



Law Council
OF AUSTRALIA

Response to Consultation Paper

Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions

Australian Human Rights Commission

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About the Law Council of Australia

The Law Council of Australia exists to represent the legal profession at the national level, to speak on behalf of its Constituent Bodies on national issues, and to promote the administration of justice, access to justice and general improvement of the law.

The Law Council advises governments, courts and federal agencies on ways in which the law and the justice system can be improved for the benefit of the community. The Law Council also represents the Australian legal profession overseas, and maintains close relationships with legal professional bodies throughout the world.

The Law Council was established in 1933, and represents 16 Australian State and Territory law societies and bar associations and the Law Firms Australia, which are known collectively as the Council's Constituent Bodies. The Law Council's Constituent Bodies are:

- Australian Capital Territory Bar Association
- Australian Capital Territory Law Society
- Bar Association of Queensland Inc
- Law Institute of Victoria
- Law Society of New South Wales
- Law Society of South Australia
- Law Society of Tasmania
- Law Society Northern Territory
- Law Society of Western Australia
- New South Wales Bar Association
- Northern Territory Bar Association
- Queensland Law Society
- South Australian Bar Association
- Tasmanian Bar
- Law Firms Australia
- The Victorian Bar Inc
- Western Australian Bar Association

Through this representation, the Law Council effectively acts on behalf of more than 60,000 lawyers across Australia.

The Law Council is governed by a board of 23 Directors – one from each of the constituent bodies and six elected Executive members. The Directors meet quarterly to set objectives, policy and priorities for the Law Council. Between the meetings of Directors, policies and governance responsibility for the Law Council is exercised by the elected Executive members, led by the President who normally serves a 12 month term. The Council's six Executive members are nominated and elected by the board of Directors.

Members of the 2018 Executive as at 1 January 2018 are:

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The Secretariat serves the Law Council nationally and is based in Canberra.

Acknowledgement

The Law Council is grateful to the Queensland Law Society, the Law Society of New South Wales and the Law Society of South Australia for their assistance with the preparation of this submission, as well as input from its Family Law Section and National Human Rights Committee.

Executive Summary

1. The Law Council welcomes the opportunity to make a submission to the Australian Human Rights Commission (**AHRC**) in relation to its Consultation Paper *Protecting the Human Rights of People Born with Variations in Sex Characteristics in the context of Medical Interventions* (**Consultation Paper**).
2. The Law Council respects the assertion articulated in the Darlington Statement that intersex people 'are experts in [their] own lives and lived experience' and are therefore best placed to provide expertise on intersex issues.¹ Where possible, this submission draws on the views of intersex stakeholders consulted with during the course of the Law Council's Justice Project.²
3. This submission has also benefitted from input provided by several Law Council Constituent Bodies and Advisory Groups. The Law Council received responses to some, but not all, questions posed within the Consultation Paper. This submission therefore comments broadly on questions of oversight and policy that may improve practices affecting the human rights of people born with variations in sex characteristics.
4. In 2013, the Senate Committee on Community Affairs (**Senate Committee**) released a report on the *Involuntary or Coerced Sterilisation of Intersex People in Australia*. (**Senate Report**).³ In July 2017, the recommendations of the Senate Committee were endorsed in the Concluding Observations of the Fifth Periodic Report of Australia to the UN Committee on Economic, Social and Cultural Rights.⁴ These recommendations are yet to be implemented. The Law Council endorses a number of key recommendations contained in the Senate Report, as noted in the body of this submission.
5. The Law Council makes the following key recommendations in this submission:
 - Considering the strong human rights concerns associated with medical interventions performed on people born with variations in sex characteristics without the capacity to consent, judicial oversight over these decisions is required.
 - Nationally consistent clinical guidelines should be developed to guide medical decisions in this context. Generally, these guidelines should implement a human rights-based approach, which involves a holistic analysis of the best interests of the child and the rights of the child. A non-interventionist approach to medical interventions should be preferred until such time as the child has capacity to give informed consent. Guidelines should be drafted in consultation with key intersex stakeholders.
 - To address the lack of data and limited transparency with respect to medical interventions, a patient registry for intersex people should be developed, and research funded to investigate health outcomes for intersex patients.

¹ *Darlington Statement: Joint consensus statement from the intersex community retreat in Darlington, March 2017* (2017) [46] < <https://darlington.org.au/statement/>>.

² See generally, Law Council of Australia, *Justice Project: LGBTI+ People (Part 1)* (2018) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/Final%20Report/LGBTI%20People%20%28Part%201%29.pdf>.

³ Senate Standing Committee on Community Affairs, Parliament of Australia, *Involuntary or coerced sterilisation of intersex people in Australia* (2013).

⁴ Economic and Social Council, *Concluding observations on the fifth periodic report of Australia*, 47th mtg UN DOC E/C.12/AUS/5 (11 July 2017) [50]; Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%2020%20Aileen%20Kennedy.pdf>.

- To address the limited support services available to assist persons with variations in sex characteristics and their families, funding should be provided to legal assistance services and organisations capable of facilitating access to legal assistance services, as part of a multi-disciplinary servicing approach which responds holistically to legal and non-legal needs, including the need for peer support.

Terminology

6. Intersex is an umbrella term used to describe people born with a wide range of variations in sex characteristics. The Law Council has previously adopted the description of the UN High Commissioner for Human Rights:

*Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that are more diverse than stereotypical definitions for male or female bodies. For some people these traits are apparent prenatally or at birth, while for others they emerge later in life, often at puberty.*⁵

7. Appropriate classifications include 'people born with variations in sex characteristics', as well as terminology referring to 'intersex status' or 'intersex people'. Caution should be taken to avoid terminology that 'medicalises' this group or unnecessarily compounds existing stigma, such as use of the term 'disorders of sexual development'.⁶ As the Senate Report noted, while some people born with variations in sex characteristics may require medical intervention, being intersex does not necessarily involve a medical condition or any health risks.⁷

Human Rights Concerns

8. While intersex people make up a small percentage of the overall population, they are affected by acute and specific human rights concerns, in particular those associated with deferrable or non-essential medical interventions that are sometimes performed to alter the sex characteristics of infants and children without their informed consent.⁸
9. The Senate Report outlined concerns about current approaches that 'medicalise' intersex people and press for medical interventions, which are often justified as necessary for 'psychosocial' purposes despite not being medically required on the basis of concrete health risks. Psychosocial purposes generally refer to addressing ill-effects associated with 'looking different', and include factors such as 'minimising family concern, and mitigating the risks of stigmatisation'.⁹
10. While early intervention may be necessary on medical grounds in some cases, there is an increasing body of evidence that non-essential surgery should be used sparingly. A range of studies have found that non-therapeutic medical interventions to alter sex characteristics regularly lead to ongoing physical¹⁰ and psychological complications;¹¹

⁵ Office of the High Commissioner for Human Rights, *Intersex Awareness Day* (24 October 2016) <www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>; *Darlington Statement: Joint consensus statement from the intersex community retreat in Darlington, March 2017* (2017) <<https://darlington.org.au/statement/>>.

⁶ Senate Standing Committee on Community Affairs, Parliament of Australia, *the involuntary or coerced sterilisation of intersex people in Australia* (2013) [2.2].

⁷ *Ibid.*, [1.12].

⁸ These include non-therapeutic medical intervention performed in early childhood, including genital 'normalisation' procedures, sterilisation procedures and hormone treatments: Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%20Aileen%20Kennedy.pdf>.

⁹ Senate Standing Committee on Community Affairs, *Involuntary or coerced sterilisation of intersex people in Australia* (2013) [3.42, 3.53, 3.59, and 3.130].

¹⁰ Senate Standing Committee on Community Affairs, *Involuntary or coerced sterilisation of intersex people in Australia* (2013) [3.55]; See also Birgit Kohler et al, 'Satisfaction with genital surgery and sexual life of adults with XY disorders of sex development: results from the German clinical evaluation study', (2012) 97 *Journal of Clinical Endocrinology and Metabolism* 2.

¹¹ An Australian survey of intersex people identified high levels of depression and suicide ideation amongst participants, many of whom 'explicitly linked mental health struggles with the medical interventions that had

or, in the words of the National LGBTI Health Alliance, 'creat[e] a sickness when there was no sickness'.¹²

11. The Senate Report outlined the lack of medical consensus and research on the issue and concluded:

*Enormous effort has gone into assigning and 'normalising' sex: none has gone into asking whether this is necessary or beneficial. Given the extremely complex and risky medical treatments that are sometimes involved, this appears extremely unfortunate.*¹³

12. In addition to strong concerns regarding their medical or scientific justification, deferrable medical interventions to alter sex characteristics where informed consent cannot be obtained may breach a number of international human rights instruments ratified by Australia. The *Convention on the Rights of the Child* affirms at Article 24 the right of the child to the enjoyment of the highest attainable standard of health, and the Committee on the Rights of the Child has emphasised 'the rights of all adolescents to freedom of expression and respect for their physical and psychological integrity' and condemned 'forced surgeries or treatments on intersex adolescents'.¹⁴ Deferrable, non-therapeutic medical interventions to alter sex characteristics may also breach the *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*¹⁵ and the right to privacy affirmed by the *International Covenant on Civil and Political Rights*.¹⁶
13. UN treaty bodies and experts have raised concerns that medical interventions to alter sex characteristics of infants and children before they are able to provide informed consent breach fundamental human rights. In a 2018 report on Australia's compliance with the *Convention on the Elimination of Discrimination against Women*, the UN Committee on the Elimination of Discrimination against Women classified such interventions as a 'harmful practice' and called on the Australian Government to adopt clear legislative provisions explicitly prohibiting them.¹⁷ In 2017, the Committee on Economic, Social and Cultural Rights expressed concerns about Australian medical practice in this respect.¹⁸ Further, a 2013 report presented to the Human Rights Council by the Special Rapporteur on Torture stated that 'genital normalizing

been imposed on them in childhood'. Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%2020%20Aileen%20Kennedy.pdf> citing Tiffany Jones et al, *Intersex: Stories and Statistics from Australia* (Open Book Publishers, 2016) 122-3. See also Lisa Brinkmann, Karsten Schuetzmann and Hertha Richter-Appelt, 'Gender Assignment and Medical History of Individuals with Different Forms of Intersexuality: Evaluation of Medical Records and the Patients' Perspective', (2007) *The Journal of Sexual Medicine* 4, 977.

¹² Senate Standing Committee on Community Affairs, *the involuntary or coerced sterilisation of intersex people in Australia* (2013) [3.55].

¹³ Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%2020%20Aileen%20Kennedy.pdf>.

¹⁴ Committee on the Rights of the Child, *General comment No. 20 (2016) on the implementation of the rights of the child during adolescence* (6 December 2016), CRC/C/GC/20, 34.

¹⁵ Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez* (1 February 2013), 23rd session, agenda item 3, A/HRC/22/53, 76.

¹⁶ Anti-Slavery Australia et al, *Australia's Compliance with the International Covenant on Civil and Political Rights: Australian NGO coalition submission to the human rights committee* (2017) 82.

¹⁷ Committee on the Elimination of Discrimination against Women, *Concluding observations on the eighth periodic report of Australia* (20 July 2018), CEDAW/C/AUS/CO/8, 25.

¹⁸ Economic and Social Council, *Concluding observations on the fifth periodic report of Australia*, 47th mtg UN DOC E/C.12/AUS/5 (11 July 2017) Recommendations 49 and 50.

surgeries... are rarely medically necessary' and such surgeries 'arguably meet the criteria for torture, and they are always prohibited by international law'.¹⁹

Consent in the Absence of Legal Capacity

14. Unless court orders provide otherwise, parents and guardians have responsibility to make decisions for their child with respect to their long-term care and welfare. Parents and guardians continue to hold final decision-making power until it is determined that the child is *Gillick* competent. A child is classified as *Gillick* competent when they have demonstrated the requisite level of maturity and intelligence to understand and appraise the nature and implications of the proposed treatment, including the risks and alternate courses of action.²⁰
15. As noted in the Consultation Paper, in some cases, court oversight of medical procedures will be required, regardless of whether parental consent has been obtained, or whether the child is *Gillick* competent.²¹ *Marion's Case* outlined the limitations on parental authority in relation to procedures that are non-therapeutic, invasive or irreversible, or where there is significant risk that making a decision, which may be incorrect and irreparable, with grave consequences. These types of interventions are classified as 'special medical procedures'.²² The Family Court's 'Guidelines for Independent Children's Lawyers' (**Family Court Guidelines**) set out some guidance around *Gillick* competency and special medical procedures.²³
16. In cases where hospitals or parents have applied to the Family Court of Australia to seek authorisation for medical interventions, including 'normalising' surgical procedures, these have not been identified as 'special medical procedures' under *Marion's Case*.²⁴ As a result, these matters were left to be determined by parents or guardians, without being subject to judicial oversight.
17. Generally, there is a lack of clarity regarding the Family Court's role with respect to special medical procedures in the context of intersex medical interventions. The Family Court Guidelines do not offer a firm view of the law in this regard.²⁵ This contributes to confusion experienced by parties who are seeking to make a determination in these cases.
18. The 2016 case of *Re Carla* is an illustrative example. In this case, the Family Court made an order authorising the parents of a five-year-old girl to consent to her undergoing certain medical procedures, including a procedure to remove her gonads, which would also lead to sterilisation of the child.²⁶ The evidence before the court was

¹⁹ Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez* (1 February 2013), 23rd session, agenda item 3, A/HRC/22/53, 81.

²⁰ *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] (1985) 3 All ER 402 (HL).

²¹ Australian Human Rights Commission, *Consultation Paper on Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions* (2018), 15.

²² *Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] HCA 15.

²³ Family Court of Australia, *Guidelines for Independent Children's Lawyers* (2013) <<http://www.familycourt.gov.au/wps/wcm/connect/fcoaweb/about/policies-and-procedures/guidelines-independent-childrens-lawyer>>.

²⁴ Australian Human Rights Commission, *Consultation Paper on Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions* (2018), 15.

²⁵ Family Court of Australia, *Guidelines for Independent Children's Lawyers* (2013) <www.familycourt.gov.au/wps/wcm/connect/fcoaweb/about/policies-and-procedures/guidelines-independent-childrens-lawyer>.

²⁶ *Re Carla* (2016) 54 Fam LR 576; Human Rights Law Centre, *Queensland Family Court approves sterilising surgery on 5 year old intersex child* (20 January 2016) <www.hrlc.org.au/human-rights-case-summaries/2017/4/21/queensland-family-court-approves-sterilising-surgery-on-5-year-old-intersex-child>.

that as Carla's gonads were in the wrong place, she had a 28 percent increased risk that cancer would develop. However, other circumstances were considered, such as evidence that Carla had developed a female identity. At the time of the case, Carla had previously undergone surgery twice to enhance her female appearance without judicial oversight. The decision held that the Court's sanction was not required in the factual circumstances of the case, as the treatment was 'therapeutic'.²⁷

19. This judgment has been criticised by groups including Intersex Human Rights Australia and the Human Rights Law Centre for determining that judicial scrutiny was not required despite the serious implications of the procedure and for not sufficiently considering available medical literature about the potential negative consequences of these kinds of procedures.²⁸ The Human Rights Law Centre has explained why judicial oversight is important in such circumstances:

Many advocates believe that scrutiny and oversight for decisions made for medical treatment of infants born with intersex variations is absolutely necessary due to the severity of possible risks. Many of the gender-related procedures can cause permanent infertility, pain, incontinence, loss of sexual sensation, and lifelong mental suffering, including depression. Advocates also contend that given the procedures are performed when the child is too young to be part of the decision-making, they may violate the child's rights to physical integrity, to be [free] from torture and ill-treatment, and to live free from harmful practices.²⁹

20. The Senate Report emphasised the need for thorough and independent judicial oversight of these medical decisions and considered that all intersex medical interventions for people without capacity to provide informed consent should require authorisation beyond the managing clinicians. Specifically, it recommended that:

- *All proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.*
- *That civil and administrative tribunals be adequately funded and resourced to consider every intersex medical intervention proposed for a child.³⁰*

21. The Senate Report envisioned an approach where 'more common or routine procedures would have to adhere to agreed national guidelines before being authorised'.³¹ More complex procedures would be referred to a 'Special Medical Procedures Advisory Committee' that would provide expert guidance to the relevant tribunal or the Family Court.³²

²⁷ *Re Carla* (2016) 54 Fam LR 576, [49].

²⁸ Human Rights Law Centre, *Queensland Family Court approves sterilising surgery on 5 year old intersex child* (20 January 2016) <www.hrlc.org.au/human-rights-case-summaries/2017/4/21/queensland-family-court-approves-sterilising-surgery-on-5-year-old-intersex-child>; Aileen Kennedy, *Submission No 21* citing *Re Carla* (2016) 54 Fam LR 576 [2], [16]; Justice Project Consultation, 12/09/2017, Sydney (Intersex Human Rights Australia).

²⁹ Human Rights Law Centre, *Queensland Family Court approves sterilising surgery on 5 year old intersex child* (20 January 2016) <www.hrlc.org.au/human-rights-case-summaries/2017/4/21/queensland-family-court-approves-sterilising-surgery-on-5-year-old-intersex-child>.

³⁰ Senate Standing Committee on Community Affairs, *the involuntary or coerced sterilisation of intersex people in Australia*, (2013) Recommendations.

³¹ *Ibid*, [5.27].

³² *Ibid*, [5.27].

22. In giving consideration to the most appropriate forum for oversight, the Senate Report noted that the 'flexibility of tribunals is a significant benefit'.³³ However, it also considered that in cases of particular legal complexity, the Family Court may be best placed to assist, and it was reluctant to 'close this avenue of expertise'.³⁴
23. As identified in the Senate report, there is the potential for both the Family Court and tribunals to hear medical intervention cases. There are competing views within Law Council as to whether an administrative tribunal is an appropriate forum in which to determine intersex medical interventions. For example, the Queensland Law Society has noted that the Queensland Civil and Administrative Tribunal, which already deals with healthcare decisions relating to guardianship matters, and similar tribunals in other states and territories, may be an appropriate alternative to the Family Court for particular matters provided that adequate resourcing is made available to any such court or tribunal which is given this additional jurisdiction. It added that any new avenue created for judicial determination or review should include appropriately qualified adjudicators with experience in the field.
24. Conversely, the Family Law Section maintains the view that Family Court is best placed to deal with intersex medical interventions given its expertise in matters relating to children's rights and the particular skills and expertise of Family Court Judges in dealing with disputes concerning children. The Family Law Section further supports this view by noting that the Family Court has, by virtue of subsection 67ZC(1) of the *Family Law Act 1975* (Cth), assumed the common law *parens patriae* jurisdiction of the State Supreme Courts. This means it is the Family Court that has jurisdiction to make orders regarding the welfare of children, rather than the child's parents, for non-therapeutic medical interventions if the child is not *Gillick* competent. The Family Law Section notes that the Family Court is a federal court, meaning decisions made are more likely to be consistent (or have greater consistency) for all intersex children no matter which jurisdiction they reside in.
25. In its response to the Senate Report, the Commonwealth Government stated that:
- The question of whether or not bringing the medical treatment of intersex variations into the jurisdictions of guardianship tribunals would lead to better outcomes for intersex people is one that would benefit from further research and consideration....*³⁵
26. Since the Senate Report, there have been continued calls for the recommendations within it to be addressed, both internationally,³⁶ and domestically.³⁷ In 2018 the

³³ Ibid, [5.27].

³⁴ Ibid, [5.29].

³⁵ Australian Government, *Australian Government response to the Senate Community Affairs References Committee reports: Involuntary or coerced sterilisation of people with disabilities in Australia, Involuntary or coerced sterilisation of intersex people in Australia* (2015), 19 <www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Government_Response>.

³⁶ See Economic and Social Council, *Concluding observations on the fifth periodic report of Australia*, 47th mtg UN DOC E/C.12/AUS/5 (11 July 2017) Recommendations 49 and 50; UN Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez* (1 February 2013), 23rd session, agenda item 3, A/HRC/22/53.

³⁷ See eg *Darlington Statement: Joint consensus statement from the intersex community retreat in Darlington, March 2017* (2017) <<https://darlington.org.au/statement/>>; Intersex Human Rights Australia, *NSW Legislative Council calls for implementation of Senate report on sterilisation* (2014) <<https://ihra.org.au/28073/nsw-motion-iad-2014/>>; Emma Cornish, *Health Alliance calls for implementation of Intersex Report* (22 November 2013) <<http://www.lotl.com/News/Health-Alliance-calls-for-implementation-of-Intersex-Report/>>; Edward Santow, *Intersex Rights are Human Rights*, Australian Human Rights Commission (26 October 2017) <www.humanrights.gov.au/news/stories/intersex-rights-are-human-rights>.

Australian Law Reform Commission in its Issues Paper on the Review of the Family Law System stated that it had received concerns about approaches taken by the welfare jurisdiction of the family court towards intersex children, raised *Re Carla* as an illustrative example, noted the Senate Report, and called for responses on this issue.³⁸

Recommendation:

- **The following Senate Report recommendation should be implemented:**
 - **Recommendation 5: In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, oversight of these decisions is required.**

National Guidelines

27. There are no national guidelines in Australia outlining an approach to medical interventions performed on people with variations in sex characteristics. The Senate Report recognised the need for national guidelines informed by human rights frameworks to guide medical decisions, and made the following recommendations:

The committee recommends that all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.

*The committee recommends that the special medical procedures advisory committee draft guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles. These guidelines should be reviewed on an annual basis.*³⁹

28. The Law Council endorses these recommendations. Generally, it considers that the clinical approach to treatment of people born with variations in sex characteristics as outlined in national guidelines, should implement a human rights based approach, which involves a holistic analysis of the best interests of the child and the rights of the child, with a focus on the long-term health and wellbeing of the child. A non-interventionist approach should be preferred until such time as the child has capacity to give informed consent.
29. Further, the Law Council notes the position of the Australian Medical Association (**AMA**) which reports that there are no known benefits of genital surgery undertaken for cosmetic reasons and warns that a range of potential complications and adverse outcomes are associated with these procedures.⁴⁰ It advises that genital surgery for cosmetic purposes should not be undertaken on children or adolescents under the age of 18, and cautions that normalising cosmetic surgery on intersex infants should be

³⁸ Australian Law Reform Commission, *Review of the Family Law System*, Issues Paper 48 (2018) 45-46.

³⁹ Senate Standing Committee on Community Affairs, *Involuntary or coerced sterilisation of intersex people in Australia* [3.130].

⁴⁰ Australian Medical Association, *Position Statement on Sexual and Reproductive Health* (2014) <<https://ama.com.au/position-statement/sexual-and-reproductive-health-2014>>.

avoided until a child can fully participate in decision making.⁴¹ On non-intersex girls, the carrying out of non-emergency genital surgery such as female genital mutilation is a criminal offence in all states and territories.⁴² Therefore, there are strong grounds for national guidelines to specifically recommend against 'normalising' genital surgery until a child is capable of consent.

30. The following considerations could also usefully be incorporated into national guidelines:

- (a) direction regarding the types of procedures and scenarios where judicial oversight is necessary;
- (b) specific guidelines on the treatment of different types of variations in sex characteristics as distinct components of the overall national guidelines;
- (c) provisions for peer support and access to information for children, parents and guardians;
- (d) appropriate direction for clinicians, parents, guardians and patients with respect to a patient who either can and cannot give consent; and
- (e) a requirement for dialogue to be commenced with the child by appropriately qualified medical and psychological experts to assist the child in determining an outcome.

31. The Consultation Paper notes the Victorian Department of Health's 2013 *Decision-Making Principles for the care of infants, children and adolescents with intersex conditions* (**Victorian Principles**). The Victorian Principles endorse a set of ethical principles; human rights principles; principles for supporting parents and patients; and legal principles. It emphasises the need for great caution in 'normalising' surgery for a number of reasons, including that the need for it is strongly disputed by the intersex community.⁴³

32. The Victorian Principles do not go so far as to recommend against the use of genital normalising surgery until informed consent can be given, nor do they successfully create a clear approach to the imposition of treatment with respect to particular circumstances. However, they may be a good starting point upon which to base the development of nationally consistent clinical guidelines.

33. In its response to the Senate Report, the Commonwealth Government highlighted that provision of medical care is 'generally a state and territory responsibility' and substantive regulation of medical treatment is therefore a matter for state and territory governments.⁴⁴ In this regard, the Commonwealth Government encouraged state and territory governments to:

⁴¹ Ibid.

⁴² Australian Government, Attorney-General's Department, *Review of Australia's Female Genital Mutilation Framework* (2013) 12
<www.ag.gov.au/Publications/Documents/ReviewofAustraliasfemalegenitalmutilationlegalframework/Review%20of%20Australias%20female%20genital%20mutilation%20legal%20framework.pdf>.

⁴³ Victorian Department of Health, *Decision-Making Principles for the care of infants, children and adolescents with intersex conditions* (2013)
<www2.health.vic.gov.au/about/publications/policiesandguidelines/Decisionmaking-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions>.

⁴⁴ Commonwealth, *Parliamentary Debates*, Senate, 17 June 2015, 3755-3769 (Senator Fifield).

[R]eview the Victorian Decision-making principles for the care of infants, children and adolescents with intersex conditions, and consider adopting or developing specific principles for their jurisdiction in consultation with intersex support groups and medical experts as appropriate.⁴⁵

34. However, no state or territory government besides Victoria has yet adopted guidelines or principles to protect the rights of children born with variations in sex characteristics in the context of medical interventions. Moreover, states and territories developing guidelines in isolation could lead to an inconsistent approach as between jurisdictions. The Commonwealth Government should therefore raise the issue with state and territory governments, and coordinate the process of developing national guidelines. It is submitted that the Commonwealth Government has a responsibility to promote a consistent, human rights based approach to this issue between jurisdictions, in light of Australia's obligations under international human rights treaties.
35. National Guidelines could foreseeably be developed by a 'Special Medical Procedures Advisory Committee' as envisioned by the Senate Report, or otherwise by a similarly styled committee consisting of both medical and non-medical experts.
36. The development of guidelines should include thorough consultation with key stakeholders, including for example, patient and support organisations and individuals who are able to impart lived experiences. Contributors who assisted in the development of the Darlington Statement are a valuable reference of key groups in this respect.

Recommendations:

- **The following Senate Report recommendations should be implemented:**
 - **Recommendation 3: All medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.**
 - **Recommendation 9: The special medical procedures advisory committee draft guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles. These guidelines should be reviewed on an annual basis.**
- **Further, national guidelines should be drafted in consultation with intersex stakeholders.**

Access to Medical Records and Lack of Data

37. There are no firm figures available for intersex people in Australia, and estimates vary widely. The Senate Report cited the Australasian Paediatric Endocrine Group which indicated incidences in the realm of '1 in 125 boys for a mild variant, to 1 in 4,500

⁴⁵ Ibid, 3755-3769 (Senator Fifield).

babies where genitalia appear significantly ambiguous at birth such that the sex of the infant is unable to be immediately determined'.⁴⁶ Intersex Human Rights Australia estimates that intersex people make up 1.7 per cent of all births.⁴⁷

38. The Consultation Paper notes the existing lack of data and evidence about the number and types of medical interventions occurring in Australia, and limited evidence and understanding with respect to the long-term outcomes of intervention, as well as outcomes of not undertaking medical interventions.⁴⁸ The AHRC has also previously noted 'an overall absence of policy regarding intersex people'.⁴⁹
39. Intersex stakeholders consulted during the Law Council's Justice Project expressed strong concerns about a perceived lack of transparency in the health sector that impacts on recognition of intersex people and their health and justice needs. They called for the establishment of an intersex patient registry, unrestricted access to medical records for intersex people, and disclosure of data on medical interventions, both current and historic.⁵⁰
40. Aileen Kennedy, a lecturer from the University of New England's law school, in her submission to the Law Council's Justice Project, referred to the 'legal and medical erasure of intersex, including the failure to establish and maintain a patient registry'.⁵¹ A patient registry 'could ensure adequate recording and reporting of information on diagnoses and procedures, and ensure access to justice'.⁵² Kennedy also emphasised that a lack of an evidence base and genuine consultation with intersex organisations has led to 'government making policy without knowing who the population is'.⁵³
41. In this regard, the Senate Report recommended that:
- The Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients.*⁵⁴
42. A complementary step would be to ensure intersex considerations are integrated into broader data collection methodology. The National LGBTI Health Alliance has noted issues with data integrity in government surveys, medical research and clinical settings as they rarely account for non-binary people in their methodology and forms and sometimes engage in 'misgendering'.⁵⁵

⁴⁶ Senate Standing Committee on Community Affairs, Parliament of Australia, *the involuntary or coerced sterilisation of intersex people in Australia* (2013) [1.14] quoting Australasian Paediatric Endocrine Group, submission 88.

⁴⁷ Intersex Human Rights Australia, *On the Number of Intersex People*

<www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features10July+2013>.

⁴⁸ Australian Human Rights Commission, *Consultation Paper on Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions* (2018), 22.

⁴⁹ Australian Human Rights Commission, National Consultation Report, *Resilient Individuals: Sexual Orientation Gender Identity & Intersex Rights*, (2015), 57.

⁵⁰ Justice Project Consultation, 12/09/2017 Sydney (Intersex Human Rights Australia); Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%2020%20Aileen%20Kennedy.pdf>.

⁵¹ Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <<https://www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%2020%20Aileen%20Kennedy.pdf>> citing Senate Standing Committee on Community Affairs, Parliament of Australia, *the involuntary or coerced sterilisation of intersex people in Australia* (2013).

⁵² Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%2020%20Aileen%20Kennedy.pdf>.

⁵³ Justice Project Consultation, 12/09/2017, Sydney (Intersex Human Rights Australia).

⁵⁴ Senate Standing Committee on Community Affairs, *the involuntary or coerced sterilisation of intersex people in Australia*, (2013) Recommendations.

⁵⁵ Gávi Ansara, *Making the Count: Addressing Data Integrity Gaps in Australian Standards for Collecting Sex and Gender Information* (White Paper, National LGBTI Health Alliance, 2016).

Recommendation:

- **The following Senate Report recommendation should be implemented:**
 - **Recommendation 13: The Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients.**

Access to Support Services and Peer Support

43. While this submission makes several recommendations which involve minimal or no cost, it also includes a recommendation which calls for government expenditure. This reflects the Law Council's findings in the Justice Project that it is often the right people and services, rather than law or policy reform on its own, which make the critical difference to people in need.

44. There is presently limited medical, psychological, legal and support services available to assist persons with variations in sex characteristics and their families. The Darlington Statement drew attention to the fact that:

Intersex peer support remains largely unfunded, advocacy funding remains precarious and limited, and intersex-led organisations rely on volunteers to address the many gaps in services left by other, well-resourced health, social services and human rights institutions.⁵⁶

45. Intersex Human Rights Australia is an advocacy and support organisation that receives no public funding and relies on philanthropic support.⁵⁷ In consultation with the Law Council, it observed that parents and intersex children primarily need access to peer support, and community organisations could usefully be funded to provide information and support in this context.⁵⁸ Early peer support and access to information is necessary to inform parents and individuals about factors and risks relevant to medical decision-making, and therefore ensure their informed consent.⁵⁹

46. Parents of intersex children may not seek advice or legal assistance about their children's needs and interests, as a result of a history of silence, stigma, and limited information about intersex issues.⁶⁰ Intersex Human Rights Australia observed the intense pressure for children to be 'normal', and associated fear of difference, which feeds into parental decision-making.⁶¹ The provision of educational material, resources and peer support to parents at an early stage, may help to eliminate some of this fear.

47. Intersex people and their families may also require legal assistance to challenge medical decisions, participate in test cases, or to seek redress for improperly made

⁵⁶ *Darlington Statement: Joint consensus statement from the intersex community retreat in Darlington, March 2017* (2017) preamble <<https://darlington.org.au/statement/>>.

⁵⁷ Justice Project Consultation, 12/09/2017, Sydney (Intersex Human Rights Australia); Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%2020%20Aileen%20Kennedy.pdf>.

⁵⁸ Justice Project Consultation, 12/09/2017, Sydney (Intersex Human Rights Australia).

⁵⁹ *Ibid.*

⁶⁰ *Ibid.*

⁶¹ *Ibid.*

decisions.⁶² Additionally, they may require assistance to obtain their medical records from hospitals.⁶³ Parents or guardians may also require legal advice regarding registration of sex at birth.⁶⁴ A 2011 survey by the Inner City Legal Centre highlighted the need for legal advice to be provided to gender diverse and intersex people who wish to change their legal identity documents.⁶⁵

48. Ideally, organisations such as Intersex Human Rights Australia should have sufficient public resourcing to facilitate access to peer support, legal advice and social work for families facing medical intervention decisions, at the earliest opportunity.⁶⁶ The Senate Report recommended that ‘intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases’.⁶⁷

49. Gender services and clinics may also require greater resourcing and expansion to address the support needs of people born with variations in sex characteristics and their families. One example of such a clinic is the Lady Cilento Children’s Hospital Gender Team in Queensland which provides support for children and families from a multi-disciplinary health-team and is guided by an internal ethics committee. The Queensland Law Society noted that there is a severe lack of funding for the clinic, and as a result it is unable to provide the necessary services to a number of young people and their families who seek assistance.

Recommendation:

- **To address the limited support services available to assist persons with variations in sex characteristics and their families, funding should be provided to legal assistance services and organisations capable of facilitating access to legal assistance services, as part of a multi-disciplinary servicing approach which responds holistically to legal and non-legal needs, including the need for peer support.**

⁶² Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%20%20Aileen%20Kennedy.pdf>.

⁶³ Aileen Kennedy, *Submission No 21 to the Justice Project* (2017) <www.lawcouncil.asn.au/files/web-pdf/Justice%20Project/JP%20Submissions/S21%20-%202017%2009%20%20Aileen%20Kennedy.pdf>; Senate Standing Committee on Community Affairs, Parliament of Australia, *the involuntary or coerced sterilisation of intersex people in Australia* (2013) [3.125].

⁶⁴ Intersex Human Rights Australia, *Intersex Legislative Issues* (2012) <<https://ihra.org.au/21053/intersex-legislative-issues/>>; Justice Project Consultation, 12/09/2017, Sydney (Intersex Human Rights Australia).

⁶⁵ Inner City Legal Centre, *Outing Injustice* (December 2011), 31 <www.iclc.org.au/outinginjustice/>.

⁶⁶ Justice Project Consultation, 12/09/2017, Sydney (Intersex Human Rights Australia).

⁶⁷ Senate Standing Committee on Community Affairs, Parliament of Australia, *the involuntary or coerced sterilisation of intersex people in Australia* (2013) Recommendations.