

# AIS Support Group Australia Inc.

*Providing support for families affected by AIS and similar intersex conditions since 1985*

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LGBTI Discrimination Consultation  
Australian Human Rights Commission  
GPO Box 5218  
Sydney NSW 2001

Dear Australian Human Rights Commission,

## **INTERSEX COMMUNITY SUBMISSION – LGBTI DISCRIMINATION**

Thank you for the opportunity to provide the Australian Human Rights Commission (AHRC) with a submission regarding intersex discrimination in Australia. The AISSGA is particularly grateful to the AHRC for the 2009 paper "*Surgery on intersex infants and human rights*" in which the human rights and discrimination faced by children with intersex conditions was finally formally recognised by an Australian government agency.

As you are aware, the Androgen Insensitivity Support Group Australia (AISSGA) is a self-funded peer support group run by volunteers for people affected by intersex conditions, their parents, families and partners. It was established in 1985 by the then Director of Paediatric Endocrinology at the Royal Children's Hospital Melbourne, Dr Garry Warne. The AISSGA is part of a globally respected intersex support and advocacy network that continues to work with other groups and agencies to provide a united public voice working towards eliminating the shame, stigma and taboo faced by people affected by intersex conditions. Committee members of the AISSGA have also held positions with a number of genetic support groups, government advisory groups and hospital ethics and community liaison committees.

Over the last ten years the AISSGA has lodged submissions regarding discrimination and law reform to the Attorneys General and Health Ministers of each Australian state and territory, the Australian Law Reform Commission, the National Health and Medical Research Council (NHMRC), the Anti Discrimination Board of NSW and the Victorian Equal Opportunity and Human Rights Commission.

### **Introduction**

Foetal sexual differentiation is a complex process that usually results in a baby that is male or female. In the case of infants with intersex conditions, sexual development occurs differently than most other children, so the sex chromosomes and/or reproductive system are not exclusively male or female. This causes a lot of anxiety



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and stress for parents of diagnosed infants, and doctors need to ascertain the cause of the variation as quickly as possible to help determine the most appropriate medical treatment (if any) and the most appropriate sex of rearing in cases where the child's genitals are 'ambiguous'. Even with the best current available medical science, this process can take up to 5 days.

Although those with intersex conditions were revered in mythology, history is full of examples of people with intersex conditions who have lived with considerable discrimination and ridicule, and who have been treated as curiosities or 'freaks of nature'. The medical profession, regardless of whether they believed they were working in their patient's best interests or not, have for centuries treated people with intersex conditions as defective people with less rights than others. Now that the aetiology of intersex conditions has been understood for over 50 years and many advancements made in the areas of medicine and human rights, intersex advocacy groups are seeking changes to ensure that discrimination on the basis of their genetic condition ends. The AISSGA, for and on behalf of the wider intersex community, is working closely with the medical profession and government and is proud to be at the forefront of discussions in Australia that are working towards eliminating discrimination against people with intersex conditions.

Infants born with intersex conditions largely grow up successfully, have careers and lead fulfilled lives. They are not considered any different to non-intersex men and women in society. Many marry and become parents of adopted or foster children. Some children with intersex conditions, however, have a difficult beginning to life because of the way their condition was medically and socially managed. Aside from causing death through mis-diagnosis, probably the most severe mistake that is likely to be made when raising a child with an intersex condition is incorrectly assigning their sex of rearing. Mistakes of sex of rearing are inevitable, however, due to the nature of intersex conditions and the difficulties in determining the gender of identification of a child who is physically both male and female. Fortunately for the majority of people with intersex conditions, these errors are made only in about 5 to 10 percent of all children with intersex conditions. The possibility of errors of sex of rearing is one of the reasons intersex advocacy groups agree that while children need to be raised exclusively male or female, medically unnecessary normalising cosmetic surgeries should stop. Other errors made when raising children with intersex conditions include withholding the truth from parents about their child's condition, lying to children about their condition, repeated medical genital examinations (often with a large number of doctors and medical students present), medical photography of children and not providing professional and peer support services to help parents and children openly discuss their conditions and meet others affected by them. Intersex advocacy groups and Paediatricians all agree that the most important factor in raising a well-adjusted person with intersex conditions is a healthy parent-child relationship.

Individuals affected by intersex conditions may experience direct or indirect discrimination on the basis of their genetic condition, physical attributes, gender



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identity and disability or impairment as a result of their intersex condition. This discrimination is usually the result of ignorance about and/or unfamiliarity with intersex conditions and the issues faced by those living with them. This submission will discuss these issues in further detail.

## Definitions

The AISSGA supports the definition used by the AHRC for intersex –

*“A person who is intersex is a person whose chromosomal, gonadal or anatomical sex is not exclusively ‘male’ or ‘female’. A person who is intersex may or may not identify their sex and/or gender identity as intersex.”*

We also support the definition used by the Australian Medical Association –

*“A person with an intersex condition is born with sex chromosomes, external genitalia or an internal reproductive system that is not exclusively either male or female. This word replaces hermaphrodite.”*

The definition adopted by the ACT Legislative Assembly via the Legislation Act 2001 (ACT) is also acceptable –

*“An intersex person is a person who, because of a genetic condition, was born with reproductive organs or sex chromosomes that are not exclusively male or female.”*

Of concern, however, is the AHRC’s use of the phrase *“people who identify as intersex”*. As shown by the medical profession’s definition, being intersex is a statement of fact, not an identity. Like any other biological variation, one wouldn’t say that they “identify as having diabetes” or “identify as having Downs Syndrome” or “identify as having blue eyes” because these are all statements of fact. They either have the attribute or not.

It is also important to note that the vast majority of people with intersex conditions have a gender identity that is exclusively male or female and are satisfied with the sex they were raised. They go about their lives like other people without intersex conditions but generally have issues about body image, infertility, sexual adequacy (real or perceived), hormone therapy, and/or osteoporosis. We nonetheless note that a small percentage of people with intersex conditions may also identify as having a gender that is intersex. That is, that they have a gender identity that is not exclusively male or female. In this case we ask that the AHRC use the phrase *“people with intersex conditions who have an intersex gender identity”*.



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The use of the term “gender diverse” has increased in popularity in recent times to erroneously include all people with intersex conditions. People with intersex conditions, if anything, are “sex diverse” in that their gender is in the main exclusively male or female but their biological sex isn’t.

The term “Disorder of Sexual Development” (or “DSD”) has also been used in recent years, predominantly in the United States of America. The AISSGA does not support the use of this term as it is pathologising.

Although there is still some controversy about the use of the term “people with intersex conditions”, it remains the best descriptor for our community.

## **Genetic Discrimination**

It is a natural human desire and expectation to be treated with respect and dignity without prejudice due to being different by ways including physical attributes, disability, race, colour, gender, sex, sexual orientation, social status, education level and a multitude of other attributes. People with intersex conditions and their relatives are no different.

All discrimination against people with intersex conditions because of their condition and any associated symptoms is discrimination on the basis of an impairment or disability. More specifically, however, it is genetic discrimination. The AHRC should liaise with the NHMRC and the peak genetic support networks in each state to develop legislative protection for people with genetic conditions (including intersex conditions) and their families.

Additional information about genetic discrimination can be accessed via the NHMRC’s website at:

[http://www.nhmrc.gov.au/your\\_health/egenetics/ethics/discrimination.htm](http://www.nhmrc.gov.au/your_health/egenetics/ethics/discrimination.htm)

## **Employment and Insurance**

Genetics gives humanity the ability to predict the possibility of an individual or family being affected by a variety of conditions including heart disease, diabetes and intersex conditions. It is precisely because of the apparently predictive nature of genetic information that we need to exercise the utmost care when considering using genetic information for employment and insurance purposes. As with other attributes in equal opportunity legislation, only current ability to perform inherent requirements of the job should be considered, but the temptation is to use genetic information to predict future ability (or inability) to undertake particular occupations is great. Insurers, particularly those offering personal non-population risk based insurance, are increasingly asking for access to genetic information for policy risk assessments.



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Provision of clearly defined job descriptions by employers is an integral part of any approach that relies on assessment of the competency of an applicant or incumbent for a particular role. We support proposals that peak employer associations should encourage members to produce clearly defined job descriptions for all positions in the workplace, but believe this information should be provided to a medical practitioner to determine if an applicant or incumbent is medically suitable for a position rather than the applicant providing medical or genetic information to their employer. Using this approach a certificate of fitness to undertake a particular role would then be provided to an employer by an applicant's physician, negating the need for disclosure of medical information to employer groups. Such an approach also safeguards employer groups, as they no longer require procedures to safeguard medical information on file about their employees. In most cases for example, having an intersex condition will not impact on a particular career and employers do not have the right to know one's current - or possible future - medical information if it does not impact on the position in which they are employed.

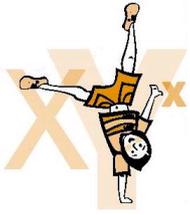
The AISSGA is aware of instances where people with genetic conditions have been denied personal insurance or been quoted premiums that are prohibitively high because of pre-conceived ideas about their condition. The United Kingdom has settled on a two-tiered system for assessment of personal insurance policies, such as life insurance. Insurance policies with an insured sum up to a pre-determined limit, require no genetic testing for approval as, like health insurance, they are population risk based. Where a policy is requested for a higher than average insured sum insurers are authorised by law to ask for genetic testing prior to approving the policy. We believe this is the fairest compromise between balancing the interests of insurer groups and guaranteeing access to insurance for those who need it.

## **Sport**

One of the most important elements of Australian life is involvement in sport. Whether it's competing, organising or spectating, sport provides enjoyment, employment and a sense of personal and national achievement for most of us. So it's important that equal opportunity and anti-discrimination is made an integral part of all sporting activities.

Denying women with intersex conditions the right to compete as women denies them the right to compete because of their genetic condition. This is discriminatory and would exclude them from all gender specific sporting activities.

Although women with intersex conditions have been discriminated against in sport throughout the 20th Century, the Sydney 2000 Olympics heralded a turning point for women with intersex conditions. Genetic (chromosome) testing of female athletes in the Olympics had in the past exposed private medical information about women with Androgen Insensitivity Syndrome. In many cases the women themselves were unaware there was any reason for anyone to question their sex as they had not been



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told about their condition. Fortunately, the International Olympic committee stopped performing these tests for the Sydney 2000 Olympics specifically because women with AIS are clearly women with absolutely no physical advantage over non-AIS women yet their chromosomes are 46XY (the typical male pattern).

The recent experience with sprinter Caster Semenya raises concerns about the way people with intersex conditions are treated in sport. The AISSGA recommends that the AHRC assists the prohibition of determining the sex of athletes on chromosomes alone, and for gender testing to be made in light of an athlete's human rights.

## **Recognition of gender identity**

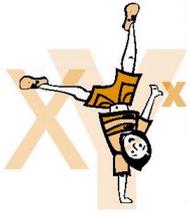
Most people with intersex conditions are typical men and women and they have a gender that has never been questioned by anyone including themselves. For about 5 to 10% of people with intersex conditions, however, gender identity is an issue. Some of these individuals feel that in addition to being biologically both male and female, they also identify as having a gender that is both male and female. Hence, they are intersex in both sex and gender.

The AISSGA believes that people with intersex conditions who identify their gender as being intersex should be able to have this legally recognised. This should, however, be limited to adults with medically confirmed intersex conditions only, as people without intersex conditions claiming to be 'intersex' could cause a number of social, medical and legal problems.

## **Irreversible, non-therapeutic surgeries – a fundamental human rights issue**

Although there have been recent cases where doctors have sought the approval of the Family Court to conduct irreversible "normalising" genital surgeries on children with intersex conditions, this is still not common practice in Australia. The AISSGA believes the High Court's decision in Marion's Case should be upheld, and that children with intersex conditions should be afforded the same legal protection as other children who cannot provide legal consent for irreversible non-therapeutic medical procedures.

Rather than banning "normalising" surgeries on children with intersex conditions completely, a more pragmatic, ethical and considered approach is to seek the approval of the Family Court who could best consider representation and outcomes for all parties and ensure that full disclosure of options is made. The involvement of the Family Court may also ensure that doctors are more willing to consider alternatives to surgical intervention, such as support and counselling, rather than opting for irreversible methods as a first option and may further provide a degree of legal protection for all parties that currently does not exist.



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Sadly the decision of the High Court has been ignored by successive state and territorial governments, Health Ministers, Medical Defence Organisations, Offices of the Public Advocate, Hospitals and Attorneys General and therefore requires the intervention of the AHRC to protect the human rights of children with intersex conditions.

## **Government departments and agencies**

The AISSGA has had cause to work with various commonwealth government departments and agencies over the years and have found them all to be very understanding and helpful in relation to identity documents and services. These agencies have included the Department of Foreign Affairs and Trade, Centrelink and Medicare.

## **Relationship recognition and marriage**

The *Marriage Act 1961* (Cth) is problematic for people with intersex conditions as it defines marriage as occurring between a man and a woman. Ideally, marriage should be defined based on a bona fide relationship and lifelong commitment irrespective of gender.

## **Recommended further actions by the Australian Government**

In addition to the actions recommended previously in this submission, the AISSGA strongly encourages the AHRC to conduct public sector and community education programs that aim to increase awareness of intersex conditions. The AISSGA would be prepared to assist with the development of the education program and material.

Please do not hesitate to contact me should you require any additional information. I was unable to attend the scheduled community panels but would be very happy to meet with the AHRC to discuss this submission in detail.

Sincerely,

Cr Tony Briffa JP  
**AIS SUPPORT GROUP AUSTRALIA INC.**