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Submission to the

ACT Chief Minister and Department of Justice and Community Safety

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Regarding

Discrimination against People affected by Intersex Conditions

By

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For and on behalf of the

**Androgen Insensitivity Syndrome Support Group Australia
(AISSGA)**

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ABOUT THE AIS SUPPORT GROUP AUSTRALIA AND THIS SUBMISSION.

The Androgen Insensitivity Support Group Australia (AISSGA) is a self-funded peer support group run by volunteers for those with 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 a globally respected genetic support group and continues to work with other intersex support and advocacy groups to provide a united public voice working towards eliminating the shame, stigma and taboo faced by those affected by intersex conditions by educating the community about these conditions. Committee members of the AISSGA also hold committee positions with groups such as the Genetic Support Network of Victoria.

Intersex conditions may be broadly described as genetic conditions able to be identified at birth that result in the birth of a child with anatomical or biological sex differentiation that varies from that most commonly found in male and female births. Intersex conditions have a direct physical effect on reproductive organs and/or sex chromosomes and do not include those born with completely male or female biology but with the 'brain sex' of the opposite gender. People born with completely male or female biology but with a 'brain sex' of the opposite gender are commonly referred to as trans-gender or transsexual. Care should be taken not to confuse intersex conditions with transsexualism, particularly as some transsexual people have been making erroneous claims that transsexualism is an intersex condition. Intersex conditions were previously known as hermaphroditism and are as common as 1 in 1000 births.

The role of the AISSGA is to provide direct support and information about intersex conditions, contact with others with the conditions, contact with the medical profession and advocacy services. Our membership includes medical practitioners considered by the AISSGA to provide best practice treatment of members, particularly those that challenge older inappropriate practices by advocating full disclosure to patients about their condition and challenging early surgical-based intervention. Our membership also includes genetic counsellors and geneticists. We have strong links with the Genetic Support Network of Victoria, Royal Children's Hospitals in Melbourne and Brisbane, the Mater Children's Hospital in Brisbane and various other paediatric hospitals and genetic services around Australia. Members of the AISSGA also sit on Bio-ethics boards and have assisted formulation of ethical guidelines used to perform certain medical and research functions related to intersex conditions.

The AISSGA has a direct interest in preventing discrimination against people with intersex conditions in the ACT. This submission is a response to the ACT GLBTI issues paper, and details sections and areas of ACT legislation and current Bills identified as likely to directly or indirectly discriminate against people with intersex conditions. Formulation of legislation is a difficult and complex function by virtue of the considerable diversity in Australian society. We realise that inadvertent discrimination is unavoidable, but look forward to working with the government of the ACT to make necessary amendments to laws that ensure people with intersex conditions are not discriminated against on the basis of their physical attribute, genetic condition, medical history, gender identity, disability or impairment.

We thank the ACT Government for their proactive, inclusive and well considered issues paper.



ABOUT THE AUTHOR.

Anthony (Tony) Briffa is the current third term President of the AISSGA. He has previously held other positions on the support group's committee, including that of Secretary. Tony represents those with intersex conditions on Government and other advisory committees and has been instrumental in assisting drafting and introduction of various legislative changes in Australia, including anti-discrimination legislation providing protection for those with intersex conditions. Tony has wide experience as an advocate for people with intersex conditions, having been quoted in many magazine and newspaper articles about the subject and interviewed for television and radio programmes. Tony is also a vocal supporter of the rights of all minority groups including gay, lesbian, bisexual and transgender people.

Apart from his work for those with intersex conditions, Tony is also the Treasurer of the Genetic Support Network of Victoria, community representative on the Western Health Ethics Committee and a community advisor on a number of government advisory committees. Tony is a tertiary qualified engineer with considerable experience in the aviation industry and with a broad technical background. He is also a foster parent.

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

- Article 7, The Universal Declaration of Human Rights



P R E F A C E

The first question people (including parents) ask when a child is born is “is it a boy or is it a girl?” For parents of infants diagnosed with intersex conditions the answer is not clear. The AISSGA recognises the difficulties parents face and their important role in successfully raising a well-adjusted, happy person with an intersex condition. The following messages are from parents of children with intersex conditions and are included as examples of some of the issues faced by them. Helping people like them are the driving force of the AISSGA.

I am a mother who is seeking some good doctors who are willing to look at my child and let me know if they can help. My son Andrew was born with ambiguous genitalia. He has 46xy chromosomes but his external genitalia looks female. Please let me know if you can help me in any way.

I would like to thank you for the website and especially for the personal bio "a mother's story". It really has helped me.

My 3 month old daughter has been diagnosed with pure gonadal dysgenesis and I have been advised to have her streak gonads removed next month to prevent the type of aggressive cancer that took the life of the young girl in the story. Although this surgery will be traumatic for all of us, and it is a difficult decision as a new mother, reading the personal story reinforces my decision to act quickly.

If you have any other information on this condition, or could help hook me up with any other mothers of daughters with this I would be very grateful.

My 12 month old daughter was recently diagnosed with CAIS and Andie was nice enough to send me a copy of dAISy. After reading it, I was grateful for people like Tony Briffa and Andie for making these things possible for people to access. It sort of made me realise that there are far more worse cases of PAIS, intersex and CAIS. However, I would like to congratulate the dAISy team on doing a great job!

Hello I'm writing from Poland. I have a problem with my children . Polish doctors diagnosis is unsensitivity of androgens.the sex of my children is girl, it is doctors idea, because testosterone is small and another, but it is one way, children dont be mother in the future.my question is then tthe medicine can change this situatioins withow dangerous consecuation and not to be late j thing about to cut gonadies not important and plastiks changies with can be important for psihikal live of my children age 3 years.my children is normal like another children in this age the last neoplasm marker is normal. With greetings



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 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 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 and then discuss the various laws in the ACT that adversely impact upon those with intersex conditions.

DEFINITIONS

- Androgen Insensitivity Syndrome (AIS)** A genetic condition that causes a variation in the development of the reproductive system as a result of a complete or partial inability to respond to androgens during foetal development. People with AIS have 46XY chromosomes and are born with testes. External physical characteristics and gender identity can vary from female to male and anywhere in between.¹
- Congenital Adrenal Hyperplasia (CAH)** In individuals with 46XX chromosomes, CAH is an intersex condition where foetal sexual development is altered as a result of an excess production of adrenal androgens often leading to masculinised genitals of otherwise typical girls.²
- Gender** A person's sense of identity of maleness and femaleness. Most people have a gender that matches their sex, while transsexuals have a gender opposite to their sex.
- Gonadal Dysgenesis** A condition where an infant is born with underdeveloped gonads affecting foetal sexual development. Physical affects include sterility, genital appearance, osteoporosis and hormone deficiencies.
- Intersex**
1. A long-established medical (genetic) condition where an infant is born with reproductive organs and/or sex chromosomes that are not exclusively male or female.
 2. The current word for 'hermaphrodite'.
 3. A term used by those with intersex conditions who do not have a gender identity that is clearly male or female.
 4. Intersex conditions include Androgen Insensitivity Syndrome (AIS), 5 alpha-reductase deficiency (5AR), 17-beta hydroxysteroid dehydrogenase deficiency (17B), XY gonadal dysgenesis (also known as Swyer Syndrome), Leydig cell hypoplasia, Mayer Rokitansky

¹ Androgen Insensitivity Syndrome Support Group Australia (2002), *Androgen Insensitivity Syndrome* - brochure for people with AIS and their families. <http://www.vicnet.net.au/~aissg>.

² Definitions of intersex conditions can be found in most Paediatric Endocrinology text books as well as specialised patients booklets such as *Syndromes of Abnormal Sex Differentiation – A guide for patients and their families* by Migeon et al, Department of Paediatrics, John Hopkins Children's Centre, Baltimore, USA.



Kustner Hauser (MRKH) Syndrome (also known as vaginal agenesis), Congenital Adrenal Hypoplasia (CAH), Turner's Syndrome and Klinefelters Syndrome. Most people with these conditions are infertile and require life-long hormone treatment.

5. Approximately 25% of people with intersex conditions are born with 'ambiguous' genitalia.

Klinefelters Syndrome The term used to describe the intersex condition where an infant is born with a 47XXY sex chromosome pattern. People with this condition are usually raised as males and often have breast development, low androgen production and small testes.

Sex The biological state of being born male or female; usually made up of the factors comprising genetic sex, gonadal sex and external genitalia. These three factors are congruent at birth for all people except those born with intersex conditions.

Transgender An umbrella terms that refers to people who are biologically one sex but take on the role of the opposite sex for various periods of their lives and for various purposes. This includes cross-dressers and transsexual people. NSW legislation often specifically relates to transsexual people when it uses the term transgender.

Transsexual Refers to individuals who are born anatomically male or female but have a profound identification with the gender opposite to that assigned to them at birth.³ The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* describes the clinical investigation, identification and treatment of transsexualism, but expressly excludes those with intersex conditions from being diagnosed as transsexual. Note: NSW legislation refers to 'transgender' and 'transsexual' interchangeably although it should specifically refer to transsexual when referring to those who live full time in their self-identified gender.

Turners Syndrome The term used to describe the intersex condition where an infant is born with a 45XO sex chromosome pattern. Typical affects of this condition include gonadal streaks in lieu of ovaries, short stature, cardiovascular conditions and hormone deficiencies. Some physical manifestations of Turners syndrome have what is referred to as a Mosaic sex chromosome pattern where some or all cells in the body possess duplicate sex chromosomes such as XO/XY.

³ Victorian Government Department of Human Services, Ministerial Advisory Committee on Gay and Lesbian Health (2001), *What's the Difference? Health issues of major concern to gay, lesbian, bisexual, transgender and Intersex (GLBTI) Victorians.*



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 those with intersex conditions because of their condition and/or associated symptoms is discrimination on the basis of an impairment or disability. More specifically, however, it is genetic discrimination, which is one of the subjects currently being considered in the Australian Law Reform Commission (ALRC) enquiry on the protection of human genetic information.^{4,5}

Prenatal discrimination

Discrimination against people with intersex conditions often commences before birth due to the genetic basis of the conditions. Intersex conditions such as Klinefelters Syndrome and Turners Syndrome are particularly susceptible to this early discrimination due to the ease of prenatal diagnosis.

A report about prenatal diagnostic testing in Victoria by the Victorian Department of Human Services⁶ found that of all birth 'defects' from 1983 to 1998:

- 213 had Turners Syndrome;
- 77 had Klinefelter Syndrome;
- 189 had other sex chromosomes; and
- 229 were of 'indeterminate sex'.⁷

The data of termination following diagnosis before 20 weeks gestation was only available for the reduced period of 1989 to 1998, and of these the following were terminated because of their condition:

- 98 Turner Syndrome;
- 28 Klinefelter Syndrome; and
- 39 Conditions due to other sex chromosome anomalies.

Intersex advocacy groups and many of the specialist paediatricians that treat intersex conditions are concerned with the high rate of terminations of foetuses with these conditions. People with intersex conditions are not so physically disabled that they can't lead full and happy lives. Of the hundreds of people the AISSGA knows with intersex conditions, none of them consider their condition serious enough that they might wish they were terminated prior to birth. This feeling is also similar for parents

⁴ Australian Law Reform Commission (ALRC) website. <http://www.alrc.gov.au>.

⁵ The AISSGA has made several detailed submissions to the ALRC for their enquiry into protection of human genetic information and are available on their website at <http://www.vicnet.net.au/~aissg>.

⁶ Victorian Government Department of Human Services, Melbourne, August 2000. *Birth Defects in Victoria 1983-1998 Perinatal Data Collection Unit*.

⁷ Those births of children with 'indeterminate sex' may include some of the babies with Turners Syndrome, Klinefelter Syndrome or other sex chromosome variations.



who would have preferred to have children without intersex conditions, but don't consider intersex conditions as being so debilitating as to warrant termination. Many of the people with intersex conditions known to the AISSGA with a variety of intersex conditions have good careers, relationships and have made a contribution to society. Some of these people include those that have adopted and/or fostered children, doctors, lawyers, engineers, academics, law enforcement officers, military officers, school-teachers, journalists and scientists. The intersex community is not arguing against abortion, rather that parents should have accurate and up to date information about intersex conditions that will enable them to make an informed choice about termination of an otherwise healthy pregnancy.

In a study published in the British Medical Journal,⁸ researchers found that although prenatal diagnosis is accurate, doctors often give couples inaccurate information about sex chromosome anomalies and this led to "unnecessarily raised anxiety" among parents. Researchers also found that many health professionals who inform expectant parents of a sex chromosome anomaly lack full knowledge about these variations and often alarm patients because they cannot explain the condition and/or portrayed the anomaly as more severe than it really is. One condition highlighted in the study is an anomaly in which girls have an extra X sex chromosome the presence of which often creates no health problems whatsoever. One health professional in the study considered this genetic variation to be as "devastating" as Down syndrome despite the fact that there is absolutely no clinical basis for this opinion.

The AISSGA believes expectant parents must see a genetic counsellor if prenatal tests reveal a sex chromosome anomaly, particularly given the excellent genetic counselling services available in all States of Australia. Parents must also be put in contact with support groups for people affected by these conditions to gain a realistic understanding of the effects of living with the condition.

Employment and Insurance

Genetics gives humanity the apparent 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.

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

⁸ Dr. Lenore Abramsky et al, Imperial College of Science, Technology and Medicine. UK. British Medical Journal 2001; 322:463-466



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.

Further detailed information about genetic discrimination against those with intersex conditions in the areas of employment and insurance is available from the AISSGA submissions to the ALRC enquiry into the use and protection of human genetic information.

Sport

The Equal Opportunity Commission of Victoria writes the following in its brochure titled *Playing Fair: Guidelines for Tackling Discrimination In 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 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 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 AISSGA recommends that the policy of not determining the sex of athletes on chromosomes alone be adopted by all sporting organisations.

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.

Recommendations

In addition to making certain recommendations in our submission to the ALRC on the protection of human genetic information, the AISSGA makes the following recommendations for the purposes of this submission:

1. The AISSGA believes expectant parents must see a genetic counsellor if prenatal tests reveal a sex chromosome anomaly, particularly given the excellent genetic counselling services available in all states of Australia. They must also be given contact information for the relevant genetic support group so that they have a realistic and factual understanding of the effect of the condition.
2. Genetic testing by employer groups should be prohibited. Medical information should not be given to employers; rather they should receive a certificate of fitness from an applicant's physician based on an accurate and detailed job description.
3. Sex determination exclusively on the results of chromosome testing should be prohibited for all purposes including for the determination of the sex of athletes.
4. Those adults with intersex conditions who identify their gender as intersex should be permitted to be legally recognised as intersex in lieu of male or female.
5. Australia should introduce a two-tiered system for non-population risk based insurance similar to that operating in the United Kingdom, where only premiums above a certain financial value require genetic testing for approval.



DISCRIMINATION FROM THE MEDICAL PROFESSION

People with intersex conditions have been subjects of medicine for centuries. In the beginning of the last century a medical textbook⁹ explains intersex conditions in detail and then describes the possible incorrect assessment of sex at birth as follows:

“Frequently, however, non-decent of the testes is associated with hypospadias, and this greatly increases the difficulty of diagnosis. Thus an undoubted male may come to be regarded as a female, since in infancy sex is necessarily determined by examination of the external genitalia alone. Again, in a female, adhesion of the nymphae may occur resulting in the forward prolongation of the urethra to the clitoris... this may be associated with hypertrophy of the clitoris, and double or single, labial ovarian hernia, when the tout ensemble will closely resemble the male genitalia.”

The authors then offer advice on how those with intersex conditions that were incorrectly assigned at birth should go on to live their adult lives:

“When mistakes in the sex have been made in infancy and are not discovered until adult age has been reached, attempts to rectify the mistake are generally speaking inadvisable. The subjects of those malformations are necessary sterile, and, of course, they should not marry.”

Many medical professionals offered social commentary within their proposed ‘medical’ treatment of those with intersex conditions, but the author of a 1946 medical text questioned the claimed benefits of surgical intervention in infants with intersex conditions and wrote:

“From the nature of the disorder it is unreasonable to expect a fundamental improvement with or without treatment. The later may ameliorate the condition.”¹⁰

Unfortunately, this author was largely ignored thanks, at least in part, to the later work of Dr John Money who revolutionised the treatment of children with intersex conditions based on his hypothesis that:

- all children – whether they have an intersex condition or not – do not have a gender identity at birth, and regardless of their biology they can be gender assigned male or female until the age of two; and
- the gender of rearing of a child can be successfully made if the sexual anatomy is made to look “normal” and if the parents treat their child in what he considered to be the typical way for a child of that gender. (i.e. pink room, frilly dresses and dolls for girls, and blue rooms and toy trucks for boys).

Dr Money’s hypothesis was universally accepted as the treatment paradigm for intersex people with amazing ease. There was no empirical evidence to support his theory, except for the “Twins Case” which was subsequently discredited by Prof. Milton Diamond and Dr Keith Sigmundson¹¹.

⁹ Dr T Eden and Dr C Lockyer (1920) *Gynaecology for Students and Practitioners*. Published by J and A Churchill, London.

¹⁰ Dr Frederick Price (1946) *A textbook of the Practice of Medicine*. Published by Oxford Medical Publications.

¹¹ Diamond M, Sigmundson HK. *Sex Reassignment at Birth: A Long Term Review and Clinical Implications*. Archives of Pediatrics and Adolescent Medicine 1997; 151(March): 298-304.



In line with the belief of facilitating the bond with parents to the child with an intersex condition by making the child as “normal” as possible, Money also postulated that the truth about the child’s intersex condition should be kept from parents and even the affected person - even when the child reached adulthood.

This lack of truth disclosure affects everyone with intersex conditions and their families, even if the child was born with “normal” looking genitals, as is the case in complete AIS. This raises legal questions regarding informed consent; particularly when parents approve of medical intervention they do not understand the implications of.

**The first principle of medicine:
"Primum, non nocerum"
(First, do no harm)**

In the past, doctors may have acted in good faith when following the treatment recommended by Dr Money. The fraudulent basis of Money’s theory has been exposed, however, and many children with intersex conditions treated under this model have come out publicly to speak of their horrific experience as a result of Money’s treatment paradigm¹².

Reasons for Infant Genital Surgeries.

Crimes Acts in various States and Territories in Australia include protection from female genital mutilation. All of these Acts have similar caveats to permit genital mutilation for various reasons including if genital surgery is:

- (a) necessary for the health of the person on whom it is performed and is performed by a medical practitioner, or*
- (b) is performed on a person in labour or who has just given birth, and for medical purposes connected with that labour or birth, by a medical practitioner or authorised professional, or*
- (c) is a sexual reassignment procedure and is performed by a medical practitioner.¹³*

The Crimes Act 1900 (ACT) provides an exception for female genital mutilation if there is a “genuine therapeutic purpose” and defines a genuine therapeutic purpose as:

- (a) performed on a person in labour, or who has just given birth, and for medical purposes connected with that labour or birth, by a medical practitioner or registered midwife under the Nurses Act 1988; or*

¹² Claude Migeon et al, Johns Hopkins University School of Medicine. <http://www.hopkinsmedicine.org/medicalschoo/>.

¹³ NSW Crimes Act 1900. Section 45 *Prohibition of female genital mutilation.*



(b) necessary for the health of the person on whom it is performed and it is performed by a medical practitioner.¹⁴

The AISSGA believes ‘normalising’ surgical intervention on children with intersex conditions - including the removal of healthy gonads and ‘cosmetic’ surgeries - is prohibited by the Crimes Act 1900 (ACT) and contravenes the High Court of Australia’s findings in Marion’s Case. Further, except in circumstances that involve urinary tract repairs to prevent infections and gonadectomies to remove established dysgenic tissue, there is no demonstrable medical need to perform any normalising surgeries on infants. As doctors cannot guarantee that the sex of rearing they intend to surgically assign an infant is correct, expeditiously removing healthy tissue without contemplating all possible ramifications is reckless and negligent.

A recent study published in the journal *Pediatrics*^{15, 16} by Claude J. Migeon of the John Hopkins University School of Medicine, found that 25% of surveyed adults with intersex conditions are not satisfied with their gender of rearing. Such a large number is extremely alarming, but even the AISSGA’s estimated 5-10 percent of unsatisfied people should be sufficient for a moratorium to be declared on these questionable procedures performed without consent.

In a recent article reviewing the practice of genital normalising surgeries on infants with intersex conditions, Yale University’s Law department wrote:

“Surgeons who perform genital normalizing surgery, whether on an emergency basis or at the behest of the intersexed infant's parents, should be aware that, because genital-normalizing surgery is not necessary nor proven beneficial for the infant with clitoromegaly or micropenis, the required elements of legal informed consent are likely to have not been met. In light of the questionable scientific basis behind its use, the lack of follow-up data on its benefits, and the overwhelming evidence of its negative physical and psychological results for many intersexuals, a moratorium should be declared on the use of defenceless infants as the experimental subjects of genital-normalizing surgery.”

Some medical professionals also argue that healthy gonads must be removed because the risk of gonadal cancer is too high. This may be the case in conditions like gonadal dysgenesis where the risk is high, but in conditions such as Androgen Insensitivity Syndrome (AIS) the established risk is only between 2 to 5% in patients over 25 years of age, and the risk was deemed ‘small’ prior to that age.^{17, 18, 19} This level

¹⁴ Crimes Act 1900 (ACT) Section 76 *Exception—medical procedures for genuine therapeutic purposes*

¹⁵ <http://www.pediatrics.org/>

¹⁶ Claude Migeon et al, Johns Hopkins University School of Medicine. <http://www.hopkinsmedicine.org/medicalschoo/>.

¹⁷ The British Association of Paediatric Surgeons “Working Party on the Surgical Management of Children Born with Ambiguous Genitalia” Statement July 2001. <http://www.baps.org.uk/documents/Intersex%20statement.htm>

¹⁸ Verp, MS, Simpson, JL. Abnormal sexual differentiation and neoplasia. *Canc Genet Cytogenet*, vol 25, 1987, p 191-218.



of risk does not justify early gonadectomies, particularly given the established benefits of retaining the gonads such as improved bone mineral density and positive body self image and confidence.

In a case that involved the sterilization of a mentally retarded girl, **the High Court of Australia ruled in Marion's Case (1992) that parents cannot provide legal consent for irreversible non-therapeutic medical procedures performed on unconsenting minors.**²⁰ The AISSGA believes the same principles apply to normalizing genital surgeries performed on unconsenting minors because these surgeries are typically not a medical emergency, and no immediate surgery is required at all.²¹ Consequently, it could be argued that when performed on infants, it is not therapeutic, particularly if doctors inadvertently assign a child in the wrong sex.

Recommendations

1. The ruling of the High Court of Australia be upheld by charging the Family Court of Australia to approve non-therapeutic medical procedures on children who cannot provide legal consent.
2. Any caveats in State Crimes Acts that contravene the ruling of the High Court of Australia and reduce legal protection for those with genetic conditions should be removed.
3. Medical Defence Organisations be advised to review their position on providing medical indemnity insurance on surgeons performing these ethically, legally and medically questionable procedures.

¹⁹ Alvarez-Nava, F, Gonzalez, S, Soto, M, Martinez, C. Prieto, M. Complete Androgen Insensitivity Syndrome: Clinical and Anatomopathological findings in 23 Patients. *Genet Counselling*, vol 8, 1997, p 7-12.

²⁰ Gregory J. Boyle, Ph.D, Professor of Psychology, Bond University, Queensland, Australia.
<http://www.cirp.org/library/legal/boyle1>

²¹ Anthony Briffa, *Should the Family Court Approve Surgeries on Children with Intersex Conditions?* Published in 'dAISy', March 2002. ISSN 1446-8026. (Refer Annex B)



DISCRIMINATION FROM THE TRANSGENDER COMMUNITY

People with intersex conditions are not transgender or transsexual. At least 90% live without question of their sex or gender unless they were raised inappropriately due to a mistake at birth. Being misrepresented by a vocal minority in the transgender community is a form of discrimination against those with intersex conditions because it imputes a disadvantage based on their genetic condition. This misrepresentation has the following adverse affects:

1. Reduces the legal rights of people with intersex conditions in the law reform process by incorrectly including them in transgender legislation;
2. Confuses the community about what intersex conditions are;
3. Increases the confusion, shame, stigma and taboo experienced by parents of children with intersex conditions (with the added risk of affecting the relationships with their child);
4. Forces people with intersex conditions to withhold their medical condition to others (sometimes including medical professionals) in fear of being taken as being transgender;
5. Compromises the work of intersex support and advocacy groups by circulating misinformation about intersex conditions, gender identity and the legal status of people with intersex conditions;
6. Fails to recognise the rights of people with intersex conditions to represent themselves;
7. Perpetuates old-fashioned, offensive, stereotypical views of 'hermaphrodites';
8. Disrespects and ignores the differences between transgender and/or transsexual people and those with intersex conditions;
9. Makes role models of successful adults with intersex conditions invisible; and
10. Complicates the gender affirming process for those with intersex conditions who were raised in the wrong sex.

The AISSGA supports the transgender and transsexual communities in their fight for appropriate medical services and to be legally recognised in their self-identified gender, but requests the government consult with intersex groups about issues relating to the health and rights of those with intersex conditions. The AISSGA is also willing to continue to work with transgender groups if any issues arise that affect both communities.

Refer to "Annex A" for further information about the differences between transsexualism and intersex conditions.

Recommendations

1. The AISSGA recommends government groups recognise those with intersex conditions are not transgender or transsexual; and
2. The government consult with established support and advocacy groups run by and for those affected by intersex conditions (like the AISSGA) about matters pertinent to their care and rights.



DISCRIMINATION FROM THE LAW

With the exception of the Female Genital Mutilation section of the Crimes Act, all NSW laws affecting those with 'indeterminate sex' can be traced back to the inquiry by the NSW Law Reform Commission (LRC) into the amendment of birth certificates for transsexuals. The NSW LRC Discussion Paper 17 (1987) - Registration and Certification of Births and Deaths - asked "whether there should be any special rules concerning registration of change of particulars on birth certificates applying to transsexuals" without any mention of those born with intersex conditions. Their subsequent report²² highlighted the following differences between those with intersex conditions and transsexuals:

"4.108 The Registration Act gives the Principal Registrar considerable discretion in the means by which an alteration to the register is made. It is Registry practice to re-register the birth of a child on medical evidence that the sex of the child was recorded incorrectly, or that surgery has altered the child's apparent sex. This practice is not followed for transsexuals."

Hence, the NSW LRC not only recognised the difference between intersex conditions and transsexualism, but also the ability of those with intersex conditions to have their sex corrected on birth certificates and the inability of transsexuals to do the same. For some unknown reason the subsequent Bill put to the NSW Parliament inadvertently included those with intersex conditions by including those with indeterminate sex as transgender. This meant that the amended law could discriminate against them by unfairly treating them as transsexuals and not recognising the rights they had prior to this bill.

It is clear from reviewing the Parliamentary debates on the Transgender (Anti-Discrimination and other Acts Amendment) Bill 1996 that this legislation and the term 'transgender' were also not intended to include those with intersex conditions. One Parliamentarian noted:

"I am aware that some people are born as hermaphrodites, people who have organs of both sexes. There is a degree of sympathy in the community for those people. My heart bleeds for people who are born that way. This bill is not related to those people, who incidentally from an early age have access to surgery and hormonal treatment to change the status under which they were born. I know a girl who was born that way and at a very young age underwent surgery and hormonal treatment. She is now a woman in every respect, although, unfortunately, because of the way she was born she is unable to bear children. She was born a female and christened a female but because of a duplicity of sexual organs in her body she had to undergo surgery to change that."

The lack of opposition to this statement, which was the only reference to people with intersex conditions in the Parliamentary debate on this Bill, supports the claim that those with intersex conditions were not intended for inclusion in this Bill or under the attribute of 'transgender'.

²² NSW Law Reform Commission Report 61 (1988) - Names: Registration and Certification of Births and Deaths



On introducing this Bill for a second time, the NSW Attorney General said:

"The term "transsexuality" is the term most commonly used by the general community to describe people who are born as a member of one sex, but assume the characteristics of the other sex. However, the term has attracted criticism, especially from the transgender community, for being too narrow in scope.

There is concern that the term "transsexual" is inevitably linked with "sex-change" surgery, with the implication that the proposed discrimination amendments would only apply to post-operative transsexuals.

As estimates indicate that only about 20 per cent of persons who have assumed a different gender have undergone surgical intervention, there is an argument for employing more broadly-based terminology.

It is therefore proposed that "transgender" be the term used to identify the basis of a complaint under the Act. This includes a person who is born as a member of one sex but who has lived, or lives, or seeks to live as a member of the other sex. A reference to a transgender person would also include a person being thought to be a transgender person, whether he or she is in fact a transgender person or not. This is consistent with the definition of what constitutes discrimination on the grounds of age and homosexuality.

The term transgender in the legislation has therefore been used to refer to all transgender persons, regardless of whether they have undergone surgical intervention. This is considered necessary because the discriminatory conduct usually occurs as a reaction to a person's dress, behaviour and other characteristics being at variance with that person's original gender. Such conduct should be unlawful whether or not there has been surgical intervention."

Even the Attorney General made no mention of the impact of this Bill on those with intersex conditions. Given the higher prevalence of those with intersex conditions than those who are transsexual, any intent to include intersex conditions would surely have been documented.

The Attorney General concluded his speech with the statement:

"During the drafting of the bill all relevant interest groups were consulted and indicated their general support for the bill."

This further adds weight to the argument for inadvertent inclusion of those with intersex conditions in the Bill because intersex advocacy and support groups were not involved in any of the consultations.

Unfortunately, in addition to the Anti-Discrimination Act 1977 and Births, Deaths and Marriages Registration Act 1995, further legislative changes in NSW adopted the definition of transgender used in the Transgender (Anti-Discrimination and other Acts Amendment) Bill including the Law Enforcement



(Powers and Responsibilities) Act 2002, Terrorism (Police Powers) Act 2002 and the Crimes (Forensic Procedures) Act 2000. These all require amendment to exclude those with intersex conditions from the definition of transgender.

The effects of the Transgender (Anti-Discrimination and other Acts Amendment) Bill 1996, however, are not confined to the state of NSW. Other states have modelled their transgender legislation on NSW thus perpetuating the negative effects on those with intersex conditions. A recent example is Queensland's Discrimination Amendment Bill 2002. This Bill included those with 'indeterminate sex' (i.e. intersex conditions) under the definition of transgender and limited their ability to have their birth certificate corrected if a mistake was made in the gender they were raised. The AISSGA only learnt of the Bill after it was introduced to Parliament, although the transgender (i.e. cross-dresser and transsexual) groups were consulted in the drafting of the Bill. Fortunately, with the support of major paediatric hospitals, paediatricians, child welfare groups and Church groups, the AISSGA were able to obtain the following assurance from the Attorney General in Parliament²³:

"The existing law, without this change, allows errors in the assessment that was made at the time of birth to be corrected. We have clarified that with the people who have circulated that concern about intersex people [the AISSGA] —that they have under the existing law the capacity to rectify errors in the original birth certificates."

The AISSGA appreciates the assurances of the Queensland Attorney General, but are still requesting the legislation be amended to correct the errors in the Bill and to ensure people with intersex conditions are not labelled as transgender and apply for corrections to their birth certificates under the proper section of the Registration of Births, Deaths and Marriages Act.

Law of the Australian Capital Territory

Like other States in Australia, the ACT has enacted legislation that is closely derived from NSW law. As has occurred elsewhere, this perpetuates misrepresentation of issues unique to people with intersex conditions, even though this is not the intention. The AISSGA has worked to minimise the effects of such laws where consultation has taken place only after enactment, but a far more effective approach is to be involved in the consultation process from the earliest possible opportunity. Whilst the ACT legal reform process has commenced and consultation of the GLBTI community has taken place later than the ideal, the process is not so far advanced that it renders consultation completely ineffective.

Infant Genital Surgeries and Informed Consent

The AISSGA believes 'normalising' surgical intervention on children with intersex conditions including the removal of healthy gonads and cosmetic surgeries is prohibited by the Crimes Act and contravenes the High Court of Australia's findings in "Marion's" Case. Further, except in circumstances that involve urinary tract repairs to prevent infections and gonadectomies to remove established dysgenic tissue, there

²³ The Hon Rod Welford MP, QLD Attorney General, Parliament 29 November 2002.



is no demonstrable medical need to perform any normalising surgeries on infants. This issue was discussed earlier in greater detail in the section headed “[Discrimination from the Medical Profession - Reasons for Infant Genital Surgeries](#)”.

The AISSGA believes 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, and a decision made by the Family Court would best consider representation and outcomes for all parties and ensure that full disclosure of options is made. Involvement by 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 a scalpel as a first option and may further provide a degree of legal protection for all parties that currently does not exist.

Recommendations

1. All state legislation defining the term ‘transgender’ to be corrected to expressly exclude those with intersex conditions.
2. All state legislation defining terms for the surgical procedures for transsexual (sex reassignment) surgery be reviewed to remove any confusion with the surgeries performed on those with intersex conditions to minimise any ambiguities as a result of their genetic condition.
3. State legislation for female genital mutilation be amended to make obvious that only surgeries performed on those with intersex conditions for a demonstrable medical need are permitted (i.e. urinary tract repairs to prevent infections and gonadectomies to remove pathologically-confirmed dysgenic gonads), except by order of the Family Court of Australia.
4. New legislation is adopted to provide protection from discrimination against those with genetic conditions.
5. Any of the following recommendations specific to each Act and Bill.

“Surgeons who perform genital normalizing surgery, whether on an emergency basis or at the behest of the intersexed infant's parents, should be aware that, because genital-normalizing surgery is not necessary nor proven beneficial for the infant with clitoromegaly or micropenis, the required elements of legal informed consent are likely to have not been met. In light of the questionable scientific basis behind its use, the lack of follow-up data on its benefits, and the overwhelming evidence of its negative physical and psychological results for many intersexuals, a moratorium should be declared on the use of defenceless infants as the experimental subjects of genital-normalizing surgery.”

Yale Law & Policy Review 469, "First, Do No Harm",
The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants.



REVIEW OF GAY, LESBIAN, BISEXUAL, TRANSGENDER AND INTERSEX ISSUES PAPER

The GLBTI Issues Paper is well researched, inclusive and respectful and the AISSGA look forward to working with the ACT Government and the rest of the GLBTI community on the law reform proposed. We are, however, concerned about the proposed first stage of the law reform process (i.e. the current Bills) as they commenced without important consultation with the GLBTI community and some of the contents are against the proposals and views expressed in the issues paper. These issues will be discussed in detail later in this paper.

Relationship Recognition

The intersex community supports any law reform that recognises domestic relationships and recommends the definition used to include all relationships be “irrespective of gender”. The use of this definition in lieu of ‘same sex’ is important for those with intersex conditions because it includes all sexes and not just male and female. This definition has been successfully used in Victoria and Western Australia in their relationship recognition reform.

The definition of domestic partner proposed in the Legislation (Gay, Lesbian and Transgender) Amendment Bill 2002 uses similar wording which would also recognise the relationships of people with intersex conditions.

Discrimination and transgender and intersex people

The Issues Paper adopted definitions for transgender and intersex and also recognised that people with intersex conditions are a distinct and separate group from transgender people.

The definition of transgender adopted is ‘*the term used to refer collectively to people who cross dress, cross-live in a different gender, and to transsexuals who permanently alter their bodies to more closely conform with their gender identity*’.²⁴ The AISSGA supports this definition and are pleased people with intersex conditions are not included within it.

The definition of intersex is very good, although the intersex community would argue that both sex and gender are unclear at birth in infants with intersex conditions. The definition used is:

An intersex person is someone whose gender was ambiguous at birth – ie. the person is born with sex chromosomes, external genitalia, or an internal reproductive system that are not considered ‘standard’ for either male or female. An intersex person may identify as exclusively male or female, or neither exclusively male nor exclusively female.²⁵

The AISSGA is concerned that although the distinction between transgender and intersex was recognised in the issues paper, the Legislation (Gay, Lesbian and Transgender) Amendment Bill 2002 still used the

²⁴ Definition from Transgender Outreach Canberra – Glossary: <http://www.tgo.org.au/>

²⁵ Definition from the Intersex Society of North America: <http://www.isna.org/>



old definition of transgender which included those with intersex conditions. **This should be amended as a matter of urgency and certainly prior to its reintroduction into the Parliament.**

The AISSGA respectfully disagrees with the statement “many of the issues for transgender people and intersex people are similar”. There are some issues common to both transgender and/or transsexual and people with intersex conditions, particularly in about 5-10% of people with intersex conditions who were raised in the wrong sex, but not many. Issues such as infant/childhood medical intervention, disclosure and genetics do not affect transgender people.

The AISSGA believes there is sufficient reason to define transgender, transsexual and intersex in legislation, particularly given the high degree of confusion in the current legislation and within society. It will also help correct the misconception that people with intersex conditions are transgender. These definitions should be consistent, and should recognise a person’s self-identified sex regardless of whether they are transsexual or have an intersex condition. The definition of intersex, however, should be based on the physical reality of having an intersex condition and not on the basis of merely identifying as intersex. Permitting people to identify as intersex without actually having an intersex condition would be akin to having an able-bodied person perform in the Paralympics or Special Olympics. It also fails to recognise the right of self identification for those with intersex conditions. (Also refer to earlier section on discrimination from the transgender community).

If these definitions are not to be included in law reform, the AISSGA respectfully request that intersex conditions be expressly excluded from any definition of transgender and/or transsexual in the legislation.

The AISSGA respects the right of the transsexual community group to be the authority on transsexual rights and believe those with transsexualism should be fully recognised in their self-identified gender based on living full-time and not surgical status. Requiring a person to have surgical intervention to recognise their gender is not only inappropriate, but also inhumane.

Discrimination Act 1991 and people with intersex conditions

The AISSGA believes those with intersex conditions are already adequately covered in the Discrimination Act 1991 (ACT) under the attribute of impairment, which is defined:

impairment means—

- (a) total or partial loss of a bodily function; or
- (b) total or partial loss of a part of the body; or
- (c) malfunction of a part of the body; or
- (d) malformation or disfigurement of a part of the body; or
- (e) the presence in the body of organisms that cause or are capable of causing disease; or
- (f) an illness or condition which impairs a person’s thought processes, perception of reality, emotions or judgment or which results in disturbed behaviour; or
- (g) an intellectual disability or developmental delay.



The definition of impairment in the Discrimination Act 1991 clearly includes those with intersex conditions under parts (a), (b), (c) and/or (d) because intersex conditions result in a total or partial loss of several body functions and causes various 'malformations' including infertility, genital variations, breast development in males with Klinefelters, short stature and cardiovascular conditions for women with Turners Syndrome, masculinisation in women with partial AIS and partial Gonadal Dysgenesis and feminisation in men with partial AIS and partial Gonadal Dysgenesis. As intersex conditions are also genetic conditions, any future specific genetic discrimination legislation will provide additional protection.

Here is a brief article from a young woman with Turners Syndrome²⁶:

"My name's [name removed] and I'm 16 years old, and a month ago I finished Growth Hormone injections. I was so happy because I could finally stop having needles after 4 years of 6 nights a week. I mean, who wouldn't be excited? It was also the day of my 16th birthday so it was a pretty spectacular present. My doctor was also excited for me because I'd been wanting to stop for a long time. I'm happy with the height I am which is 156.4 cm tall.

All together I've had 1398 needles. It was all worth it in the end because I was only meant to reach 150 cm so I grew an extra 6.4 cm so the pain and bruising paid off. So keep going and one day you'll be as happy as I am. I would also like to thank Dr Warne and associates for all their help and support. Debbie, thanks for teaching me how to give the injections and Dr Cameron, for giving me the best news possible."

Reproductive and parenting rights

Although people with intersex conditions are fully recognised by law for all relationship and parenting rights if they are in heterosexual relationships, those in gay or lesbian relationships are prohibited to adopt, be recognised as the mother of a child born through ART or be recognised as the parents of a child born pursuant to a substitute parent agreement. The AISSGA supports the Gay and Lesbian community in having the same parenting rights as heterosexual couples.

- 1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.**
- 2. Marriage shall be entered into only with the free and full consent of the intending spouses.**
- 3. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.**

- Article 16, The Universal Declaration of Human Rights

²⁶ Victorian Turner's Syndrome Support Group Newsletter March 1999. <http://www.turnerssyndrome.org.au/>



Anti-vilification legislation

The AISSGA believes there is sufficient protection against vilification for those with intersex conditions in the Discrimination Act 1991, but would welcome further protection to prohibit acts of vilification against gay, lesbian, bisexual, transgender and intersex people, and people with HIV/AIDS.

Defence of provocation

The AISSGA believes the defence of provocation should be abolished. It is completely unreasonable and un-Australian to support a law that accepts violence is a reasonable response to a non-violent homosexual advance.

Births, Deaths and Marriages Registration Act 1997

The interpretation in the issues paper about the way the Births, Deaths and Marriages Registration Act 1997 affects those with intersex conditions is incorrect, although it highlights the need for urgent clarification and amendment. Further, those with intersex conditions are not transgender, and do not have 'sex reassignment surgery'.

Approximately 25% of people with intersex conditions are born with atypical genitalia. In these cases in particular, doctors make a choice about the sex of rearing based on things like the possible success of surgical intervention without conclusively knowing the way a person identifies. Regrettably, for between 20 to 40% of these children, the choice made by doctors is incorrect. These unfortunate individuals should not be labeled 'transgender' and treated as such (including denying them a *corrected* birth certificate and therefore the legal right to marry) because a mistake was made for them at birth. The Federal Attorney General has already provided written confirmation to the AISSGA that the corrected birth certificates of people with intersex conditions will be recognised for the purpose of marriage.

The ability to have birth certificates corrected already exists in all State and Territories when an error in the recording of the registerable event has been established. In the ACT, people with intersex conditions can have the sex on their birth certificates corrected under section 40 "Correction of Register" rather than amended as a 'recognised transgender' (i.e. a transsexual). This is because the Registrar has an obligation to ensure the register is correct and medical documentation confirming an error at birth due to an intersex condition provides sufficient proof to establish the error to necessitate a correction to the register. People with intersex conditions in other States in Australia have had their birth certificates corrected by the registrar in this way already. This ensures they are fully recognised in their gender for all legal purposes in all jurisdictions.

Treating people with intersex conditions as transgender would be difficult for any government to argue on the basis of human rights, medicine or anti-discrimination legislation. For further information about the difference between intersex conditions and transsexualism see "Annex A" of this submission.



Section 23

sexual reassignment surgery means a surgical procedure involving the alteration of a person's reproductive organs that is carried out—

- (a) for the purpose of assisting a person to be considered to be a member of the opposite sex; or
- (b) to correct or eliminate an ambiguity relating to the sex of the person.

transsexual person means a person whose record of registration of birth has been altered under section 26.

The definition of sexual reassignment surgery should expressly exclude those with intersex conditions as it unnecessarily includes them even though their sex is not re-assigned. Sexual reassignment surgery is surgery performed on a biological male or female following strict guidelines including psychiatric assessments, life experience and informed consent to make them as physiologically of the opposite sex as medically possible. This is certainly not the medical procedure carried out on people with intersex conditions, they are not born physically clearly male or female and give informed consent to remove their healthy organs to make them look like the opposite sex. Consenting people with intersex conditions undergo cosmetic surgeries to correct congenital malformations to make themselves more comfortable with the bodies they were born with. They have a right to do this without prejudice. Part (b) should also be removed because those with transsexualism do not have physical 'ambiguities' about their sex until after medical intervention has commenced. They are unambiguously completely male or female but with the brain sex of the opposite gender.

People with intersex conditions have surgery to correct a physical birth variation in much the same way people do for many other genetic variations. To treat them less favourably because their condition affects sexual organs rather than other parts of their bodies is unreasonable and discriminatory.

Section 24

(2) Subject to subsection (3), the parents or guardian of a child—

- (a) whose birth is registered in the Territory; and
- (b) who has undergone sexual reassignment surgery;

may apply to the registrar-general for alteration of the record of the child's sex in the registration of the child's birth.

Given the Act's definition of sexual reassignment surgery and the fact that sex reassignment surgery is not performed on transsexuals until they are adults, this section specifically details the process of



changing the birth registration of a child with an intersex condition. This section should be removed as children with intersex conditions have their birth certificates corrected under section 40 of the Act.

Section 40 Correction of register

- (1) The registrar-general may correct the register—
 - (a) to reflect a finding made on an inquiry under division 7.2; or
 - (b) to bring an entry about a particular registrable event into conformity with the most reliable information available to the registrar-general of the registrable event.
- (2) The registrar-general shall, if satisfied that, in view of a finding of a court, an entry in the register is incorrect, correct the register in accordance with the finding.
- (3) A correction of the register is effected by adding or cancelling an entry or by adding, altering or deleting a particular contained in an entry.

Section 41 Registrar-general's powers of inquiry

- (1) The registrar-general may conduct such inquiries as he or she deems fit to find out—
 - (a) whether a registrable event has happened; or
 - (b) particulars of a registrable event; or
 - (c) whether particulars of a particular registrable event have been correctly recorded in the register.

It is highly discriminatory if people with genetic conditions who are unfortunate enough to be raised as the wrong gender are not permitted to have their birth certificates corrected under this section of the Act. People with intersex conditions deserve the right to a normal life including recognition of their sex and the ability to marry and found a family (albeit through adoption or foster care). Not permitting people with intersex conditions who were raised as the wrong gender to have a completely corrected birth certificate punishes them for being born with a genetic condition and for an honest mistake made by doctors when they were born.

It is worth noting that provision already exists in all Australian States and Territories to correct errors made in registerable events under the relevant Births, Deaths and Marriages legislation. Consequently, those with intersex conditions can have their birth certificates corrected in all States and Territories in Australia and the Commonwealth Attorney General has confirmed in writing that corrections made to registers in this manner will be recognised for all purposes by the Commonwealth including marriage. Some corrections have already been made and the AISSGA has the support of paediatric hospitals, Churches of all denominations, child advocacy groups and bioethics groups in requesting these changes to the Act.

The AISSGA believes the power of the Registrar to conduct an inquiry and obtain medical evidence confirming an error made at birth is sufficient for a correction to a birth certificate as it is in other Australian States.



Case Study

A baby is born with genitals that look partially male and partially female. A large clitoris and a vagina is noted, as are two lumps in the labia that are thought to be testes. Doctors explain to the parents that the sex of their child is unclear and that it will take several days to establish the best sex of rearing. The parents are told they probably have a daughter. They are obviously stressed and very confused. Genetic counselling and peer support is offered.

Following several days of tests that include blood tests, a sex chromosome test, ultrasounds and a bilateral gonadal biopsy, doctors establish the child has testes, a vagina, typical male sex chromosomes (i.e. 46XY) and no ovaries. Discussions with the family revealed two of the mother's maternal Aunts never had children and one female cousin was infertile. The diagnosis was Partial Androgen Insensitivity Syndrome (PAIS).

The doctors decide that the child's gender is probably female and it should be raised as such. This decision is based on anecdotal evidence that indicates that most people with similar levels of androgen insensitivity identify as female and surgically constructing male genitalia is extremely problematic. Surgical intervention to remove the testes and create female genitalia was not performed to allow for the possibility of an error in the sex of rearing.

Discussion:

Cases where the sex of the child is unclear occurs in about one in 4500 births. They are not transgender. Provision must be made in law for errors to be corrected for those whose sex is unclear at birth. In this case, raising the child female is appropriate and her birth certificate indicates she is female.

If this child constantly exhibits typical male behaviour she will receive psychological support and psychiatric assessment to determine if a mistake was made. The ideal time for this is prior to starting primary school and again prior to adolescence. If an error was made, this child should have his birth certificate corrected and reissued as per section 45 of the Births, Deaths and Marriages Registration Act 1995 and not assessed as a transsexual under section 32B.

The DSM-IV excludes those with intersex conditions as being transsexual or having 'gender identity disorder'. This child is clearly not transsexual and was assigned the wrong sex at birth. Managing this child's birth certificate correction as an amendment under the transgender legislation will prohibit him from marriage when he becomes an adult.



Other legislative provisions

While it is clear the legislation attempts to afford people respect and dignity by allowing them to be searched by officers and medical staff of the same sex, this may cause serious complications for a small number of people with intersex conditions, particularly those identifying as male or who have a non-typical male or female bodies. Some men for example, may have breasts and atypical genitalia and feel highly distressed being searched by men. This feeling may be further exacerbated by past negative experiences from the medical profession such as repeated unnecessary medical examinations, medical photography etc.

The AISSGA recommends that people being searched be permitted to nominate the sex of the searching officer and/or medical staff.

Crimes Act 1900

Section 73 (Part 4 Female Genital Mutilation)

female genital mutilation means—

- (a) clitoridectomy or the excision of any other part of the female genital organs; or
- (b) infibulation or similar procedure; or
- (c) any other mutilation of the female genital organs.

Section 74 Prohibition of female genital mutilation

- (1) A person shall not intentionally perform female genital mutilation on another person.

Maximum penalty: imprisonment for 15 years.

- (2) It is not a defence to a prosecution for an offence against this section that the person on whom the female genital mutilation was performed, or a parent or guardian of that person, consented to the mutilation.

Section 75 Removal of child from ACT for genital mutilation

- (1) A person shall not take a child from the ACT, or arrange for a child to be taken from the ACT, with the intention of having female genital mutilation performed on the child.

Maximum penalty: imprisonment for 7 years.

- (2) In proceedings for an offence against subsection (1), if it is proved that—

- (a) the defendant took a child, or arranged for a child to be taken, from the ACT; and
- (b) female genital mutilation was performed on the child while outside the ACT;



it will be presumed, in the absence of proof to the contrary, that the defendant took the child, or arranged for the child to be taken, from the ACT with the intention of having female genital mutilation performed on the child.

(3) In this section:

child means a person under the age of 18 years.

76 Exception—medical procedures for genuine therapeutic purposes

- (1) It is not an offence against this part to perform a medical procedure that has a genuine therapeutic purpose or to take a person, or arrange for a person to be taken, from the ACT with the intention of having such a procedure performed on the person.
- (2) A medical procedure has a genuine therapeutic purpose only if—
 - (a) performed on a person in labour, or who has just given birth, and for medical purposes connected with that labour or birth, by a medical practitioner or registered midwife under the Nurses Act 1988; or
 - (b) necessary for the health of the person on whom it is performed and it is performed by a medical practitioner.
- (3) A medical procedure that is performed as, or as part of, a cultural, religious or other social custom is not of itself to be regarded as being performed for a genuine therapeutic purpose.

77 Exception—sexual reassignment procedures

- (1) It is not an offence against this part to perform a sexual reassignment procedure or to take, or arrange for a person to be taken, from the ACT with the intention of having a sexual reassignment procedure performed on the person.
- (2) In subsection (1):

sexual reassignment procedure means a surgical procedure performed by a medical practitioner to give a female person, or a person whose sex is ambivalent, the genital appearance of a person of the opposite sex or of a particular sex (whether male or female).

The World Health Organisation (WHO) defines Female Genital Mutilation (FGM) as comprising ‘*all procedures involving partial or total removal of the female external genitalia or other injury to the female genital organs whether for cultural or other non-therapeutic reasons*’²⁷. The AISSGA believes all children have the right to protection from non-therapeutic medical intervention regardless of their gender or appearance of their genitals.

Female genital mutilation (FGM) like most genital surgical intervention on children with intersex conditions, is ‘*medically unnecessary and has adverse physical, sexual and psychosocial consequences*’²⁸. It also violates, amongst other international human rights laws, the right of the child to

²⁷ *Female Genital Mutilation*. A joint WHO/UNICEF/UNFPA statement. World Health Organisation 1997, p.3.

²⁸ Royal Australian College of Obstetricians and Gynaecologists (1997). *Female Genital Mutilation*.



the “*enjoyment of the highest attainable standard of health*”, as laid down in article 24 (paragraphs 1 and 3) of the Convention on the Rights of the Child.

The AISSGA believes 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. On other occasions this is done via an order from the Family Court of Australia who consider representation and outcomes for all parties and ensure that full disclosure of options occurs prior to a decision being made. This same procedure could be adopted in the case of irreversible medical treatment of children with intersex conditions. Involvement by the Family Court is also likely to ensure doctors are more willing to consider alternatives to surgical intervention, such as support and counselling, rather than opting for a scalpel as a first option and may further provide a degree of legal protection for all parties that currently does not exist.

Recommendations

The AISSGA recommends amending section 77 of the Crimes Act 1900 to exclude those with intersex conditions and to add another paragraph requiring prior approval from the Family Court of Australia for any non-therapeutic medical intervention on people with intersex conditions who cannot provide legal informed consent. We also recommend the Department of Justice notifies medical professional associations (including medical defence organisations) of the actual caveats of the female genital mutilation legislation and that surgical intervention on children with intersex conditions should be considered on a case-by-case basis in determining whether intervention ‘has a genuine therapeutic purpose’ and ‘necessary for the health of the person on whom it is performed’.

The AISSGA also recommends that any definition of *µsexual reassignment surgery¶*, *µtransgender¶* and/or *µtranssexual¶* expressly exclude those with intersex conditions or those with *µambivalent¶*, *µambiguous¶* or *µindeterminate¶* sex.

Please refer to the section “Discrimination from the Medical Profession – “Reasons for Infant Genital Surgeries” for further information and recommendations about non-therapeutic medical intervention.

Policy, programs and priorities

The AISSGA welcomes working collaboratively with the ACT Government on policy development and community consultation in all areas including health, human rights, policing, corrections and discrimination.

We look forward to consulting with the Government and assisting its current review of policies and procedures for the management of transgender and intersex persons detained at the Belconnen Remand Centre, Symonston Temporary Remand Centre and Periodic Detention Centre.



REVIEW OF ACT DISCRIMINATION AMENDMENT BILL 2002 (NO 2)

5 Section 4 (1), new definitions

insert

domestic partner, of a person, means a person who lives with the person in a domestic partnership, and includes a spouse.

domestic partnership means the relationship between 2 people, whether of a different or the same sex, living together as a couple on a genuine domestic basis.

The AISSGA appreciates this definition of domestic partnership as it includes those whose sex may be unclear or in between male and female. This will have positive affects on the recognition of relationships where one or both partners are either transgender or have an intersex condition.

10 New section 5AA

after section 5, insert

5AA Meaning of impairment

(1) In this Act:

impairment means—

- (a) total or partial loss of a bodily function; or
- (b) total or partial loss of a part of the body; or
- (c) malfunction of a part of the body; or
- (d) malformation or disfigurement of a part of the body; or
- (e) the presence in the body of organisms that cause or are capable of causing disease; or
- (f) an illness or condition which impairs a person's thought processes, perception of reality, emotions or judgment or which results in disturbed behaviour; or
- (g) an intellectual disability or developmental delay.

This definition of impairment clearly includes those with intersex conditions under parts (a), (b), (c) and/or (d) because intersex conditions result in a total or partial loss of several body functions and causes various 'malformations' including genital variations, breast development in males with Klinefelters, short stature and cardiovascular conditions for women with Turners Syndrome, masculinisation in women with partial AIS and partial Gonadal Dysgenesis and feminisation in men with partial AIS and partial Gonadal Dysgenesis. As intersex conditions are also genetic conditions, any future specific genetic discrimination legislation will provide additional protection.



REVIEW OF LEGISLATION (GAY, LESBIAN AND TRANSGENDER) AMENDMENT BILL 2002

The ACT Government has been very mindful of the needs and issues of people with intersex conditions, and have openly recognised the differences between transgender people and people with intersex conditions. The ACT GLBTI issues paper, in recognising the inappropriateness of including people with intersex conditions under the transgender term, adopted the definition of transgender used by the Transgender Outreach Canberra group which is “people who cross dress, cross-live in a different gender, and transsexuals who permanently alter their bodies to more closely conform with their gender identity”.

Section 4 New sections 169 and 169A

insert

169A References to transgender people

- (1) A transgender person is a person who—
 - (a) identifies as a member of the opposite sex by living, or seeking to live, as a member of the opposite sex; or
 - (b) has identified as a member of the opposite sex by living as a member of the opposite sex; or
 - (c) is of indeterminate sex and identifies as a member of a particular sex by living as a member of that sex;whether or not the person is a recognised transgender person.
- (2) A transgender person includes a person who is thought of as a transgender person, whether or not the person is a recognised transgender person.
- (3) A recognised transgender person is a person the record of whose sex is altered under the Births, Deaths and Marriages Registration Act 1997, part 4 or the corresponding provisions of a law of a State or another Territory.

The Legislation (Gay, Lesbian and Transgender) Amendment Bill 2002, however, fails to recognise these differences and unfortunately uses an inappropriate definition of transgender that includes those of ‘indeterminate sex’ (i.e. people with intersex conditions) which is also detailed in this Bill’s Explanatory Memorandum.

This inappropriate definition affects the following ACT legislation:

- Casino Control Act 1988
- Children and Young People Act 1999
- Confiscation of Criminal Assets Act 2002
- Crimes Act 1900
- Crimes (Forensic Procedures) Act 2000
- Custodial Escorts Regulations 2002
- Dangerous Goods Act 1975
- Drugs of Dependence Act 1989



- Firearms Act 1996
- Periodic Detention Act 1995
- Periodic Detention Regulations 1995
- Remand Centres Regulations 1976

Most of these Acts require that a person of the same sex conduct a body search. It is understandable that transgender people would want to be searched by those of the same sex, but this is not necessarily the case for people with intersex conditions. This is particularly so for people with intersex conditions who have non-typical external anatomy or who have had negative experiences from the medical profession such as repeated childhood medical examinations and medical photography. As is the case with the Department of Corrections in Victoria, the AISSGA believes people with intersex conditions being searched should be permitted to nominate the sex of the searching officer and/or medical staff.

Recommendations

Part 1(c) of the definition of transgender person be removed as a matter of urgency and prior to the Bill being reintroduced into the ACT Parliament.

“The situation of the transsexual is that they are born normal males, and that is what we are talking about in transsexuals. The person who has an abnormality, such as a Y chromosome, might have Klinefelter's syndrome, Turner's syndrome or androgen insensitivity syndrome. There was a Spanish hurdler who created a lot of interest a few years ago. New Scientist published an article about this person who had androgen insensitivity syndrome and problems with the buccal smear, but she was not a transsexual. The transsexual person, per documents I have read over the past months and years, is a physically normal male—they test correctly as a male. If you test them with a buccal smear, they will show as having a Y chromosome. They will have had male gonads at some stage, so they will have the male chromosomes and other male reproductive organs, and testosterone will have been a part of their system until they started the change, but the transsexual male is different from the person who is an intersex.

When reading the literature I have noticed that intersex people are never mentioned. The popular literature, the media magazines, mix up the hermaphrodite with the transsexual. People mix them together. There was an article in the Australian a while ago, maybe in the past two months. They opened the article with an example of a hermaphrodite and it looked as though they were trying to relate it to a transsexual. Of course, I felt quite upset at this. I thought, ‘No, this is a hermaphrodite, this is a person who is an intersex and who has a bit of both sexes.’ That is different from being a transsexual. No-one has found a biological basis for transsexualism. They are different.”

Senate Legal and Constitutional References Committee – Sexuality Discrimination Inquiry
7 August 1996



Annex A - Comparison between Intersex Conditions and Transsexualism

This fact sheet is the result of misinformation advanced by a small number of transsexuals who falsely claim that transsexualism is an intersex condition. It is meant to merely highlight the differences between the two groups, although we fully acknowledge their right to identify and be legally recognised in their self-identified gender.

Comparison Chart

	Intersex	Transsexualism
Definition	One of the many long-established biological conditions where a child is born with reproductive organs, genitalia and/or sex chromosomes that are not exclusively male or female.	A recognised medical condition where people are born with a completely male or female body but with a “brain sex” of the opposite gender.
Terminology	The previous word for intersex is hermaphrodite.	Transsexualism is also referred to as ‘gender dysphoria’ or ‘gender identity disorder’.
Diagnosis	Biologically determined	Self identified condition
Gender identity issues	Approx 5 to 10% of people with intersex conditions have some question about their gender identity, and often this is a direct result of earlier inappropriate medical treatment.	100% of transsexuals have gender identity issues and reject their biological sex.
Sex of rearing	People with intersex conditions are preliminarily assigned a sex of rearing at birth if there is an obvious ambiguity as to the child’s sex. A decision is made for them. Others with intersex conditions are diagnosed later when they fail to menstruate etc.	100% of transsexuals are raised from infants as their obvious biological sex. No doctor would support raising a biologically complete male or female as the opposite sex.
Biological or psychological?	Long established biological condition and specifically excluded from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV).	Long established psychological condition and listed in the DSM-IV.



Treatment	Children and infants with intersex conditions endure repeated examinations and medical procedures including orchidectomies, vaginoplasties and hormone treatment without their consent. A standard of care does not exist, but treatment is generally based on invalidated research from the 1960s.	Transsexuals receive treatment as adults under the HBGDA Standards of Care and give full disclosure and consent to any medical intervention. Care is specifically taken to ensure mistakes are not made.
Fertility	People with intersex conditions cannot reproduce without medical intervention except in very rare circumstances.	Most transsexuals are naturally able to reproduce. (Many do prior to rejecting their biological sex).
Issues	Treatment of children with intersex conditions, support for parents, accurate and timely diagnosis, and access to medical specialists.	Legal status of their self-identified gender, particularly for amendments to their birth certificates and for the right to marriage.
Genetic Condition	Long-established genetic condition with many cases of intersex conditions running in the family. The AISSGA has many families where more than one child in the one immediate family has AIS. In cases of identical twins, both have the intersex condition.	Not a genetic condition. There are many cases of identical twins with only one being transsexual. This is currently the subject of international research.

Variations of Sexual and Gender Development

People with intersex conditions have a medically recognised variation of biological sexual development. Only those with biological physical variations where a child is born with reproductive organs, genitalia and/or sex chromosomes that are not exclusively male or female (and not an incongruent “brain” and biological sex) have an intersex condition.

Transsexualism is sometimes considered a variation of gender development as affected people physically develop prenatally as one biological sex, but their self identified gender is of the opposite sex. Sexual orientation amongst those with transsexualism varies as it does with the wider population.

The AIS Support Group Australia supports the hypothesis that there may be a biological basis for transsexualism, but this still does not make transsexualism an intersex condition for all the reasons explained above. The global intersex community respectfully requests those few transsexuals who claim that transsexualism is an intersex condition to respect our different experiences and issues.



Annex B - Should the Family Court Approve Surgeries on Children with Intersex Conditions?

By Tony Briffa,

Published in 'dAISy', March 2002. ISSN 1446-8026

An article written by Dr Sonia Grover and published in the February 2002 Medical Journal of Australia (Vol 176, Number 3) discussed the issue of menstrual and contraceptive management in women with intellectual disabilities. Although this is not directly relevant to children with intersex conditions, I was interested in the level of legal protection some with intellectual disabilities rightly have to their physical integrity.

When a young woman with an intellectual disability has problems with heavy or irregular bleeding which affects her quality of life, doctors must first obtain the authority of the Family Court of Australia if their recommended treatment involves irreversible procedures such as hysterectomy. Further, "surgical options were considered only after all other approaches, including education, support and medical treatments, had failed." As a consequence, of the 107 patients seen by the author over the years 1990 to 1999, only two had surgical intervention.

The requirement for the Family Court of Australia to approve these surgeries is a direct result of the judgment of the High Court of Australia in "Marion's Case", which found that a disabled person had a presumption of the right to physical integrity. Given that some people with intellectual disabilities are considered unable to give legal consent to these irreversible procedures, doctors must seek authority from the Family Court who will make that decision on their behalf.

I believe there are similar quality of life and human rights issues that warrant children with intersex conditions being afforded the same legal protection. Children with intersex conditions have no less a right to their physical integrity. Where a child with an intersex condition is too young to give consent to irreversible surgeries, some of which may render them infertile (particularly given the rate of improvement in assisted reproductive technologies), a decision made by the Family Court would best consider representation and outcomes for all parties and ensure that full disclosure of options is made. Involvement by 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 a scalpel as a first option and may further provide a degree of legal protection for all parties that currently does not exist.