

## National LGBTI Health Alliance

lesbian, gay, bisexual, transgender, intersex and other  
sexuality, sex and gender diverse people and communities  
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12 March 2012

Committee Secretary  
Senate Standing Committees on Community Affairs  
PO Box 6100  
Parliament House  
Canberra ACT 2600

### **RE: Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia**

Dear Committee Secretary

The National LGBTI Health Alliance (the Alliance) is pleased to make a submission to the Senate Committee Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia. We commend the Committee for extending the Terms of Reference for this Inquiry to include “current practices and policies relating to the involuntary or coerced sterilisation of intersex people, including: (a) sexual health and reproductive issues; and (b) the impacts on intersex people.”

#### **About the National LGBTI Health Alliance**

The Alliance is the national peak health organisation for a range of organisations and individuals from across Australia that work together to improve the health and well-being of targeting lesbian, gay, bisexual, transgender, and intersex people and other sexuality, sex and gender diverse people (LGBTI). We support measures which contribute to improved health and well-being for LGBTI Australians.

Formed in 2007, the Alliance includes the major providers of services for LGBTI people in Australia, with Members drawn from each State and Territory. The Alliance provides a representative national voice to: develop policy and to support LGBTI health issues; seek increased commitment to services for LGBTI people; develop the capacities of LGBTI organisations; and support evidence-based decision-making through improved data collection covering sexuality, sex and gender identity.

#### **Involuntary or Coerced Sterilisation and Health of Intersex People in Australia**

As documented in [the Submission to this Inquiry](#) by our Member Organisation, Organisation Intersex International (OII) Australia, intersex people in Australia are disproportionately affected by involuntary or coerced medical interventions that affect their long-term health and wellbeing.

We are concerned by the current practice in Australia of medically unnecessary interventions that attempt to make intersex infants’ bodies conform to “female” or “male” standards. Consent for these procedures is typically delegated to third parties such as medical and mental health professionals, parents or the Family Court. Evidence documents that these procedures lead to involuntary sterilisation, physical and psychological trauma, poor adult sexual health outcomes and urogenital damage that can cause permanent incontinence and scarring in intersex infants and children. As documented in the OII Australia Submission, the Family Court has failed to protect intersex young people from medical abuse.

We are also concerned that many intersex adolescents and adults report having felt coerced by medical and mental health professionals, parents and others into agreeing to medical procedures that have been documented to cause sterilisation, psychological trauma, scarring, permanent incontinence and impaired adult sexual function. Intersex people report that risk assessments used by medical professionals to justify these interventions often do not communicate available evidence in a balanced scientific way.

Unlike people labelled as “female”, Australia does not currently provide legislative protection for intersex people of all ages who are subject to involuntary or coerced sterilisation and other medical interventions that lead to poor health outcomes. This includes procedures that would be criminalised as genital mutilation if they were done to children classified as “female” (e.g., clitoridectomy) as well as non-surgical procedures such as involuntary or coerced hormone administration. These medically unnecessary “normalising” procedures are usually justified as “therapeutic”, a classification that allows medical professionals to avoid prosecution.

Additional sexual health and reproductive issues within the Terms of Reference for this Inquiry are:

- The current off-label prescribing of Dexamethasone and reported pregnancy terminations to prevent intersex births in Australia.
- The absence of a suitable PBS item code for intersex women who need Androcur and multiple reports that intersex women’s medical records have listed “Item code 1404 - To reduce drive in sexual deviations in males”. Use of this item code stigmatises intersex women by conflating them with sex offenders.

Medical intervention on intersex adults and children of all ages in the absence of their informed consent, except in cases of medical necessity, is a clear breach of their inalienable human rights. This concern has been raised in a 2012 [Report on bioethical issues relating to intersexuality](#) by the Swiss National Advisory Commission on Bioethics and in [a 2013 Report](#) by the UN Special Rapporteur on Torture and other cruel, inhuman or degrading treatment or punishment, both of which advocated for criminalization of these practices. In particular, the UN Report explained the need to criminalise abuses in health care settings. We refer you to the Submission by OII Australia for more detailed discussion of these reports.

## **Recommendations**

We recommend that the Australian Government fulfil Australia’s obligations under international treaties and instruments by undertaking immediate legislative reform to protect these rights.

The national legislative reforms that the Alliance recommends are:

- The creation of a national Statutory Body in the form of an expert tribunal that would replace Family Court involvement in decisions about intersex medical interventions.
- That this expert tribunal needs to include intersex people and intersex-led community organisations as members on an equal footing with medical professionals.
- The criminalisation of medically unnecessary interventions that seek to “normalise” intersex people’s bodies without their own informed consent, on a par with legislation that protects women and girls from genital mutilation. This should include non-surgical interventions.
- The criminalisation of abuses in health care settings such as interventions that medical professionals may inappropriately classify as “therapeutic” to avoid prosecution.
- Legislative protection for intersex people of all ages from having their consent for unnecessary medical procedures delegated to third parties (i.e., medical and mental health professionals and

parents). Parents should not be able to consent to procedures that will permanently sterilise or genitally alter their children without an urgent medical reason.

- Legislative protections for intersex people should not require any particular gender identity.
- A ban on the off-label use of Dexamethasone to prevent intersex births.
- Legislative protection of intersex people's privacy through the option of an "unspecified" sex classification and the ability to alter sex assignments without medical intervention.
- Addition of a suitable PBS item code for intersex women who take Androcur.

Australian regulations for health professionals working with intersex people and their families should:

- Specify that, where no urgent medical need is present and the intersex person is unable to give informed consent, the ethical principle of "primum non nocere" (the first thing is to do no harm) should prevail. This means treating family support and acceptance as a priority over surgical intervention and deferring medical intervention whenever possible until the intersex person is able to give their informed consent to the [Gillick competency](#) standard.
- Provide intersex people and their families with the option of an "unspecified" sex classification and inform them about their option to alter sex assignments without medical intervention.
- Mandate national data collection on all intersex births, sex of rearing assignments, pregnancy terminations, rationale for surgical interventions and negative outcomes of intervention.
- Require that, after individually identifying information has been removed, these data be reviewed on an ongoing basis by the expert tribunal and cases of suspected abuse investigated.
- Bar professionals from participating in or recommending medical interventions made solely based on psychosocial adjustment, perceived family attachment, stigma, genital appearance or assumptions about future gender identity, sexuality or sexual behaviour.
- Require that *necessary* medical intervention on minors will preserve the potential for different gender identities, sexualities and sexual behaviours until the patient has Gillick competence and not treat consent for necessary intervention as general consent for unnecessary intervention. For example, an intersex person's consent for medically necessary urethral reconstruction surgery should not be treated as automatic consent for unnecessary genital alteration.
- Require the use of respectful, non-pathologising language about intersex people and recognition that people's intersex biological variations do not automatically constitute 'disorders'.
- Require professionals making care decisions to provide balanced information that includes:
  - a) Information about and referrals to intersex-led support and education organisations;
  - b) Counselling that discusses how intersex people can lead healthy and successful lives without medical intervention; and
  - c) Discussion of available evidence about potential complications and negative outcomes of proposed medical intervention.

The Australian Government should also engage in consultation with national intersex organisations such as our Member Organisations OII Australia and Androgen Insensitivity Syndrome Support Group Australia (AISSGA) about how to fulfil their resourcing needs.

Yours sincerely

Warren Talbot  
GENERAL MANAGER