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## Shadow Report submission: Australia

### 1 About this report

This Report is submitted by **Intersex Human Rights Australia (IHRA)**, a national organisation run by and for people born with intersex variations. Formerly known as Organisation Intersex International (OII) Australia, IHRA is a not-for-profit company, with charitable status. The submission was written by co-executive director Morgan Carpenter, M.Bioeth. (Sydney), with input from the board and members of IHRA. Contact [morgan.carpenter@ihra.org.au](mailto:morgan.carpenter@ihra.org.au)

This submission is endorsed by:

The **Androgen Insensitivity Syndrome Support Group Australia (AISSGA)**, a peer support, information and advocacy group by and for people affected by androgen insensitivity syndrome (AIS) and/or related intersex variations and variations of sex characteristics, and their families: <http://aissga.org.au>

**Disabled People's Organisations Australia (DPO Australia)**, a national coalition of Disabled People's Organisations, which are run by and for people with disability and grounded in a normative human rights framework: <http://www.dpoa.org.au>

The **National LGBTI Health Alliance**, the national peak health organisation in Australia for organisations and individuals that provide health-related programs, services and research focused on lesbian, gay, bisexual, transgender, and intersex people (LGBTI) and other sexuality, gender, and bodily diverse people and communities: <http://lgbtihealth.org.au>

**People with Disability Australia (PWDA)**, a national disability rights and advocacy organisation, and member of DPO Australia. PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also have a large associate membership: <http://pwd.org.au>

The report may be published.

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### 3 Summary

The Convention on the Rights of the Child (CRC) sets out obligations to recognise the human rights of children.<sup>1</sup> The joint CRC and CEDAW General Comment 18 calls for the elimination of harmful practices.<sup>2</sup>

A pattern of human rights abuses on infants, children and adolescents born with intersex traits occurs in Australia, without effective, independent oversight, often based on gender stereotypes, and lacking a scientific basis. Evidence of such practices includes the 2016 Family Court of Australia case *Re: Carla (Medical procedure)* which facilitated the unnecessary sterilisation of a 5-year old child. Incidental disclosure in that child's medical history of a clitorrectomy and labioplasty was described by the judge as follows:

*Surgery already performed on Carla has enhanced the appearance of her female genitalia*<sup>3</sup> (at [2])

*In 2014, Carla underwent two operations. In March that year, Dr B, performed a 'clitoral' recession and labioplasty to feminise Carla's external appearance.* (at [16])

The judgment cites “Minnie Mouse underwear”, “glittery sandals”, “Barbie bedspreads” and other gender stereotypes (at [15]) in support of the sterilisation of the child.

Harmful practices occur despite rhetoric by Australian governments that denies or asserts changes to clinical practices, and that asserts recognition and valuing of intersex people.<sup>4</sup>

A 2013 Senate committee inquiry made recommendations for change to clinical practice. The Australian government has rejected those recommendations; federal and State governments have failed to act. The Family Court has been unable to perform an independent role sought by the Senate inquiry. A 2017 intersex community consensus statement defines a set of demands, the *Darlington Statement*, in response.<sup>5</sup>

We urge the Committee to make strong recommendations in line with its prior recommendations,<sup>6</sup> and those of other Treaty Bodies.

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<sup>1</sup> United Nations. Convention on the Elimination of All Forms of Discrimination against Women. 1981. <http://www.ohchr.org/Documents/ProfessionalInterest/cedaw.pdf>.

<sup>2</sup> CEDAW, CRC. Joint general recommendation No. 31 of the CEDAW/general comment No. 18 of the CRC on harmful practices. 2014. Report: CEDAW/C/GC/31-CRC/C/GC/18.

<sup>3</sup> Family Court of Australia. *Re: Carla (Medical procedure)* [2016] FamCA 7.

<http://www.austlii.edu.au/cgi-bin/sinodisp/au/cases/cth/FamCA/2016/7.html>

<sup>4</sup> Carpenter M. The human rights of intersex people: addressing harmful practices and rhetoric of change. *Reproductive Health Matters*. 2016;24(47):74–84.

<sup>5</sup> AISSGA, ITANZ, IHRA, Black E, Bond K, Briffa T, et al. *Darlington Statement*. 2017.

<https://darlington.org.au/statement>

<sup>6</sup> Similar wording in CRC/C/NZL/CO/5, 2016, para 25, and CRC/C/ZAF/CO/2, 2016, paras. 39 to 40.

## 4 Recommendations

We respectfully request that the Committee asks the government of Australia to recall “Joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child on harmful practices”<sup>7</sup> and:

1. Ensure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guaranteeing the rights of children to bodily integrity, autonomy and self-determination.<sup>8</sup>
2. Specifically, to “Adopt clear legislative provisions explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children before they reach the legal age of consent, implement the recommendations of the 2013 Senate inquiry on involuntary or coerced sterilisation of intersex persons”.<sup>7</sup>
3. Promptly investigate incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions to provide redress to victims of such treatment, including adequate compensation.<sup>8</sup>
4. Provide families with intersex children with adequate independent counselling and support.<sup>9</sup>
5. Educate and train medical and psychological professionals on the range of biological and physical sexual diversity and on the consequences of unnecessary surgical and other medical interventions on intersex children.<sup>8</sup>
6. Develop and implement a transparent human rights and child rights-based health-care protocol for intersex children, setting the procedures and steps to be followed by health teams.<sup>8</sup>

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<sup>7</sup> From CEDAW/C/AUS/CO/8, 2018, para 26

<sup>8</sup> Similar wording in CRC/C/NZL/CO/5, 2016, para 25

<sup>9</sup> Similar wording in CRC/C/NZL/CO/5, 2016, para 25, with the addition of the word “independent”

## 5 Intersex people

IHRA defines intersex people in line with a 2016 statement by human rights experts, published by the OHCHR:

*Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit the typical definitions for male or female bodies.<sup>10</sup>*

We acknowledge the diversity of intersex people in our identities, legal sexes assigned at birth, genders, gender identities, and the words we use to describe our bodies. At least 40 different intersex variations are known,<sup>11</sup> most genetically determined. Clinicians frequently use a stigmatising label, “Disorders of Sex Development” (“DSD”), referring to intersex variations.

## 6 Human rights framework

### 6.1 The international human rights framework

The 1948 Universal Declaration of Human Rights states that all “human beings are born free and equal in dignity and rights” (article 1), “without distinction of any kind” (article 2).<sup>12</sup> In September 2015, the then UN High Commissioner for Human Rights commented:

*Those foundational, bedrock principles of universality and equality mean that all of us, without exception, and regardless of our sex characteristics, are equally entitled to the protections of international human rights law.<sup>13</sup>*

In 2013, the then Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, condemned “irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed [on intersex children] without their informed consent, or that of their parents, ‘in an attempt to fix their sex’, leaving them with permanent, irreversible infertility and causing severe mental

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<sup>10</sup> OHCHR, et al. End violence and harmful medical practices on intersex children and adults, UN and regional experts urge. 2016.

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

<sup>11</sup> Hiort O. I-03 DSDnet: Formation of an open world-wide network on DSD at clinician conference, “4th I-DSD Symposium”. 2013. [http://www.gla.ac.uk/media/media\\_279274\\_en.pdf](http://www.gla.ac.uk/media/media_279274_en.pdf)

<sup>12</sup> United Nations, Office of the High Commissioner for Human Rights. Universal Declaration of Human Rights [Internet]. [cited 2015 Nov 26]. Available from:

[http://www.ohchr.org/EN/UDHR/Documents/UDHR\\_Translations/eng.pdf](http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf)

<sup>13</sup> United Nations High Commissioner for Human Rights. Opening remarks by Zeid Ra’ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert meeting on ending human rights violations against intersex persons [Internet]. 2015 [cited 2015 Sep 16]. Available from:

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E>

suffering.”<sup>14</sup> The Committee on the Rights of the Child has described such interventions in similar terms,<sup>15</sup> including in relation to practices by our neighbour, New Zealand.<sup>16</sup>

Kirsten Sandberg, a member and former chair of the UN Committee on the Rights of the Child has written on the human rights issues engaged by discrimination and medical interventions on children born with variations in sex characteristics, identifying relevant cross-cutting “general principles”, in addition to specific provisions in the CRC:

*These are Article 2 on the right to non-discrimination, Article 3 no. 1 on the best interests of the child, Article 6 on the right to life, survival and development and Article 12 on the right to be heard. The right not to be discriminated against because of an intersex condition is a different issue from the question of whether or not a child should undergo surgery and other forms of treatment for its intersex condition.*

*Other relevant CRC provisions are Article 24 on the right to health, Article 8 on the right to identity, Article 16 on the right to private life, Article 19 on protection from all forms of violence, and Article 24(3) on harmful practices<sup>17</sup>*

Committee on the Rights of the Child General Comment 14 “on the right of the child to have his or her best interests taken as a primary consideration” states:

*34. The flexibility of the concept of the child’s best interests allows it to be responsive to the situation of individual children and to evolve knowledge about child development. However, it may also leave room for manipulation; the concept of the child’s best interests has been abused by Governments and other State authorities to justify racist policies<sup>18</sup>*

The Committee on the Rights of the Child General Comment 13 on “Article 19: The right of the child to freedom from all forms of violence” states that interpretations of best interests ‘cannot be used to justify practices ... which conflict with the child’s human dignity and right to physical integrity’:

*54. Article 3 (Best interests of the child): The Committee emphasizes that the interpretation of a child’s best interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence. It cannot be used to justify practices, including corporal punishment and other forms of cruel or degrading punishment, which conflict with the child’s human dignity and right to physical integrity. An adult’s judgment of a*

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<sup>14</sup> A.HRC.22.53. 2013, 1 February 2013

<sup>15</sup> For example, in CRC/C/GBR/CO/5, 3 June 2016

<sup>16</sup> CRC/C/NZL/CO/5, 7 October 2016

<sup>17</sup> Sandberg K. Intersex Children and the UN Convention on the Rights of the Child. In: Scherpe J, Dutta A, Helms T, editors. The Legal Status of Intersex Persons, Cambridge, England: Intersentia; 2018, p. 515–48.

<sup>18</sup> CRC/C/GC/14, 29 May 2013

*child's best interests cannot override the obligation to respect all the child's rights under the Convention*<sup>19</sup>

The joint CRC/CEDAW General Comment on harmful practices recognises “sex- and gender-based attitudes and stereotypes, power imbalances, inequalities and discrimination perpetuate the widespread existence of practices that often involve violence or coercion... justified by invoking sociocultural and religious customs and values” and misconceptions.<sup>2</sup> Further:

*many women and children increasingly undergo medical treatment and/or plastic surgery to comply with social norms of the body, rather than for medical or health reasons*<sup>2</sup>

The General Comment remarks on “legal provisions that justify, allow or lead to harmful practices” and lack of adequate or effective scrutiny by State and judicial bodies.<sup>2</sup> These issues are evident in treatment of intersex children.

Many UN Treaty Bodies, including the CRC, have already commented on harmful practices on intersex infants, children, adolescents and adults. For example, in 2015 the Committee on the Rights of People with Disabilities (“CRPD”) asked Germany to implement 2011 recommendations on the rights of intersex people made by the Committee Against Torture (“CAT”),<sup>20</sup> including proper informed consent, investigation and redress, and provider training.<sup>21</sup> We note that action remains awaited in Germany, and the Committee on the Elimination of All Forms of Discrimination against Women made similar recommendations in 2017.<sup>22</sup> Progress to implement Treaty Body recommendations has been slow worldwide.

Australia is no exception to this. In a list of issues prior to reporting for the Australian government in 2016, the UN Committee against Torture cited article 16, asking the government to “provide information on the efforts made towards prohibiting the use of sterilisation without the prior, free and informed consent of the person concerned in all Australian jurisdictions”, asking “how does the State party guarantee that full, free and informed consent of the persons concerned is ensured” and how access to remedies is ensured.<sup>23</sup> In mid 2017, the Committee on Economic, Social and Cultural Rights cited article 12 and recommended implementation of the 2013 Senate report.<sup>24</sup>

At the end of 2017, the UN Human Rights Committee responded to concerns regarding practices in Australia, concluding the government should:

*26. ...move to end irreversible medical treatment, especially surgery, of intersex infants and children, who are not yet able to provide fully informed*

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<sup>19</sup> CRC/C/GC/13, 17 February 2011

<sup>20</sup> CAT/C/DEU/CO/5, 12 December 2011

<sup>21</sup> CRPD/C/DEU/CO/1, 17 April 2015

<sup>22</sup> CEDAW/C/DEU/CO/7-8, 3 March 2017

<sup>23</sup> CAT/C/AUS/QPR/6, December 2016

<sup>24</sup> E/C.12/AUS/CO/5, 23 June 2017

*and free consent, unless such procedures constitute an absolute medical necessity*<sup>25</sup>

In mid 2018, the Committee on the Elimination of Discrimination against Women made strong observations, within the context of the *Joint general recommendation* with the UN CRC. The Committee expressed concern at:

*25 ... (c) The conduct of medically unnecessary procedures on intersex infants and children before they reach an age when they are able to provide their free, prior and informed consent, and at inadequate support and counselling for families with intersex children and remedies for victims;*

And called for Australia to:

*26 ... (c) Adopt clear legislative provisions explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children before they reach the legal age of consent, implement the recommendations of the 2013 Senate inquiry on involuntary or coerced sterilisation of intersex persons, provide families with intersex children with adequate counselling and support, and provide redress to intersex persons having undergone medical treatment*<sup>26</sup>

To date, there is no indication of action to achieve these goals. In its submission to the CRC, the Australian government states, on page 27:

*The Australian Government is aware of recent decisions of the Family Court concerning medical treatment for intersex children, including Re Carla<sup>xlix</sup> and Re: Kaitlin.<sup>l</sup> The Australian Government recognises that protection of the rights of children with intersex variations is an issue that requires further consideration and is considering the implications of these decisions.*<sup>27</sup>

However, these statements are contradicted by other statements. In the same submission, and also in a later submission to CEDAW, the Australian government's submission comments:

*In 2013, an Australian Senate Committee completed an inquiry into the involuntary or coerced sterilisation of people with disability and intersex people, which made a range of recommendations. The Australian Government considered its recommendations but does not propose changes to existing arrangements.*<sup>28</sup>

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<sup>25</sup> Human Rights Committee. CCPR/C/AUS/CO/6.

<sup>26</sup> CEDAW/C/AUS/CO/8, 20 July 2018

<sup>27</sup> Attorney General's Department. Australia's joint fifth and sixth report under the Convention on the Rights of the Child, second report on the Optional Protocol on the sale of children, child prostitution and child pornography and second report on the Optional Protocol on the involvement of children in armed conflict. 2018.

<sup>28</sup> CEDAW/C/AUS/Q/8/Add.1, 22 March 2018

The government identified in its later submission to the CRPD that the Australian Law Reform Commission “is considering whether changes should be made to the Family Court’s welfare jurisdiction to support best outcomes for children, including intersex children”.<sup>29</sup> In its discussion paper for this review to the Family Law System, the Commission has questioned whether action on these issues should reside in, and be addressed by, the Family Law Act.<sup>30</sup>

## 6.2 Australian Senate inquiry

In 2013, the Senate held a committee inquiry into the involuntary or coerced sterilisation of people with disabilities, and of intersex people.<sup>31</sup> The inquiry process documented medical practices, including a public submission by the Australasian Paediatric Endocrine Group (APEG). That submission suggested there are clear indications for surgeries:

*Indications for surgery in DSD involve management of high cancer risk in the testes or ovaries, management of dysfunctional urine flow, creation of a vagina, or surgery for the purpose of appearance including reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis.*<sup>32</sup>

Management of high cancer risks and urinary issues should not be controversial. However, these issues are intertwined with non-therapeutic rationales for treatment. The Senate Committee was itself ‘disturbed’ by entwinement of different rationales in clinical reports.<sup>31</sup>

Regarding “Reconstructive reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis”, APEG states that:

*The purpose of these procedures is for functional reasons such as to allow a male individual to urinate while standing, and for psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing.*<sup>32</sup>

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<sup>29</sup> Attorney-General’s Department. Convention on the Rights of Persons with Disabilities: draft combined second and third periodic report. 2018.

<sup>30</sup> Australian Law Reform Commission. Review of the Family Law System: Discussion Paper. 2018. Para 9.108

<sup>31</sup> Senate Community Affairs References Committee. Involuntary or coerced sterilisation of intersex people in Australia. 2013.  
[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index)

<sup>32</sup> Australasian Paediatric Endocrine Group, Hewitt J, Warne G, Hofman P, Cotterill A. Regarding the Management of Children with Disorders of Sex Development. 2013.  
<http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>

These are cultural, not functional, requirements for cosmetic interventions. Subsequent to such interventions APEG notes:

*particular concern regarding sexual function and sensation*<sup>32</sup>

Beliefs underpinning medical interventions lack evidence and clear indications. For example, reflecting an earlier 2006 statement, a 2016 clinical review states:

*There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low ... There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.*<sup>33</sup>

In 2017, the Committee on Bioethics of the Council of Europe reported that no clinically-accepted standard of care:

*has emerged to explain, as a matter of science, how infant surgery will be certain to coincide with the child's actual identity, sexual interests, and desires for bodily appearance*<sup>34</sup>

In its 2013 report, the Senate committee found that:

*there is no medical consensus around the conduct of normalising surgery...*

*Normalising appearance goes hand in hand with the stigmatisation of difference...*

*There is frequent reference to 'psychosocial' reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child's avoidance of harassment or teasing, and the child's body self-image, there is great danger of this being a circular argument that avoids the central issues. Those issues include reducing parental anxiety, and ensuring social awareness and acceptance of diversity such as intersex. Surgery is unlikely to be an appropriate response to these kinds of issues.*<sup>31</sup>

The Senate report called for protocols and guidelines consistent with recommendations by IHRA (then named Organisation Intersex International Australia):

*3.129 The proposals put forward by Organisation Intersex International have merit, and are consistent with the committee's conclusions. The committee believes that a protocol covering 'normalising' surgery should be developed,*

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<sup>33</sup> Lee PA, Nordenström A, Houk CP, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics*. 2016;85(3):158–180.

<sup>34</sup> Zillén K, Garland J, Slokenberga S. 'The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties'. 2017.

*and then adhered to in all cases of intersex children. Such a guideline should be consistent with Organisational Intersex International's recommendations*<sup>31</sup>

Responding to the Senate inquiry, the federal government stated “the substantive regulation of medical treatment is a matter for state and territory governments”.<sup>35</sup> No Australian government has implemented the Senate committee recommendations.

### 6.3 Darlington Statement

The *Darlington Statement* is a 2017 community consensus statement by Australian and New Zealand intersex organisations and advocates.<sup>5</sup> Demands include:

- “**prohibition as a criminal act** of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent
- “mandatory independent access to funded counselling and peer support
- “appropriate **human rights- based, lifetime, intersex standards of care** with full and meaningful participation by intersex community representatives and human rights institutions
- “independent, effective **human rights-based oversight mechanism(s)** to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations”<sup>5</sup>

## 7 The unnecessary medicalisation of intersex bodies

### 7.1 A policy of concealment

Medical practices have historically – and may still currently – be grounded in a model of concealment. In 1998, Cheryl Chase discussed what Kipnis and Diamond consider an ‘epistemological black hole’ that Chase notes ‘precludes follow-up of intersex surgeries’:

*the purpose of surgery is to hide intersexuality, therefore intersexuals must be lied to about their histories and surgeries, and thus follow-up cannot be done because the patients would learn the truth.*<sup>36</sup>

In 2018, the New Zealand Office of the Privacy Commissioner stated:

*The recommended medical approach in the latter half of the twentieth century was to treat patients with ‘normalisation’ procedures, including*

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<sup>35</sup> Attorney General’s Department. Australian Government response to the Senate Community Affairs References Committee reports on involuntary or coerced sterilisation. 2015.

<sup>36</sup> Chase C. Surgical Progress Is Not the Answer to Intersexuality. *Journal of Clinical Ethics*. 1998;9(4):385–92.

*surgery, and to raise the individual according to their normalised sex, often without providing full information to the patient as they grew up. Over the past 15-20 years, leading health professionals internationally have advocated for talking with children and young people in age-appropriate ways about their diagnosis and any treatment they might have had. The extent to which this more open practice has been taken up in New Zealand seems to be variable, so some people will have grown up knowing about their diagnosis and treatment, while others will not.*<sup>37</sup>

Australia and New Zealand share medical and clinical associations, and the same variability exists in current practices in Australia. Additionally, individuals who exited the paediatric hospital system at age 18 during the existence of current or historic policies of concealment may remain unaware of the nature of medical interventions that they have experienced.

## **7.2 Partial information disclosure**

Parents may be told skewed and partial information about their child in ways that have a direct impact on the medical interventions experienced by their child. Streuli and others, for example, have identified how:

*Parental decisions concerning early sex assignment surgery for DSD children depend on the health professional counseling received, to a degree of which neither parents nor professionals appear fully aware.*<sup>38</sup>

In a 2018 clinical paper, Timmermans and others found that:

*Generally, as in our study, there is little evidence to suggest that the number of genital surgeries in DSD patients has declined since the 2005 consensus conference ... Due to their epistemic advantages and the presentation of surgery as a solution, clinicians boost their professional authority by strategically deploying uncertainties to steer the decision-making process.*<sup>39</sup>

They commented that: “Professional medical authority proves highly resilient and tends to lead to selective appropriation rather than capitulation” to attempts to reform clinical practice. “In other words, professionals may interpret and implement patient-centered care in self-serving ways.”

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<sup>37</sup> Blackwood V, Office of the Privacy Commissioner. Handling health information of intersex individuals [Internet]. Office of the Privacy Commissioner. 2018 [cited 2018 Mar 7]. Available from: <https://www.privacy.org.nz/blog/handling-health-information-of-intersex-individuals/>

<sup>38</sup> Streuli JC, Vayena E, Cavicchia-Balmer Y, Huber J. Shaping Parents: Impact of Contrasting Professional Counseling on Parents’ Decision Making for Children with Disorders of Sex Development: Parent Decision in Disorders of Sex Development. *The Journal of Sexual Medicine*. 2013 Aug;10(8):1953–60.

<sup>39</sup> Timmermans S, Yang A, Gardner M, Keegan CE, Yashar BM, Fechner PY, et al. Does Patient-centered Care Change Genital Surgery Decisions? The Strategic Use of Clinical Uncertainty in Disorders of Sex Development Clinics. *Journal of Health and Social Behavior* 2018;002214651880246. doi:[10.1177/0022146518802460](https://doi.org/10.1177/0022146518802460).

Furthermore, silence and secrecy mean that there is no longitudinal research underpinning irreversible clinical practices, their necessity, indications, timing or even evaluation.

### 7.3 Flawed rationales for medical intervention

Current protocols, set out in a 2006 Chicago 'Consensus statement on management of intersex disorders' suggested that: 'Appearance-altering surgery is not urgent' yet, at the same time, it states explicit rationales for 'early reconstruction' including 'minimizing family concern and distress' and 'mitigating the risks of stigmatization and gender-identity confusion'.<sup>40</sup>

Clinicians and parents may make decisions based upon delivery room distress,<sup>41</sup> and social and cultural bias. Julie Greenberg states that:

*safeguards are needed because parents may be making decisions at a time when they are suffering distress about giving birth to and raising an "abnormal" child. Under these circumstances, it is difficult for parents to objectively determine the treatment that would be in their child's long term best interests, especially because the issue may affect sexuality when the child becomes an adult.*<sup>42</sup>

In a clinical study of parents of intersex children, Dayner, Lee and Houk surveyed the perspectives of 21 parents of 17 children with XX sex chromosomes and congenital adrenal hyperplasia, finding that 100% of parents agreed surgery was 'done for more "natural looking" genitalia', and 95% 'would consent to surgery if adult sexual sensation reduced'.<sup>43</sup> However, Liao et al report that 'parental regret can be high',<sup>44</sup> and parents 'may not realise that they are de facto opting for experimental surgery on their children',<sup>44</sup> with no credible non-surgical treatment pathways. In 2016, a co-author of that editorial stated in a clinical conference abstract:

*Many multidisciplinary teams are led by surgeons committed to genital surgery. In addition complex invasive surgery may be reimbursed at high*

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<sup>40</sup> Houk CP, Hughes IA, Ahmed SF, Lee PA, Writing Committee for the International Intersex Consensus Conference Participants. Summary of Consensus Statement on Intersex Disorders and Their Management. PEDIATRICS. 2006;118(2):753–7.

<sup>41</sup> Department of Health and Human Services. Ambiguous genitalia in neonates [Internet]. 2015 [cited 2017 Apr 2]. Available from: <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-e-handbook/congenital-abnormalities/ambiguous-genitalia>

<sup>42</sup> Greenberg JA. Intersexuality and the Law: Why Sex Matters. New York: New York University Press; 2012.

<sup>43</sup> Dayner JE, Lee PA, Houk CP. Medical Treatment of Intersex: Parental Perspectives. Journal of Urology. 2004;172(4):1762–5.

<sup>44</sup> Liao L-M, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery. BMJ. 2015;351:h5124.

*tariffs for health care providers. Psychological support – although less costly – is often patchy or unavailable...*

*Credible non-surgical pathways with ongoing psychological support for the family currently do not exist.*<sup>45</sup>

We note from clinical literature published in 2016 that there remains no clinical consensus regarding indications, timing, procedure or evaluation of surgical interventions to ‘normalise’ intersex bodies. A ‘Global Disorders of Sex Development Update since 2006’ states regarding genital surgeries:

*There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low ... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.*<sup>46</sup>

In 2017, the Committee on Bioethics of the Council of Europe commissioned a report examining the rights of children in biomedicine. The report authors made extensive comments and citations, including citing clinical literature showing that:

*(1) “quality of life” studies on patients into adulthood are lacking and are “poorly researched”, (2) the overall impact on the sexual function on children surgically altered is “impaired” and (3) the claim that gender development requires surgery is a “belief” unsubstantiated by data...*

*On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion*<sup>47</sup>

The report of the Committee on Bioethics found that:

- *surgery ... in infancy [is done] on the assumption that parental rearing could steer gender development.*

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<sup>45</sup> Creighton S. Surgical Management of DSD: New Insights. 2016 Aug 19 [cited 2016 Aug 31]; Available from: <http://abstracts.eurospe.org/hrp/0086/hrp0086con1.2.htm>

<sup>46</sup> Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics*. 2016;85(3):158–180.

<sup>47</sup> Zillén K, Garland J, Slokenberga S, Committee on Bioethics of the Council of Europe. *The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties*. 2017.

- *all evidence-based reviews concur that gender identity and sexual orientation of children with differences in sex development cannot be predicted with accuracy*
- *the medical literature has not addressed the implications of whether clinicians and parents have a right to assign these identities surgically and irreversibly on children<sup>47</sup>*

It stated that no clinically-accepted standard of care:

*has emerged to explain, as a matter of science, how infant surgery will be certain to coincide with the child's actual identity, sexual interests, and desires for bodily appearance<sup>47</sup>*

Surgeries do not create 'normal' bodies: early surgeries create bodies that need further surgeries due to physical development during adolescence; sterilisations create bodies that have a lifelong need for hormone treatment; scarring creates visible difference; and all surgeries affect physical sensitivity.<sup>48</sup>

However, parents and individuals subjected to medical intervention may be unaware that early interventions lack firm evidence and lack clinical consensus. Parents and caregivers may also have no idea that early medical interventions may trigger a lifetime of medical interventions and surgeries.

#### **7.4 Flawed principles**

A 2010 framework for the treatment of intersex children was developed in Melbourne, Australia.<sup>49</sup> It claimed that psychosocial risks that can be minimised through medical intervention include:

- *Risk that child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding with associated negative consequences*
- *Risk of social or cultural disadvantage to child, for example, reduced opportunities for marriage or intimate relationships<sup>49</sup>*

The mention of marriage prospects is highly unusual, demonstrating similarity between rationales for intersex genital surgeries and rationales favouring FGM in countries where that practice remains a norm. As marriage in Australia excluded same-sex couples until December 2017, such rationales also promote a heterosexual ideal. The paper was criticised by some clinicians at the time, for example as:

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<sup>48</sup> See note 36 and: Australian Senate Community Affairs References Committee. Hearing: Involuntary or coerced sterilisation of people with disabilities in Australia. Thursday 28 March 2013, Hansard [Internet]. Canberra; Mar 28, 2013. Available from: <http://www.aph.gov.au/hansard>

<sup>49</sup> Gillam LH, Hewitt JK, Warne GL. Ethical Principles for the Management of Infants with Disorders of Sex Development. *Hormone Research in Paediatrics*. 2010;74(6):412–8.

*responding to the major DSD debate of a decade ago, namely over genital surgeries in infancy...*

*The authors have opted to ignore the existing DSD ethics literature in an effort to arrive at principles putatively unburdened by previous ethical engagement.<sup>50</sup>*

In 2013, a derivative framework was published by the State of Victoria, with limited community input.<sup>51</sup> Yet a Victorian Department currently (May 2018) states:

*Potential for cosmetic surgical correction of **ambiguous genitalia** for virilised[sic] females should be discussed with the endocrinologist. Most surgical correction is now delayed until 6 months of age or later.<sup>52</sup>*

That Department's current (May 2018) page on congenital adrenal hyperplasia (CAH) states:

*Girls with CAH may need surgery to reduce the size of the clitoris to normal, separate the fused labia and enlarge the vaginal entrance. The technical name for this operation is 'clitoral recession or reduction and vaginoplasty'. It is done either in one or two stages.*

*The clitoral reduction or recession is done in the first few months of life. The vaginoplasty is sometimes done at the same time as the clitoral reduction, but may be left until adolescence<sup>53</sup>*

Thus 2013 Victorian guidelines have not been binding on the State or its hospitals, have been disregarded in subsequent policy, and do not protect children's rights. Nevertheless, they were commended in the federal government response to the Senate report.<sup>35</sup>

Further, as the Senate report noted:

*3.98 One of the difficulties that is seldom discussed is how to establish what constitutes 'normal', particularly in relation to what genitals 'should' look like. Oll expressed concern about 'the absence of standard objective measures for cosmetic perceptions of "normal" female genitals'...*

*3.100 What little research exists regarding 'adequate' or 'normal' genitals, particularly for women, raises some disturbing questions ... The committee*

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<sup>50</sup> Dreger A, Sandberg DE, Feder EK. From Principles to Process in Disorders of Sex Development Care. *Hormone Research in Paediatrics*. 2010;74(6):419–20.

<sup>51</sup> Department of Health. Decision-making principles for the care of infants, children and adolescents with intersex conditions. 2013.

<sup>52</sup> Department of Health & Human Services. Congenital adrenal hyperplasia (CAH) in neonates. <https://www2.health.vic.gov.au:443/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-e handbook/conditions/congenital-adrenal-hyperplasia>

<sup>53</sup> Department of Health & Human Services. Congenital adrenal hyperplasia (CAH). 2014. <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/congenital-adrenal-hyperplasia-cah>

*received no information indicating whether or not this natural variation in genital size and shape is taken account of ...or how medical specialists learn about the diversity of appearance of genitals or how they define 'normal' in their clinical practice.<sup>31</sup>*

## 7.5 Data on rights violations

Lack of transparency underpins practices that violate children's human rights. Limited statistical information is available. Internationally, such data does not support any claims of changes to numbers of procedures over the period since 2006.<sup>54</sup>

In Australia, the Royal Children's Hospital Melbourne reported to the media in 2013 that it performs 10-15 "genital reconstruction operations a year often on girls under the age of two".<sup>55</sup> This hospital also reported that:

*It is our opinion that early surgery has psychological benefits for the child, as it allows them to grow up with more normally appearing genitalia, which reduces psychosocial and psychological stigma associated with DSD and also minimises parental anxiety<sup>56</sup>*

This opinion also lacks evidence, also stating:

*we acknowledge that outcomes related to current approaches remain to be established<sup>57</sup>*

In Sydney, "13 cases were brought to" a forum of the local children's hospital network in one year (2014/5), mostly to evaluate cancer risk, but also "Severely virilised females with CAH are also reviewed with regard to early versus late clitoral reduction and

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<sup>54</sup> Creighton SM, Michala L, Mushtaq I, Yaron M. Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same? *Psychology and Sexuality* 2014;5:34–43.

Klöppel U. Zur Aktualität kosmetischer Operationen „uneindeutiger“ Genitalien im Kindesalter. *Gender Bulletin* 2016.

Human Rights Watch. "I Want to Be Like Nature Made Me." 2017.

Timmermans S, Yang A, Gardner M, Keegan CE, Yashar BM, Fechner PY, et al. Does Patient-centered Care Change Genital Surgery Decisions? The Strategic Use of Clinical Uncertainty in Disorders of Sex Development Clinics. *Journal of Health and Social Behavior* 2018:002214651880246..

<sup>55</sup> Bock A. It takes more than two. *The Age*. 2013 Jun 20; <http://www.theage.com.au/national/it-takes-more-than-two-20130619-2oj8v.html>

<sup>56</sup> Royal Children's Hospital Melbourne. Submission of the Royal Children's Hospital Melbourne to the Senate Inquiry Into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development. Royal Children's Hospital Melbourne; 2013.

<sup>57</sup> Royal Children's Hospital Melbourne. Submission of the Royal Children's Hospital Melbourne to the Senate Inquiry Into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development. Royal Children's Hospital Melbourne; 2013.

vaginoplasty”.<sup>58</sup> This statement does not indicate the total number of presupposes that surgery will happen (either early or late), and the role of parents as well as children appears secondary.

Additional data from the Australian Institute of Health and Welfare (AIHW) is available,<sup>59</sup> including for “vulvoplasties”, defined as “any surgery performed on the outside female genital structures”, and also masculinising genitoplasties often described as “hypospadias repair”, including multistage “repairs”.<sup>61</sup> According to analysis of AIHW data<sup>59</sup> and a 2014 Department of Health review:

- The Department found a “marked increase” of 105% in numbers of publicly-funded vulvoplasties in adolescents and adults between 2003/4 and 2012/13.<sup>61</sup> Numbers in 0-19 year age groups increased from 101 in 2002/3 to 258 in 2014/5.<sup>60</sup>
- An average of 71.5 vulvoplasties were performed per year in children aged under 15 between 2002/3 and 2014/5; between 57-95 per year.<sup>60</sup>
- There were 371 publicly-funded vulvoplasties for so-called “congenital malformations” between 2007/8 and 2011/2; averaging 74.2 per year.<sup>61</sup>
- Additional “feminising” surgeries take place under different categories such as “procedures for anomalies of genitalia”.<sup>60</sup>
- Hundreds of masculinising surgeries are performed each year, including hundreds of repeat surgeries for “second stage hypospadias repair” and the iatrogenic “repair of postoperative urethral fistula”.
- There is no evidence of any overall reduction in numbers of surgeries relevant to minors with intersex variations between 2002/3 and 2014/5.<sup>59</sup>

Exemptions in Australia regarding FGM do not apply to cosmetic interventions and the WHO recognises that medicalisation does not justify FGM, but clitorectomies, labioplasties and other vulvoplasties (including for aesthetic purposes) clearly happen.<sup>62</sup>

The Australian framework on FGM shows profound confusion about intersex, appearing to describe intersex infants as “neither female or male” regardless of actual sex assignment, until surgically reinforced.<sup>63</sup> The FGM framework does not discuss necessity or evidence.

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<sup>58</sup> O’Connor M. The treatment of intersex and the problem of delay: The Australian Senate inquiry into intersex surgery and conflicting human rights for children. *J Law Med* 2016;23:531–43.

<sup>59</sup> Carpenter M. The ‘normalisation’ of intersex bodies and ‘othering’ of intersex identities. In: Scherpe J, Dutta A, Helms T, editors. *The Legal Status of Intersex Persons*. 2018 (forthcoming).

<sup>60</sup> Australian Institute of Health and Welfare. *Procedures data cubes*. 2017.

<http://www.aihw.gov.au/hospitals-data/procedures-data-cubes/>

<sup>61</sup> Department of Health. *MBS Reviews Vulvoplasty Report*. 2014.

[http://www.health.gov.au/internet/main/publishing.nsf/content/E393B5FFC5978400CA257EB9001EEC59/\\$File/Vulvoplasty\\_Review\\_Report.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/E393B5FFC5978400CA257EB9001EEC59/$File/Vulvoplasty_Review_Report.pdf)

<sup>62</sup> Shahvisi A, Earp BD. The Law and Ethics of Female Genital Cutting. In: Creighton S, Liao L-M, editors. *Female Genital Cosmetic Surgery: Interdisciplinary Analysis & Solution*. 2018.

<sup>63</sup> Attorney General’s Department. *Review of Australia’s Female Genital Mutilation legal framework*. 2013.

Medical rationales, including parental distress, appearance “enhancement” and marriageability, mirror rationales evident for FGM in societies where FGM is the norm.

## 8 Family Court cases on the treatment of intersex children

Few cases on the treatment of intersex children are put to the Family Court for consideration. Such cases have typically involved sterilisation (irrespective of fertility) or been incidental to treatment for gender dysphoria in an intersex child. In each situation, the individuals consequently require a lifetime of hormone replacement. It is notable that relevant Family Court cases rarely employ the term intersex, nor the current clinical term ‘disorders of sex development’; they most frequently refer to a specific intersex variation using a diagnostic term.

A subset of recent and recently cited cases is discussed in this section. They include cases before the federal Family Court in both 2016 and 2017 that demonstrate what Melinda Jones describes as ‘the culpability of health systems and the medical profession’ and a ‘failure of the state to protect the rights’ of children with intersex variations.<sup>64</sup> A third 1993 case cited by the then Chief Justice of the Family Court in her submission to the 2013 Senate inquiry is also discussed.<sup>65</sup> The cases give rise to serious concerns about equality before the courts and tribunals, including access to justice, undue restrictions on legal capacity, and legal and governmental complicity in harmful, current clinical practices.

In 2017, the government announced a review of the family law system. In 2018, and pre-empting the conclusions of that review, the government has published an intention to merge the Family Court and the Federal Circuit Court.<sup>66</sup> In our view, this merger will not itself address the issues that we raise in our Shadow Report, and any observations by the Committee would be timely and helpful for the review of the family law system.

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<http://www.ag.gov.au/Publications/Pages/ReviewofAustraliasFemaleGenitalMutilationlegalframework-FinalReportPublicationandforms.aspx>

<sup>64</sup> Jones M. Children’s Health Rights and Gender Issues. In: Children’s Rights in Health Care. Leiden: Brill; (forthcoming).

<sup>65</sup> The Hon. Diana Bryant, AO, Chief Justice. Submission to the Senate Community Affairs Committee Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia. 2013 Feb 22. Available from: <http://www.aph.gov.au/DocumentStore.ashx?id=75906320-b2bb-43dd-9d0a-3fe58a7d93f9&subid=16140>

<sup>66</sup> Wangmann, Jane, and Miranda Kaye. ‘A New Family “super Court” May Not Save Time or Result in Better Judgments’. *The Conversation*, 31 May 2018. <http://theconversation.com/a-new-family-super-court-may-not-save-time-or-result-in-better-judgments-97454>.

## 8.1 *Welfare of a Child A (1993)*

In 2013, the Hon. Diana Bryant AO made a submission to the Senate inquiry on involuntary or coerced sterilisation. In her submission, the former Chief Justice cited the case of *Welfare of a Child A* [1993] FamCA 68.<sup>67</sup> The adolescent boy in this case was diagnosed with congenital adrenal hyperplasia (CAH) at birth (at [5]) and presented as suicidal.

Legally registered with a male name (at [7]), the child was described clinically as a ‘genetic female’ due to XX sex chromosomes, and subjected to early ‘feminising’ surgeries (at [10]).

Furtado and others have stated in a 2012 clinical review that generally ‘between 8.5–20% of individuals with DSDs’ will experience distress associated with their gender assignment, including one in ten individuals with CAH. They state nonetheless that: ‘Early surgery seems to be a safe option for most’ children with that diagnosis.<sup>68</sup> Even discounting known consequences for sexual function and sensation (not mentioned in this clinical review), there is no method of distinguishing those whose gender identity will change from those whose identity will not. Such surgeries remain the standard protocol for children with CAH.

Justice Mushin, now an adjunct professor of law at Monash University, Victoria, did not question these ‘feminising’ surgeries in his judgment but was, instead, critical of the parents, blaming the mother for the child’s male gender identity. He stated:

*9. The application which is made by the mother seeks authorisation from the court that A be permitted to undergo bilateral mastectomies, a hysterectomy and oophorectomy...*

*10. The background for this is well expressed by the surgeon. His report, to the extent that it is relevant, is in the following terms:  
Following investigation after birth, this child was correctly assessed as being a genetic female with an extreme degree of masculinization. The degree of masculinization is variable and depends on the severity of the original abnormality in the adrenal gland. In some children this is mild and in others it is severe. However, in all cases it would be standard medical practise (sic) to raise the child as a female with a potential for normal female fertility. The genitalia are therefore operated on in the postnatal period to make them feminine in appearance. This advise (sic) and treatment was carried out in (A's) early years and she had genital reconstruction to give her a feminine appearance. She was also given cortisone hormone treatment to replace the absent hormone and prevent any further masculine hormones being produced by the abnormal adrenal gland...*

*12. Further in that report the endocrinologist states:*

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<sup>67</sup> *Welfare of a Child A* [1993] FamCA 68; (1993) FLC 92-402 16 Fam Lr 715 Children (30 June 1993).

<sup>68</sup> Furtado PS, Moraes F, Lago R, Barros LO, Toralles MB, Barroso U. Gender dysphoria associated with disorders of sex development. *Nature Reviews Urology*. 2012;9:620–7.

*As (A's) endocrinologist, I consider her to be completely male in her outlook due to the prenatal and postnatal exposure to excessive levels of adrenal androgen. I do not believe that this situation is reversible...*

*13. I am critical of both the parents, and particularly the mother, that the treatment recommended by the doctors at the time of the A's birth was not pursued. It appears on the basis of the material which is available to me that had that treatment been undertaken it may well have been possible to avoid the appalling situation which has now arisen and in respect of which I am asked to make this decision.*

We note that the difficult situation presented in the judgment would not have been appalling at all, had the boy not been subjected to unnecessary early surgeries, yet the judge did not comment at all on their necessity or the appalling consequences for this child. All subsequent surgeries were in line with the child's legal sex, original sex assignment and gender identity, and were sought to support his male sex of living.

In most scenarios, the early 'feminising' surgeries on children with XX sex chromosomes (a 'genetic female') would be described as female genital mutilation. If child A was to be regarded as a girl, as clinicians did, then policies prohibiting female genital mutilation should have applied. However, we note a specific exemption in Australian policy frameworks that (perhaps inadvertently) permit medical interventions despite lack of evidence of necessity.

The judge was egregious in criticism of the parents. As identified by the Committee on Bioethics of the Council of Europe, there is no evidentiary basis to claim that medical interventions or parents can influence gender development.<sup>47</sup>

In her comments on the case in 2013, the Chief Justice of the Family Court stated that 'the trial judge found that A had "an overwhelming expectation and desire to have the operations referred to so that he may assume what he regards as being his right and expectation, that is to become a male in all possible respects".'<sup>65</sup> That is, the Chief Justice of the Family Court also chose not to comment on the appropriateness, indications, necessity or evidence for earlier 'feminising' surgeries.

## **8.2 Re: Carla (Medical procedure) (2016)**

The case of *Re: Carla (Medical procedure)* [2016] FamCA 7 was initiated by the parents of a child pseudonymously named Carla and adjudicated in the State of Queensland. An anonymous State government department was appointed as a friend of the court.<sup>69</sup>

Carla was 'born in 2010, is now five years of age and is about to start school', and 'was born with a sexual development disorder, described, in more particular medical terms, as 17 beta hydroxysteroid dehydrogenase 3 deficiency' (at [1]), with XY sex chromosomes, testes, and predominantly female genitalia.

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<sup>69</sup> *Re: Carla (Medical procedure)* [2016] FamCA 7 (20 January 2016)

Justice Forrest stated that ‘the proposed surgery for Carla involving the bilateral removal of her gonads (“gonadectomy”) ... may be authorised by either of Carla’s parents’. This has taken similar cases out of Court jurisdiction.

Justice Forrest argued that the gonadectomy (sterilisation) was justifiable on the basis of a potential cancer risk, stating that ‘the Consensus Statement for Management of Disorders of Sexual Development puts the risk of germ cell malignancy at 28% ... said to be an intermediate level of risk of malignancy’ (at [19]) and it was ‘...virtually impossible to regularly monitor them for the presence of tumours’ (at [20]). There is no evidence for this. A German multidisciplinary team advised Amnesty International this year that, cancer risk can be monitored effectively even for high risk groups.<sup>70</sup>

Indeed, the medical journal article referenced in the judgment was consciously misquoted, seemingly to avoid mentioning the word intersex, and the actual ‘Consensus statement on management of intersex disorders’, citing a risk of 28%, itself states that clinicians should ‘monitor’ gonads in children with 17 beta hydroxysteroid dehydrogenase 3 deficiency (17βHSD).<sup>71</sup> In other words, the current international position recommends against surgery in favour of a more cautious monitoring, and this was ignored in the case decision.

A more recent clinical review published in 2010 reduces estimates of risk levels to 17%.<sup>72</sup> According to clinical literature, the retention and monitoring of gonads should have been unambiguously supported. This is in line with best practice, as evidenced by the German team that advised Amnesty International.

It should also be noted that the World Health Organization’s International Classification of Diseases 11 Foundation mentions gonadectomy only in situations where a child undergoes feminizing genitoplasties in connection with female gender assignment; such interventions are stipulated “depending on the expected results of masculinizing genitoplasty”.<sup>73</sup> The implication from these current medical documents is that sterilisation is not required except in order to fulfil gender stereotypes.

Given the length and detail of the supporting information, it appears that gender stereotyping substantively comprises the rationale for sterilisation, mostly on the basis of parental reporting and clinical affidavits:

*15. In 2014, when Carla was almost four years of age, she was reviewed by Dr S who formed the opinion that Carla had developed a female gender identity and identified as a female and that this was unlikely to change in the future. Dr S formed this opinion based on the following observations:*

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<sup>70</sup> Amnesty International. First, Do No Harm: ensuring the rights of children born intersex. 2017. Available from: <https://www.amnesty.org/en/latest/campaigns/2017/05/intersex-rights/>

<sup>71</sup> Hughes IA, Houk C, Ahmed SF, Lee PA, LWPES/ESPE Consensus Group. Consensus statement on management of intersex disorders. Archives of Disease in Childhood. 2006;91:554–63.

<sup>72</sup> Pleskacova J, Hersmus R, Oosterhuis JW, Setyawati BA, Faradz SM, Cools M, et al. Tumor Risk in Disorders of Sex Development. Sexual Development. 2010;4(4–5):259–69.

<sup>73</sup> Carpenter M. Intersex Variations, Human Rights, and the International Classification of Diseases. Health and Human Rights 2018;20.

- a. Her parents were able to describe a clear, consistent development of a female gender identity;
- b. Her parents supplied photos and other evidence that demonstrated that Carla identifies as a female;
- c. She spoke in an age appropriate manner, and described a range of interests/toys and colours, all of which were stereotypically female, for example, having pink curtains, a Barbie bedspread and campervan, necklaces, lip gloss and 'fairy stations';
- d. She happily wore a floral skirt and shirt with glittery sandals and Minnie Mouse underwear and had her long blond hair tied in braids; and
- e. Her parents told Dr S that Carla never tries to stand while urinating, never wants to be called by or referred to in the male pronoun, prefers female toys, clothes and activities over male toys, clothes and activities, all of which are typically seen in natal boys and natal girls who identify as boys. (at [15])

The reliance on such crude gender stereotyping illustrates clearly our concerns with current medical practices, and is disturbing. These were third party report; the Court is not required to give a child an opportunity to express their own views.<sup>74</sup> Carla is not yet an independent agent and presumably the gender performance described in the above extract reflects the parents' choices and actions rather than (or at least as much as) the preferences of Carla herself. Given the absence of clear medical evidence in support of Carla's sterilisation, her current gender presentation and future gender identity are irrelevant. Similarly, no-one can be confident of her future gender identity and sexual orientation; these are simply unknown. However, we note that Australian clinical literature, published in 2009, states:

*As is well known, spontaneous change of gender identity from female to male occurs after the onset of puberty in 46,XY children with ... 17 $\beta$ -hydroxysteroid dehydrogenase deficiency.<sup>75</sup>*

The medical literature on this issue is clear: many children with Carla's diagnosis undergo spontaneous change of gender identity at puberty. The conclusion of the psychiatric expert expressing confidence that Carla's gender identity was stable at age 3/almost 4 (at[15]) is directly at odds with the 'well known' experience evidenced in the clinical literature.

Further, Justice Forrest suggested that sterilisation should deliberately proceed early, prior to the child's ability to consent, stating that it would be:

*less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure (at [30])*

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<sup>74</sup> Commonwealth of Australia. Family Law Act 1975 - Sect 60CD How the views of a child are expressed [Internet]. Available from: [http://www8.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/consol\\_act/fla1975114/s60cd.html](http://www8.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/consol_act/fla1975114/s60cd.html)

<sup>75</sup> Hewitt JK, Warne GL. Management of disorders of sex development. *Pediatric Health*. 2009;3(1):51–65.

This action appears to infringe articles 14 and 24 of the ICCPR,<sup>76</sup> guaranteeing equality before the law and protection without discrimination, and article 12 of the Convention on the Rights of Persons with Disabilities guaranteeing equal recognition before the law and the exercise of legal capacity.<sup>77</sup> Despite this justification for early sterilisation, we note that Justice Forrest made no such claim about trauma arising from a different possible medical intervention:

*Carla may also require other surgery in the future to enable her vaginal cavity to have adequate capacity for sexual intercourse. (at [18])*

This focus on the suitability of Carla's body for heterosexual intercourse reflects heteronormative assumptions and values; and approach validated in a Victorian 2010 ethical framework that enumerated marriage prospects amongst rationales for medical intervention.

Despite rhetoric to the effect that the multidisciplinary team and the parents had patiently deferred any irrevocable intervention until Carla was developmentally able to express a fixed gender identity, the fact that feminising genital surgeries had already been performed well before the hearing indicates that the parents and medical team were not content to wait until Carla had formed a fixed gender identity before commencing interventions that explicitly and irreversibly shaped her body towards a 'feminine' appearance. The applicants and the expert witnesses had become irrevocably invested in Carla being assigned and physically shaped as a female before these proceedings had commenced.

Carla's medical history was also put before the Family Court:

*Surgery already performed on Carla has enhanced the appearance of her female genitalia. (at [2])*

*In 2014, Carla underwent ... a 'clitoral' recession and labioplasty (at [16])*

These abhorrent, irreversible, non-therapeutic and invasive interventions were disclosed as incidental to a case brought to sterilise the child. This raises concern about a conflict of interest, where both clinicians and parents are invested in the success of early surgical interventions.<sup>78</sup>

The clitoral recession and labioplasty performed on Carla fit the criteria for 'vulvoplasties', and the case of *Re: Carla* fits the criteria for so-called "congenital malformations". As described above, we note that the 2014 Department of Health Medicare Benefits Schedule

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<sup>76</sup> Office of the High Commissioner for Human Rights. International Covenant on Civil and Political Rights. 1966.

<sup>77</sup> United Nations. Convention on the Rights of Persons with Disabilities [Internet]. Geneva: United Nations; [cited 2015 Mar 23]. Available from: <http://www.un.org/disabilities/convention/conventionfull.shtml>

<sup>78</sup> An early case note can be found at: Carpenter M. The Family Court case *Re: Carla* (Medical procedure) [2016] FamCA 7 [Internet]. Intersex Human Rights Australia. 2016 [cited 2016 Dec 7]. Available from: <https://ihra.org.au/31036/re-carla-family-court/>

Review on ‘vulvoplasties’ identified 371 Medicare-funded vulvoplasties for so-called ‘congenital malformations’ during the period 2007/8 to 2011/2; an average of 74.2 per year; Australian Institute of Health and Welfare data identify a similar number of ‘vulvoplasties’ performed on children aged under 15.

Australia, in common with many other countries, maintains a legal prohibition on Female Genital Mutilation including all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for ‘non-medical reasons’.<sup>63</sup> Cultural standards relating to genital appearance are not recognised as valid medical reasons for FGM. Further, the World Health Organization and other bodies recognize that medicalization, including as a form of harm reduction, does not justify FGM.

The judge also noted that:

*the parents and medical experts agree that it is in the best interests of the child to undergo the [sterilisation] procedure*

*At the end of the hearing, with the approval of the applicants, I made the orders that the parents sought, satisfied that they were in the best interests of Carla (at [7])*

It is not clear that either Carla’s parents or the Court were provided with accurate and comprehensive information or medical evidence supporting the interventions on the child. It appears that the family have had no access to independent peer support.

In relation to *Re: Carla*, Kelly and Smith report

*Forrest J relied on the affidavit evidence of Carla’s parents and her treating medical professionals to conclude that surgery was in Carla’s best interests. In their affidavit, Carla’s parents’ stated that ‘Carla acts as a girl’ and does not identify as ‘anything but female’.<sup>79</sup>*

The judge also determined that sterilisation was in the child’s best interests for avoidance of risk of cancer. Kelly and Smith comment:

*Based on the evidence provided to him, Forrest J approved the gonadectomy, finding it to be in Carla’s best interests. Forrest J also approved ‘such further or other necessary and consequential procedures to give effect to the treatment of Carla’. Beyond oestrogen treatment these ‘consequential procedures’ are not defined and for this reason, we are of the view that it was not actually possible to determine that a range of undefined procedures planned for some time in the future, are in Carla’s best interests.<sup>79</sup>*

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<sup>79</sup> Kelly F, Smith MK. Should court authorisation be required for surgery on intersex children? A critique of the Family Court decision in *Re Carla* — (2017) 31 AJFL 118. Australian Journal of Family Law 2017;31:118–33.

In our view, unnecessary medical interventions such as genital appearance ‘enhancing’ interventions, should not be regarded as therapeutic. The child’s sterilisation should not have been approved on the basis of the evidence and reasoning presented in the judgment. Watchful waiting, and access to puberty blockers, may have permitted Carla to exercise her own judgment in her own time.

Further, the decision to enable parental choice on sterilisation has taken future sterilisation cases out of Court jurisdiction, for the ‘potential benefit of any parents, like them, who might find themselves in these very same factual circumstances in the future’ (at [8]). The far-reaching consequences of this decision are alarming given the evidence of human rights breaches. Kelly and Smith argue that the treatment in *Re: Carla* “sets a dangerous precedent”:

*the medical evidence provided to the Court to justify surgery was incomplete and the reasoning and analysis concerning the therapeutic nature of the proposed surgery lacks rigour. In addition, a concerning aspect of Carla’s earlier medical care (undertaken prior to the application to the Family Court that was made by Carla’s parents in this case), was that the surgical interventions that occurred — which were described as purely cosmetic in nature — were made by the parents and health care team without Court approval.<sup>79</sup>*

We fear that information provided to support parental decision-making may be similarly incomplete.

Kirsten Sandberg comments that psychosocial rationales have long been a rationale for regarding surgery on infants as in a child’s best interests. However, she states that parents’ “interest in having a “normal” child may influence what they think is in their child’s best interests” and physicians are similarly unable to “make a well-informed and impartial consideration of” the child’s best interests”:

*it is questionable if anybody else than the child itself is able to make an informed assessment of its best interests in this respect, both regarding the decision of whether or not to assign a sex, and not least, regarding what that sex should be. Consequently, even if one were to accept the assumption that the decision should be based on the best interests of the child, the decision would have to be postponed ... [and] the best interests of the child cannot override other rights under the CRC<sup>17</sup>*

Overall, this 2016 Family Court of Australia case is deeply disturbing, exemplifying the way that the human rights of intersex children are violated with inadequate evidence for social and cosmetic purposes.

IHRA board members and many other individuals have personally experienced similar interventions, with negative personal and familial consequences.<sup>80</sup> There are multiple publicly available documents attesting to the experiences of intersex people who have been subjected to unnecessary medical interventions such as these. It is a telling criticism that Justice Forrest seems oblivious to the strong and diverse challenges to the medicalised approach adopted by the team of experts responsible for Carla's care, despite the comprehensive outline of these challenges in the Report of the Senate Committee published in 2013.

The case also provides evidence of State complacency and complicity. In 2012, the local Department of Communities in Queensland wrote that:

*Previously it was an accepted practice to assign the external genitalia of a child during their childhood, often through surgical intervention, to determine the sex of the child early in their life. Research and investigation now advises against any irreversible or long-term procedures being performed on intersex children, unless a condition poses a serious risk to their health.*<sup>81</sup>

This cannot be said to be true in relation to the clitorectomy, labioplasty, or sterilisation of Carla.

A subsequent 2016 "Sexual Health Strategy" published by Queensland Department of Health makes no statements about the sexual health implications of medical interventions on intersex infants, children or adolescents. It states:

*Parents and carers of children born with an intersex condition which may require surgical intervention must be fully informed about the intersex condition specific to their child and have all available treatment options explained to them. Informed consent from legal guardians is also essential if treatment is to be undertaken on children and young people later in life for normalisation and gender affirmation. Medical management of children with intersex variation [sic] may be complex and ongoing interventions may*

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<sup>80</sup> Copland S. The medical community's approach to intersex people is still primarily focused on "normalising" surgeries [Internet]. SBS. 2016 [cited 2016 Dec 15]. Available from:

<http://www.sbs.com.au/topics/sexuality/agenda/article/2016/12/15/medical-communitys-approach-intersex-people-still-primarily-focused-normalising>

Overington C. Family Court backs parents on removal of gonads from intersex child. The Australian [Internet]. 2016 Dec 7 [cited 2016 Dec 7]; Available from:

<http://www.theaustralian.com.au/news/health-science/family-court-backs-parents-on-removal-of-gonads-from-intersex-child/news-story/60df936c557e2e21707eb198f1300276>

Overington C. Carla's case ignites firestorm among intersex community on need for surgery. The Australian [Internet]. 2016 Dec 8 [cited 2016 Dec 8]; Available from:

<http://www.theaustralian.com.au/national-affairs/health/carlas-case-ignites-firestorm-among-intersex-community-on-need-for-surgery/news-story/7b1d478b8c606eaa611471f70c458df0>

<sup>81</sup> Department of Communities. 'Engaging Queenslanders: A Guide to Working with Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Communities', January 2012.

*include surgery and lifelong hormone therapy... Medical treatment is sometimes necessary to help development proceed as normally as possible and for some conditions, surgical treatment may be recommended.*<sup>82</sup>

These 2016 descriptions and justifications for early medical interventions are unsupported by evidence, and fail to acknowledge the human rights and ethical implications of medical interventions, including when and where surgery may be appropriate, or when and where parental consent is adequate or permissible. The statement contains clear and repeated presumptions favouring so-called “normalisation” and “normal development”. The 2016 document was published in advance of press reporting of the case *Re: Carla (Medical procedure)*, in December 2016.<sup>80</sup>

Despite these issues, in its 2018 submission to the CRPD the Australian government cited *Re Carla* as an example of where:

*The Family Court of Australia has affirmed that any medical procedure resulting in the sterilisation of a child must be therapeutic in nature for it to be within the bounds of permissible parental authority and not require court authorisation.*<sup>29</sup>

This is troubling.

### **8.3 *Re: Lesley (Special Medical Procedure) (2008)***

In the Family Court case *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226, a judge approved the sterilisation of a young child with the same intersex variation as the child in *Re: Carla* (i.e. 17B-HSD3).<sup>83</sup> The facts of this case are substantively the same as those in *Re: Carla*, albeit that clinical rationales and any genital surgeries were not disclosed in the same manner, and the Court did not take subsequent approval processes out of Court jurisdiction. Indeed, the judge in *Re: Carla* appeared to comment in detail on the circumstances of Carla specifically in response to an invitation to consider whether or not judicial approval was required for the sterilisation of Carla. Risks of gonadal tumour were stated to be ‘significant’ (at [40]). While a later re-evaluation of risks had not yet been published,<sup>72</sup> clinical guidance recommending the monitoring of gonads had been published.<sup>71</sup> There was no clinical consensus supporting removal of gonads.

Sterilisation was intended to prevent the child’s body from virilising at puberty. According to a submission by counsel, the alternative to sterilisation included (at [39]) to:

*(a) take no action and allow [Lesley] to virilise and make a determination about her gender later*

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<sup>82</sup> Department of Health, and Queensland. ‘Health Strategies - Queensland Sexual Health Strategy (Draft for Consultation) - Publications | Queensland Government’, 25 May 2016. <https://publications.qld.gov.au/dataset/health-strategies/resource/e45a2284-d20d-431d-84bd-9d9111cb77a4>.

<sup>83</sup> *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226

That is, sterilisation was not predicated on clinical urgency regarding cancer risk, but instead to surgically reinforce a female gender assignment and pre-empt later self-determination. The alternative option of puberty blockers to support later self-determination appears not to have been examined.

#### **8.4 Re: Kaitlin (2017)**

The case of *Re: Kaitlin* [2017] FamCA 83, was taken by the parents of a child pseudonymously named Kaitlin. Kaitlin was born in 2000 with a pituitary impairment.<sup>84</sup>

An intersex and transgender child, ‘she has not undergone stage one treatment, which comprises hormone blocking, because she suffers from hypopituitarism, in consequence of which her body is incapable of naturally producing testosterone, or indeed, many other hormones’ (at [2]).

Indeed, Kaitlin ‘identified as female from a very early age. She has always resented being characterised as male’ (at [5]).

Unlike endosex (non-intersex) transgender children in Australia, where such interventions require Family Court approval: ‘At about age 12 or 13 she was prescribed testosterone in order to commence puberty’ (at [6]). This was an inappropriate, forced intervention.

When Kaitlin understood the nature of the hormone treatment, she was, because of her gender identity, understandably non-compliant with that testosterone treatment. Justice Tree approved ‘cross-sex’ hormone treatment.

In our view, Kaitlin should never have been prescribed testosterone in the first place. The adolescent child should have been consulted about her treatment, and her voice in relation to her treatment should have been respected. The Court’s failure to note and comment on the failure of the parents and medical team to obtain appropriate consent to the hormone therapy instituted when Kaitlin was age 12 is unfortunate.

#### **8.5 Commentary**

In her 2013 comments to the Senate inquiry on involuntary or coerced sterilisation, the Hon Diana Bryant, former Chief Justice of the Family Court, stated that:

*I appreciate that the Committee may be contemplating scenarios whereby permission is sought to perform surgery on a young child to give them the appearance of one sex or another, without the child being of sufficient age and maturity to express a view as to the procedure. I am not aware though of judgment having been delivered in any such case before the Family Court.<sup>65</sup>*

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<sup>84</sup> Re: Kaitlin [2017] FamCA 83.

IHRA has seen no evidence that Court oversight has ever been sought for genital so-called ‘normalising’ surgeries. Clearly, however, such interventions occur without clinicians, governments, or parents seeking Court oversight, and the former Chief Justice and other Family Court justices have had ample opportunities to become aware of this failure of process and to comment on it. Such interventions are documented in medical histories in the 1993 case *Welfare of a Child A* cited by the Chief Justice in her comments to the Senate, and in the 2016 case *Re: Carla (Medical procedure)*.

It is also clear that, where such interventions are documented in the medical histories of children whose cases appears before the Court, no comment has ever been made by the Court questioning the suitability, appropriateness, indications, rationales, outcomes, or evidence for such prior medical interventions; or, in the case of *Re: Carla (Medical procedure)*, such interventions are described as having ‘enhanced’ genital appearance. This is gravely disturbing.

Aileen Kennedy (now a director of IHRA) describes the situation as one of ‘complicity between the medical and the legal construction of variations of sex development as pathological disorders in urgent need of correction’ where a ‘tension between the medical and judicial responses to variations of sex development has disappeared’.<sup>85</sup>

The Australian healthcare system appears to regard such interventions as unambiguously therapeutic due to parental distress and potential psychosocial stigma, even when they take place on healthy intersex bodies, or where clinical evidence supports monitoring gonads, even though such interventions contravene human rights norms established by multiple UN Conventions and the conclusions of a Senate inquiry.

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<sup>85</sup> Kennedy A. Fixed at Birth: Medical and Legal Erasures of Intersex Variations. *UNSW Law Journal*. 2016;39(2):813–42.