

Equal Rights for Intersex People

Testimony of an Intersex Person

The term intersex describes human beings who have naturally occurring differences of sex anatomy and whose biological sex cannot be classified as clearly male or female. An intersex person may have the biological attributes of both sexes or lack some of the biological attributes considered necessary to be defined as one or the other sex. Intersex is always congenital; the term is not applicable to situations where individuals deliberately alter their own anatomical characteristics. Intersex people are marginalised both in society and in law. Many human rights instruments fail to identify intersex people as rights holders, rather protecting “men” and “women”. Even where their rights are explicitly protected in law, intersex people are often unable to enforce those rights. They suffer from many forms of discrimination in all aspects of life, including their family life. Gina Wilson is the President of Organisation Intersex International Australia (OII Australia), a national organisation which promotes the human rights of intersex people in Australia, and provides information, education and peer support.

1. My Background

My name is Gina Wilson and I am President of OII Australia and campaign for the equal right of intersex people to have their human rights recognised and enforced. I am intersex. As is often the case, for quite a while I was not aware that I was intersex. I have congenital adrenal hyperplasia (CAH), and although I knew that this involved having anatomical differences of sex, it was not made immediately clear to me that CAH was connected with being intersex. It was only once the internet became available that I found that CAH is one of the most common underly-

ing diagnoses of intersex. When I discovered this, I looked for groups that could provide peer support and came across Organisation Intersex International (OII), which was just starting. Initially, I joined their online forums and then got more and more involved, becoming an outreach worker providing support and information to people who were coming to terms with intersex.

Many of the challenges faced by the intersex community are borne out of a lack of understanding and awareness of what it means

to be intersex, and the problematic ways in which it has been defined and addressed within the medical field. OII prefers the term “intersex”, a scientific term which was first used in the early 20th century, over other terms which have been used, both historically and more recently. “Hermaphrodite” is scientifically inaccurate as it indicates that a person has fully functioning reproductive organs of both sexes. It also fetishises our sex, encouraging notions that we have two

have these negative connotations; it merely suggests difference, and that we are neither male nor female.

Through my involvement with OII and reflection on my personal experience, I came to realise that viewing intersex through the lens of medicine and “disorder”, as had traditionally been the case, was stigmatising and delivered no benefits to intersex people, but rather shame and secrecy. Surgery,



sets of sex organs and can “have sex with ourselves”; “intersexed” implies that something has been “done” to a person; and the recently introduced “disorders of sexual development” is stigmatising and implies that the differences of intersex people constitute an illness or a disease. Use of this kind of language leads society to believe that there is something wrong with being intersex and that it is something that should be altered, or prevented. The term “intersex” does not

drugs, or a combination of both have often been used to try to “cure” or “normalise” intersex people without their informed consent. Following a change of government in Australia in 2008, the incoming Prime Minister instituted an Australian Human Rights Consultation. I thought that this might provide an opportunity to start to view intersex through the correct lens, namely that of human rights. I decided, with some friends, to establish OII Australia, with the primary

goals of offering support to intersex people and of tackling the lack of rights and protection for intersex people in Australia and around the world, by taking the debate about intersex out of medicine and stigma and into the field of human rights.

2. OII Australia

In the early days of OII Australia, I spent a lot of time developing a network of supporters.



As I started to become involved with political lobbying and human rights activism and to build this network, I found that our strongest allies were LGBT groups and also activists in the area of disability. I believe that this is due to the two most common prejudices that people have about intersex. Firstly, intersex people are discriminated against, marginalised and victimised essentially because of homophobic prejudice. It may not be immediately clear why people with dif-

ferences of sex anatomy would be subjected to homophobia. But it became apparent to me that the desire to normalise us, and to do away with ambiguity by “invisibilising” our intersex, was to see us as “normal” males and females. The goal was to see us living heterosexual lives, whereas if we engaged in same-sex relationships, this was seen as a failure of our sex assignment. I came to see that we were often seen as either partly or completely homosexual, and were faced with homophobic prejudice. We therefore had a lot of issues in common with those being advocated by LGBT groups. Society’s second prejudice is based on a fear of the “monstrous”. Society often sees differences as negative, or even “monstrous”, and wants to erase them if at all possible. This links to some issues faced by people with disabilities, particularly those born with disabilities. In forming alliances with groups working in the area of disability and of LGBT rights, OII was welcomed with open arms. We were able to learn about activism and to speak to law makers and other activists about issues surrounding intersex, as well as bringing these issues to the attention of society as a whole. Many of the challenges faced by the intersex community arise from a lack of understanding and awareness of what it means to be intersex, and OII Australia seeks to educate people about intersex and issues affecting the intersex community.

Today, OII Australia is thriving as the Australian affiliate of OII. OII is now the world’s largest intersex organisation, with members representing almost all known intersex variations and affiliates in twenty countries, on six continents, speaking ten languages including Mandarin Chinese and Arabic. OII Australia is a not-for-profit company and charitable institution and currently has many members, including intersex individuals and non-intersex supporters. OII have been strong advocates in the fight for marriage equality, espe-

cially since an Australian federal court decision bars intersex people from marriage and the currently available non-specified birth certificates and passports are not allowed to be used under current marriage law. We have also engaged with government, lobbying for the inclusion of intersex as a protected characteristic in anti-discrimination law; for having intersex covered in laws related to health and aging; and for providing that sex is not specified in documentation.

3. Understanding the Issues

As mentioned, many of the key challenges faced by intersex people are the result of a lack of understanding and awareness of what it means to be intersex. The whole nature and relevance of sex is framed incorrectly in our society, with the systems by which we are regulated relying on this incorrect basis. There are a number of key issues.

a) Intersex and the Sex Binary

Society generally views sex as a binary notion, assuming that human beings are either male or female. Society, including the relationships between these males and females, is then regulated on the basis of the binary. However, Foucault argued effectively that the way we categorise on the basis of sex is a social construct. Not all people can be categorised as absolutely male or absolutely female and the key problem is that this inability to categorise some individuals is that it bothers some people. To be more certain of the category of those individuals, normalisation through intervention and medicine is often seen as necessary. Not long ago, homosexuality was seen as a tragedy which could be rectified using medicine and therapy. This is no longer acceptable, as LGBT people have argued their case through human rights. However, people still abuse the human rights of

intersex people by intervening in our lives to try to make us identifiable by them as male or female.

In a wider sense, the sex binary is unhelpful given that it disadvantages half the world's population. If you are classified as "female", you are more likely to be disadvantaged than advantaged. There is something fundamentally flawed about categorising human beings into male and female for the purposes of social standing. Two sexes is one sex too many. I do not believe in a "third gender" for intersex people, but rather would like to see no categorisation on the basis of sex or gender, although I am not sure that that will happen soon.

OII advocates for the right for anyone over the age of 18 to be able to choose to have an X on their passport, rather than being identified as male or female. New Zealand has already instituted this. In Australia, you are currently only allowed to have an X on your passport if you meet certain requirements. We want everyone to have the right to choose an X, which, rather than this being a third gender designation, is the right to remain silent – and hopefully to be judged on character, rather than sex.

b) Intersex and the Medical Approach

Intersex differences are so confronting to a society which operates on the basis of a sex binary that such differences have often been consigned to medicine as a problem to fix, in much the same way that homosexuality used to be pathologised. The problem is the inability of individual parents and friends to accept intersex persons as they were made. Their lack of acceptance is perpetuated by doctors who would rather reshape a newborn's body, than address a parent's phobias, and a medical establishment that prefers

to offer “cures” and surgeries than help individuals understand that their differences are natural. In third world countries where access to medicine is limited and expensive, societies have to adapt to accept such differences as they are untreatable.

That “cure” offered by the medical establishment takes the form of surgery often followed by more surgery and a lifetime of hormonal reinforcement. Intersex genital mutilation (IGM) is conducted on newborn babies when their external genitals do not look “normal” enough to pass unambiguously as male or female. IGM, like female genital mutilation (FGM), is surgery carried out upon the genitals of newborn babies, infants and children for cultural or religious reasons. Both are forms of infant genital surgery. The surgical procedures conducted can cause irreparable damage to children.

Medicine has come to act as the “normalisation police” where intersex is concerned. The medical establishment has never attempted to argue for the acceptance of intersex. Rather, it argues *against* the right to anatomical autonomy, and risks physical and psychological damage to intersex persons.

c) Invisibility in Human Rights Law

At the same time as the obsession with a medical approach to intersex, there is still a widespread failure to take a human rights approach to the issue. Currently, worldwide, there is a complete lack of human rights protection for intersex people, and anti-discrimination laws are generally inadequate to protect intersex people from rights violations resulting from their intersex. For intersex people to have rights at all, they are required to submit to the myth that they are wholly male or wholly female. Only in South Africa are intersex people explicitly granted rights.

An amendment to the South African Constitution specifically protects intersex people against discrimination, thanks to the efforts of an activist there. In other parts of the world, only males and females are granted rights and we, intersex people, are tenuously included as long as we say that we are truly male or female. When our status as male or female is challenged, we are unprotected by the law.

In some parts of the world intersex babies are routinely left to die, or young people who are discovered to be intersex chased out of the community. This is largely a remnant of historical western, colonialist attitudes. We must have worldwide acknowledgment that definitions of “male” and “female” only are not adequate to protect people’s rights on grounds of sex discrimination. First and foremost, the UN must recognise the existence of intersex people and include their specific protection in the International Bill of Rights and in their treaties. I realise that having a definition of intersex and specific protection for intersex people is “othering” ourselves, but unless we do this, we will remain invisible, unprotected and at the whim of the law.

d) State Regulation of Family Life: Marriage, Children and the Obsession with Biology

Intersex people are at the coalface of the state’s regulation of relationships. This is largely due to the problem of the sex binary and the fact that regulation of bodies is the first step in the regulation of relationships. The aim of normalisation of intersex people is to make us “marriage-ready”. If our bodies are unregulated, it is difficult to classify our relationships and society finds it difficult to see us a properly-married people when we are married.

There have been legal cases in Australia where marriages were dissolved on the basis that one of the parties was intersex, not seen as truly a male or a female, and therefore ineligible to marry. Marriage is defined as being between a man and a woman. Intersex people are only able to marry as long as we agree with the sex that we have been assigned and then, irrespective of our anatomy, find a partner who is notionally of the opposite sex. In order to be accepted in society and by the institution of marriage, we must “invisibilise” our differences, or pretend we have none, effectively living a lie. It is often said that most intersex people live as normal males and females, but, in my opinion, if you have an anatomy that defies notions of normality, and which is different to what is expected of a male or a female, then in order to live a so-called normal life, you must go along with a lie.

Same-sex marriage is currently being debated in Australia, as elsewhere. OII Australia has advocated strongly for marriage to be defined as a consensual relationship between two people, and if we succeed then intersex people will qualify for marriage under that definition. If, however, it is framed in terms of the sex binary, so that marriage needs to be between a man and a woman, or a man and a man, or a woman and a woman, then we would be excluded. OII Australia supports the right of same-sex couples to marry, but we are engaged with the broader fight for full marriage equality, so that intersex people, and indeed all consenting adults, have the right to marry.

Intersex people also face discrimination with regard to their opportunity to be parents. Intersex people are more frequently infertile than others, and the regulation of the “non-traditional” routes to parenthood, i.e. those other than traditional biological par-

enthood, are particularly important for us. For example, my partner brought children into our family from a previous relationship. The government and society do not make it easy to recognise extended families like this. It is almost impossible to live an intersex life and have a family, because it is only possible for intersex people to have a family life if we accept the erasure of our differences.

Under our current system of family regulation, these inequalities cannot be easily rectified. However, I strongly believe that we need to move away from the centrality of biological connections to the regulation of what is deemed to be a family relationship. The idea of “shared genes” being critical to defining the nature of a family is increasingly unhelpful, given the many other ways that families are constructed in the modern world, and of course this does not just affect intersex people. Society needs to have a broader idea of what makes a family, and I would like to see the legal definition of family widened. For example, I have experienced firsthand the damage that can be done by the state’s failure to adequately recognise the relationship between a carer and the person they are caring for when there is no blood relationship between the two, only a relationship of love, care and friendship. We need to move away from the obsession with blood ties and create an understanding of family which reflects social reality.

4. The Future: Towards Human Rights Protection for Intersex People

We have moved intersex rights more in the last four years than they have moved in the last four hundred. OII Australia continues to lobby and advocate for rights for intersex people.

To speak of just one recent positive example: OII Australia has been heavily involved in

campaigning and advocacy around the proposed Human Rights and Anti-Discrimination Bill 2012 which is currently being reviewed before its introduction into parliament in Australia. Legislators initially did not have a clear understanding of what intersex was, but having given evidence to Senate Committees and spoken with legislators individually we are hopeful that intersex will be a protected attribute under the Bill, with a definition of intersex as an identity different from male or female. The passage of the Bill is currently the gold standard and potentially the most significant advance towards the protection of intersex people in Australia to date.

However, there is more to be done both in terms of cultural change and in terms of legal change. Most discrimination against intersex people is not as a consequence of us identifying as intersex, but on the basis of our physical appearance and difference. It will ultimately be important to get us out of the frame of intersex “identity”. Intersex people have all kinds of identities – the same broad

spectrum of identities that the rest of humanity has. Prejudice is not about how we see ourselves, but how others see us – and this is based on a visible physical reality. There is a lot more to be done to eradicate this prejudice. In terms of the vital legal protections, the Human Rights and Anti-Discrimination Bill 2012 offers an excellent development in Australia. However, the ultimate goal would be for intersex to be included in UN treaties as this would pressure on the rest of the world to follow suit.

OII Australia is putting the rights of intersex people on the agenda and is always encouraging others to do the same and to make the call for these rights louder. Once we are seen to be fighting for our rights and are granted rights, people will know that we exist and the community at large will hopefully become more sympathetic to our cause. Although legal change to protect intersex people is vital, it is only the first step in what must be broad and deep social change that accepts diversity of every kind.