

National LGBTI Health Alliance

lesbian, gay, bisexual, transgender, intersex and other
sexuality, sex and gender diverse people and communities
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General Manager: Warren Talbot



10 April 2013

The Hon David Davis, MLC
Minister for Health, Minister for Ageing
Department of Health
GPO Box 4057
Melbourne
Victoria, 3001

Dear Minister

Policy Statement on the Victorian Department of Health Approach to Intersex Young People

The National LGBTI Health Alliance (the Alliance) wishes to commend the Department for having introduced the *Decision-Making Principles for the Care of Infants, Children and Adolescents with Intersex Conditions*. We appreciate the Department's efforts to address the substantive ethical and health concerns attendant to medical practice with intersex young people. We note some beneficial discussion of these concerns in the *Principles* document. We are also pleased that the Department included intersex-led organisations in the consultation process.

As the *Principles* document constitutes the first uniform guideline at an Australian State level specifically focused on intersex young people, we are aware that this document is likely to inform national policy on medical decision-making about intersex people. For this reason, we wish to discuss some significant concerns with the Department.

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 lesbian, gay, bisexual, transgender, and intersex people and other sexuality 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.

Our concerns about the *Principles*

Despite the positive attributes mentioned above, several elements of the *Principles* are likely to perpetuate involuntary or coerced medical treatment of intersex young people and the resultant lifelong harm to these young people and their families. We are making this letter available to initiate dialogue with the Department and to inform Alliance Members that this document does not reflect our view of best practices.



Based on our March 2013 submission to the Senate in the area of intersex health (www.lgbtihealth.org.au/submissions), we note the following:

- **The *Principles* would be improved if they incorporated intersex people's feedback and health needs adequately.** The Department could improve the *Principles* by applying the recommendation from intersex people and national intersex-led organisation, as stated to the Department during the consultation process, that pathologising or stigmatising language such as 'intersex conditions' should be avoided. Human anatomical and physiological variations do not in themselves constitute medical 'problems'. Psychological literature has documented how the framing of medical communication (termed 'framing effects') can alter or reverse people's consent to medical treatment. Thus the Department's conflation of intersex physiology itself with medical conditions common among intersex people is likely to perpetuate the practice of medically unnecessary "normalising" treatments. We are also troubled by the delegation of intersex people's own consent to third parties. We believe it essential to act on evidence from intersex people with direct personal experience and to require first-hand consent outside of genuine medical emergencies.
- **There is a body of medical and psychological literature not currently cited in the *Principles*** that could be of benefit to the Department. In particular, we note that the current version of the document could benefit from expanded discussion of studies that found frequent rejections of sex-of-rearing assignments, as well as widespread and severe surgical complications. Their evidence against medically unnecessary treatments meant that the *Principles* downplayed several major health concerns, including the necessity for multiple invasive follow-up surgeries throughout childhood and adolescence; permanent loss of sexual function in adulthood; and permanent incontinence that affects intersex young people's quality of life in adulthood. The document would also benefit from inclusion of relevant documentation regarding medically unnecessary, psychosocially motivated "normalising" surgeries that led to suicide.
- **The *Principles* retained psychosocial rationale (pgs. 5, 18-20, 22) as valid factors in medical decision-making.** In this regard, we would encourage the Department to reconsider the recommendations of the Swiss National Advisory Commission on Biomedical Ethics and the UN Special Rapporteur on Torture, both of which concluded that the inclusion of psychosocial rationale promotes involuntary or coerced, medically unnecessary treatment that often causes severe and irreversible harm to intersex people and their families. The Swiss and UN documents both recommend the criminalisation of psychosocially motivated surgeries. We support the adoption of this measure in Australia. The Department's current permission for psychosocially motivated surgeries has the unintended consequences of condoning some procedures on intersex people that would be classified as genital mutilation in 'females' and providing a loophole for health professionals to avoid prosecution merely by labelling treatments as "therapeutic".

We recommend that the Victorian Department of Health consult with the Alliance and our intersex-focused Member Organisations on revisions to the *Principles* in the near future. We appreciate your consideration of the above concerns and invite you to contact our Health Policy Officer, Mr Gávi Ansara

Yours sincerely

Warren Talbot
GENERAL MANAGER

Cc: Alliance Members