experiences, and thereby dismissing me as a liar.

Because of the unwillingness to engage with a medicalist perspective on intersex, it makes it difficult to come up with neat glossy brochures about intersex. If I reject the pathologizing approach, and yet draw up a list of conditions and treatments for intersex, would this not be a bit hypocritical? Not all these conditions give rise to intersex, not all sex-chromosome related phenomena are of themselves intersex, and not all intersex people have identifiable underlying conditions. I do not deny the existence of these conditions, nor of their gravity in some cases – but I deny that intersex itself is a medical disorder.

There is no point deciding upon becoming an intersex activist, asking for information so we can spread the word like some newly found religious gospel – if we do not have the understanding of these matters that comes from the heart, then we not speak to other people’s hearts. The sense of allowing people to be the way they are cuts right across the logic of our society, religion, and medical practice; no matter how learned or intelligent we may be, common-sense cannot be overturned by logic and validity. For the majority of people, two fixed binary genders is common sense; only relatively

recently has moving from one to the other become comprehensible – and it has taken fifty years to get to where transsexuals are today. The things I hope for, struggle to live in my life, will take a momentous shift in human consciousness. That is about a change in the way people think – a change on a par with the growing acceptance of

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same-sex sexual relationships, or possibly even greater. It will not be achieved

quickly, and it will only be achieved by trying to live it and communicate it. It is an idea many intersex groups will not attempt to address, because of their concern with the pragmatic – the ‘what is.’ Few are prepared to dare to think ‘what if we were simply allowed to be what we are.’

So, I seek to focus primarily on intersex issues, not medical conditions that have been associated with intersex in particular ways that have harmed some and excluded others. I maintain a position of being open to a wide range of LGBT as well as straight people, but not allowing intersex to become subordinate to a wider LGBT agenda that has nothing to do with intersex. Where that agenda is seeking to dismantle the edifice of gender, I am happy to work alongside LGBT people, but where it seeks to shore

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it up, however cosy it might all seem, I can’t see any benefit. Some queer theorists, such

as Jeffrey Weeks and my late supervisor Tamsin Wilton, seem on-board this project of working towards a world without gender – the ‘utopia’; this is why I prefer the term ‘queer’ to LGBT and avoiding an emphasis that maintains fixed binary gender categories. ❁

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