

8 July 2022

Chief Minister, Treasury and Economic Development Directorate  
[intersex@act.gov.au](mailto:intersex@act.gov.au)

Dear colleagues

## **Consultation on the *Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022***

Thank you for inviting feedback to help the government improve the consultation draft *Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022*.

Intersex Human Rights Australia (IHRA) is a national intersex-led charitable company that promotes the human rights and health of people with innate variations of sex characteristics. We engage in resource development, community development, and work to document human rights violations. That work includes action on ending harmful practices in medical settings, prenatal diagnosis and genetic selection, and a range of issues associated with the stigmatisation of bodily diversity.

Intersex people have innate variations of sex characteristics that do not fit medical or social norms for female or male bodies. There are more than 40 different such variations that can be determined prenatally, at birth, during puberty, when trying to conceive a child, or at other times. Examples include androgen insensitivity syndrome, gonadal dysgenesis, micropenis, sex chromosome variations, and congenital adrenal hyperplasia with XX or mosaic sex chromosomes. Because our bodies are perceived as different, we can experience stigmatisation, discrimination and harmful practices, including medical interventions to make our bodies appear or function in ways that are more typically female or male.

Misconceptions frequently associate particular gender identities or sex classifications with innate variations of sex characteristics – for example, an incorrect assumption that people with innate variations of sex characteristics necessarily have non-binary gender identities. People with innate variations of sex characteristics may grow and express the same range of identities as those represented in the wider community. Many grow to express an LGBT identity (that is, to be same sex attracted or gender diverse) but equally many grow to identify in other ways (for example, heterosexual and/or cisgender women and men). The development of these identities should lie with the individual as they come to understand themselves and should not be attributed arbitrarily according to medical or social norms or beliefs. People with innate variations of sex characteristics are at risk of human rights violations irrespective of the words we use and our agency to express any identity.

The words that individuals use to describe themselves typically respond to what we have been taught by parents and clinicians, and to our experiences of misconceptions. We encourage respect for our diversity as a population, including respect for the diversity of our identities, and for the nomenclature that individuals use.

Since December 2016, IHRA has two part-time staff positions funded by foreign philanthropy to engage in systemic advocacy. We have no core funding from Australian governments, and we rely on volunteer labour.

We are profoundly grateful for the leadership shown by the Chief Minister and his Directorate to ensure that the rights of people with innate variations of sex characteristics are protected in medical settings. We acknowledge the years of work and collaboration that this process has so far taken, including:

- collaborative discussions between IHRA, Intersex Peer Support Australia, A Gender Agenda, and the government, leading to a legislative commitment to reform
- a commitment made in the First Action Plan of 2019
- a paid contract for IHRA to advise on relevant research, policy, and practices
- feedback on a public discussion paper and a public regulatory options paper
- the holding of multiple stakeholder workshops and discussions on the proposed reforms, including legal and community workshops and events that we have been pleased to participate in or lead.

In our view, the openness and collaborative nature of work on this issue by the ACT government is commensurate with the long-neglected human rights and health issues that are addressed by proposed reforms, but this open and consultative process to legislative reform is unusual in our experience and we are immensely grateful for it. We congratulate your staff team for all their work.

### **The clinical circumstances for these reforms**

We note that many children with innate variations of sex characteristics seen by clinicians in the ACT are referred for surgical interventions to hospitals in Sydney or Melbourne. A 2016 clinical audit of cases taken to multidisciplinary team meetings in Sydney and Melbourne found that referrals to such teams was much less frequent in Sydney than Melbourne (24 new referrals in Sydney between August 2012 and May 2016 compared to 53 new referrals in Melbourne between January 2014 and May 2016).<sup>1</sup> No long-term outcomes can be discerned. Of the genitoplasties mentioned in the audit, two took place in NSW at a mean age of 18 months with 'deferral' of three other genitoplasties, and four took place in Victoria at a mean age of 9.4 months with four 'deferred'. The timeframe for 'deferral' (whether, for example, to age two years, or age 12 or 18) is not disclosed. Genitoplasties that were not the subject of clinical debate by a multidisciplinary team, for example as a

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<sup>1</sup> Komal A Vora et al, 'Multidisciplinary Team (MDT) Review of Management Decisions in Disorders/Differences of Sex Development (DSD): Experience of Two Paediatric Tertiary Hospital Networks' (at the Australasian Paediatric Endocrine Group Annual Scientific Meeting – APEG 2016, Alice Springs, NT: Alice Springs Convention Centre, 14 August 2016).

‘treatment dilemma’, are not disclosed. While gonadectomies in each jurisdiction appear rarely to receive the oversight of multidisciplinary teams, the average age of gonadectomies in the two jurisdictions may vary significantly (mean age 4.4 years in NSW, and mean age of 13.2 years in Victoria). No clear evidence of the rationales for these differences in clinical practices between jurisdictions are disclosed, despite their profound impacts for participation in decision-making by children in each jurisdiction.

The authors suggest that such teams ‘provide a viable alternative to involvement of the Family Court’,<sup>2</sup> while a Sydney-based clinician has proposed that multi-disciplinary teams offer ‘much stricter controls on such surgery’ than legal oversight.<sup>3</sup> In our view, these views cannot be justified given a lack of data on interventions not seen as clinical ‘dilemmas’ and not taken to multidisciplinary teams, and in the context of radically different referral rates in Sydney and Melbourne.

In our view, a clinical preference for alternatives to legal oversight has evolved out of the failure of the Family Court to provide an effective oversight of clinical decisions, as provided for in federal family law, but also a clinical preference for lack of any form of independent oversight. The current situation represents a failure to ensure independent external oversight, and it promotes group think decision making of only a subset of cases, without adequate consideration of human rights and ethical considerations.

Victorian paediatric surgeons rely on old and low quality research on surgical outcomes that they and their clinical teams have conducted on their own patients, often researching children and youth too young to freely express their own views and too early to ascertain long-term outcomes.<sup>4</sup> In debates with paediatric surgeons in Victoria we have heard disregard for the rights of the child, and reliance on anecdotal evidence to support current practices.<sup>5</sup>

In 2020, two NSW paediatric endocrinologists suggested that ‘surgical options’ are a valid rationale in determining sex assignment in situations of doubt.<sup>6</sup> The same clinicians also made a number of other deeply concerning statements. In particular, the authors suggest that ‘lack of universal interpretation of ‘medically necessary surgery’ means that such interventions cannot be regulated, while stating that ‘no consensus in relation to the need for, or optimal timing of, many surgical interventions’ justifies the use of individual clinician judgement in proposing such interventions.<sup>7</sup> This exemplifies a self-serving situation where both evidence and lack of evidence, and both clinical ‘consensus’ and lack of consensus, each support early surgical interventions; this is an indication that it is clinical values and

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<sup>2</sup> Ibid.

<sup>3</sup> Mike O’Connor, ‘The Treatment of Intersex and the Problem of Delay: The Australian Senate Inquiry into Intersex Surgery and Conflicting Human Rights for Children’ (2016) 23(3) *Journal of Law and Medicine* 531.

<sup>4</sup> John Hutson, ‘Short, Medium and Long-Term Outcomes for DSD at The Royal Children’s Hospital’ in John Hutson et al (eds), *Disorders/Differences of Sex Development: An Integrated Approach to Management* (Springer, 2020) 305 <[https://doi.org/10.1007/978-981-13-7864-5\\_23](https://doi.org/10.1007/978-981-13-7864-5_23)>.

<sup>5</sup> John Hutson et al, ‘Intersexion: The Birth of Ambiguity’ (at the Melbourne Medical Student Conference 2020, University of Melbourne, 23 June 2020) <<https://ihra.org.au/36471/intersexion-mdscx-2020/>>.

<sup>6</sup> Komal A Vora and Shubha Srinivasan, ‘A Guide to Differences/Disorders of Sex Development/Intersex in Children and Adolescents’ (2020) 49(7) *Australian Journal of General Practice* 417, 418.

<sup>7</sup> Ibid 420.

beliefs that underpin treatment.<sup>8</sup> Of course, the clinical view that there is a ‘lack of universal interpretation of ‘medically necessary surgery’ provides a strong justification for enacting legislative reforms.

Gender stereotypes remain evident in clinical thinking. For example, girls with innate variations of sex characteristics have been subjected to surgeries to ‘enhance’ the appearance of their genitalia,<sup>9</sup> while boys are subjected to ‘functional’ surgery aimed at ensuring ‘appropriate’ urination; that is, urination while standing.<sup>10</sup> Such surgeries are associated with impaired sexual function and sensation,<sup>11</sup> a frequent need for follow-up surgeries and treatment, and experiences of shame.<sup>12</sup>

Australian clinical authors have also proposed a straw man argument, that ‘Some patient groups advocate a complete moratorium on any genital/gonadal surgery until the individual is able to give informed consent’.<sup>13</sup> This claim was refuted in 2021 by the Australian Human Rights Commission, which stated ‘neither the Commission nor any stakeholders have advocated such a blanket prohibition’.<sup>14</sup>

These clinical circumstances provide much context for the careful, nuanced approach to reform that is proposed in the *Variation in Sex Characteristics (Restricted Medical Treatment) Bill 2022* Consultation Draft.

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<sup>8</sup> I discuss these issues in Morgan Carpenter, *Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data* (University of Huddersfield, May 2022)

<<https://morgancarpenter.com/intersex-dsd-australian-data/>>.

<sup>9</sup> Andrew Bock, ‘It Takes More than Two’, *The Age* (online, 20 June 2013)

<<http://www.theage.com.au/national/it-takes-more-than-two-20130619-2oj8v.html>>; Morgan Carpenter, ‘Intersex Variations, Human Rights, and the International Classification of Diseases’ (2018) 20(2) *Health and Human Rights* 205.

<sup>10</sup> April McLennan, “‘People Just Can’t Comprehend’ What It Means for Robert to Have Been Born Intersex’, *ABC News* (online, 14 March 2021) <<https://www.abc.net.au/news/2021-03-14/push-to-outlaw-gender-assignment-surgery-on-intersex-children/13234680>>; Australasian Paediatric Endocrine Group et al, *Submission of the Australasian Paediatric Endocrine Group 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* (Submission, 27 June 2013)

<<http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>>; Adrienne Carmack, Lauren Notini and Brian D Earp, ‘Should Surgery for Hypospadias Be Performed Before an Age of Consent?’ (2015) 53(8) *Journal of Sex Research* 1047.

<sup>11</sup> Australasian Paediatric Endocrine Group et al (n 10).

<sup>12</sup> Bonnie Hart and Jane Shakespeare-Finch, ‘Intersex Lived Experience: Trauma and Posttraumatic Growth in Narratives’ [2021] *Psychology & Sexuality* 1; Aileen Kennedy, Alice de Jonge and Morgan Carpenter, ‘ACT Releases Australian-First Draft Law to Protect Intersex Children from Irreversible Medical Harm’, *The Conversation* (online, 15 June 2022) <<http://theconversation.com/act-releases-australian-first-draft-law-to-protect-intersex-children-from-irreversible-medical-harm-184566>>.

<sup>13</sup> Vora and Srinivasan (n 6) 420; Komal A Vora et al, ‘Role of Cross-campus Multidisciplinary Team Meetings in Decision-making for Children and Adolescents with Differences of Sex Development/Intersex’ [2021] *Journal of Paediatrics and Child Health* jpc.15474.

<sup>14</sup> Australian Human Rights Commission, *Ensuring Health and Bodily Integrity: Towards a Human Rights Approach for People Born with Variations in Sex Characteristics* (Australian Human Rights Commission, 2021) 131 <<https://humanrights.gov.au/intersex-report-2021>>.

## The human rights circumstances for these reforms

Current clinical practices violate the rights of infants, children and adolescents where they involve surgical or hormonal interventions grounded in gender stereotypes or cultural norms before individuals are able to freely express their own values and preferences. Other interventions such as dilation carry the same risks.

Such practices contravene Australia's human rights obligations. In 2018, the Committee on the Elimination of Discrimination Against Women recalled 'the 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 (2014) on harmful practices'<sup>15</sup> and called on the Australian government to eliminate harmful practices:

*'(c) Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary surgical or other medical procedures on intersex children before they reach the legal age of consent, implement the recommendations made by the Senate in 2013 on the basis of its inquiry into the involuntary or coerced sterilization of intersex persons, provide adequate counselling and support for the families of intersex children and provide redress to intersex persons having undergone such medical procedures'<sup>16</sup>*

Similar recommendations have been published by the UN Human Rights Committee,<sup>17</sup> the Committee on the Rights of the Child<sup>18</sup>, and the Committee on the Rights of Persons with Disabilities.<sup>19</sup> IHRA was pleased to make submissions to each of these Committees.

As noted in the government's April 2021 listening report on responses to a discussion paper, a prohibition of deferrable interventions 'would not be legally radical and would be consistent with orthodox legal thinking about child welfare'.<sup>20</sup> These practices are also the subject of recommendations by the Senate Community Affairs References Committee in 2013,<sup>21</sup> and they implement recommendations 1, 4, 7, 8 and 9 made by the Australian

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<sup>15</sup> Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child, *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* (No CEDAW/C/GC/31-CRC/C/GC/18, 14 November 2014).

<sup>16</sup> *Concluding Observations on the Eighth Periodic Report of Australia* (No CEDAW/C/AUS/CO/8, 25 July 2018).

<sup>17</sup> *Concluding Observations on the Sixth Periodic Report of Australia* (No CCPR/C/AUS/CO/6, 1 December 2017).

<sup>18</sup> *Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Australia* (No CRC/C/AUS/CO/5-6, 1 November 2019).

<sup>19</sup> *Concluding Observations on the Combined Second and Third Reports of Australia* (No CRPD/C/AUS/CO/2-3, 23 September 2019).

<sup>20</sup> Chief Minister, Treasury and Economic Development Directorate, *Key Issues in the Prohibition of Deferrable Medical Interventions on Intersex Children: Listening Report on Submissions Received* (April 2021) <[https://www.cmtedd.act.gov.au/\\_\\_data/assets/pdf\\_file/0008/1745837/Intersex-Project-Listening-Report-final-v.2.pdf](https://www.cmtedd.act.gov.au/__data/assets/pdf_file/0008/1745837/Intersex-Project-Listening-Report-final-v.2.pdf)>.

<sup>21</sup> Senate of Australia 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)>.

Human Rights Commission in 2021.<sup>22</sup> IHRA has been pleased to contribute in significant ways to both inquiries leading to publication of these recommendations.

The bill also implements demands in the Darlington Statement of intersex community organisations and advocates in our region,<sup>23</sup> and the Yogyakarta Principles plus 10, of which I was pleased to be a co-drafter.<sup>24</sup> It addresses calls to respect human rights and end human rights abuses in 2021 clinical position statements, citing IHRA staff, made by the Australian Medical Association<sup>25</sup> and the Public Health Association of Australia.<sup>26</sup> It is consistent with views on treatment expressed in a 2018 submission to the Australian Human Rights Commission by the Royal Australian and New Zealand College of Psychiatrists.<sup>27</sup>

We attach below a detailed contribution to discussions on individual clauses of the bill. We would be happy to respond to any queries that you may have about our comments, at your convenience. We hope that the bill will be strengthened by this public consultation, and we look forward to working with you to promote public and parliamentary support for it.

Yours faithfully,

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Morgan Carpenter  
Executive director

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<sup>22</sup> Australian Human Rights Commission (n 14).

<sup>23</sup> AIS Support Group Australia et al, *Darlington Statement* (March 2017) <<https://darlington.org.au/statement>>.

<sup>24</sup> Yogyakarta Principles, *The Yogyakarta Principles Plus 10: Additional Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics, to Complement the Yogyakarta Principles* (2017) <<http://www.yogyakartaprinciples.org/principles-en/yp10/>>.

<sup>25</sup> Australian Medical Association, *Position Statement on LGBTQIA+ Health - 2021* (November 2021) <<https://www.ama.com.au/articles/lgbtqia-health-2021>>.

<sup>26</sup> Public Health Association of Australia, *The Health of People with Diverse Genders, Sexualities, and Sex Characteristics Policy Position Statement* (2021) <<https://www.phaa.net.au/documents/item/5352>>.

<sup>27</sup> Royal Australian and New Zealand College of Psychiatrists, *Re: Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions* (27 September 2018) <<https://www.ranzcp.org/files/resources/submissions/1-president-to-e-santow-hrc-re-intersex-interventi>>.

## **IHRA feedback on the *Variation in Sex Characteristics (Restricted Medical Treatment) Bill 2022* Consultation Draft**

This analysis has been drafted by Morgan Carpenter, executive director of Intersex Human Rights Australia (IHRA). It reflects consultation and discussion on the draft bill with board members and staff, Steph Lum, Gilbert + Tobin, Relationships Australia, Equality Australia, and others. IHRA is solely responsible for our interpretation of these discussions and our analysis.

### **Overarching comments**

In our view, the proposed legislation is innovative in its application to the needs and circumstances of people with innate variations of sex characteristics, but not in its principles or in providing for the regulation of medicine. Similar legislation already exists, particularly in relation to mental health, but also to female genital mutilation, conversion practices, and, in some jurisdictions, in relation to some cosmetic surgeries. The proposed legislation brings together established concepts and procedures in new ways in order to provide for equal protection of the law for people with innate variations of sex characteristics.

The bill also sets parameters determining which treatments are acceptable and which fail to meet fundamental human rights norms. It recognises that authorisation of treatment is not the same as consent to treatment, and it provides for independent oversight and transparency about medical practices in order to ensure that the legislative goals are achieved.

In our view, the draft bill should:

- Promote deferral of medical interventions wherever possible until individuals are able to freely make their own decisions about treatment.
- Promote supported decision-making by individuals about their own treatment, shifting practice towards recognition that everyone needs support to make decisions.
- Provide for a lightweight non-adversarial mechanism for independent oversight to ensure that treatments meet human rights norms.
- Impose penalties where treatments do not fit human rights norms, commensurate with those in other related areas of law such as female genital mutilation.
- Support treatments that are necessary for physical health and, where individuals are able to freely express their wishes, their psychological health.

Over time, the legislation will enable certainty about medical procedures, enabling the proper consideration of human rights norms and clinical evidence. Uncertainty in the short term will favour deferral of unnecessary and other non-urgent treatment, in line with the purpose of the bill.

We recommend that the government publish guidelines to help individuals, parents, carers and clinicians to interpret the legislation, and in particular provisions relating to objects,

general principles, determination of decision-making capacity, reporting obligations, and procedures to assist in interactions with the expert panel and its president.

## Scope

We acknowledge that terminology in this area is sometimes contentious, and changeable and vague in its application, particularly to traits including hypospadias, sex chromosome variations, congenital adrenal hyperplasia and MRKH. In each of these circumstances, we believe that efforts to disassociate particular diagnoses from umbrella terms like intersex and DSD are associated with unfounded confidence about the values and preferences of future adults with these traits, assumptions about the ‘normality’ of their identities and ‘unaffected’ sex characteristics, and poorly evidenced beliefs about the correctness of early medical interventions.<sup>28</sup> The same is true of people with hypogonadism and hyperandrogenism. While there are differences in the types of surgical or non-surgical medical interventions each of these populations face, and differences in typical age at diagnosis, each of these traits is associated with efforts to continue deferrable medical interventions before infants and children are able to freely express their own values and preferences. In this regard, opposition to inclusion of some trait within proposed regulations appears to reflect opposition to the objects of the legislation.

Sadly, early so-called “normalising” interventions on these populations, sometimes coinciding with contemporaneous necessary interventions, do not respect the actual diversity of values, preferences, identities, and self-understandings of people with these traits.

We seek to respect individual informed choices about treatment and nomenclature, free of coercion. IHRA has always favoured approaches that maximise such opportunities. Our work has always focused on populations defined by experiences of stigma and harm due to innate biological characteristics. Despite widespread misconceptions about people with intersex traits, our work has never focused on populations defined by matters of identity. We recognise the role of different preferences for nomenclature, and misconceptions about innate variations of sex characteristics that frequently underlie such preferences, in creating and perpetuating divisions within our population.<sup>29</sup> We also note that such divisions can be instrumentalised, and they serve to maintain the status quo of unnecessary early medical interventions for some populations.

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<sup>28</sup> For discussions in relation to hypospadias, congenital adrenal hyperplasia and in relation to some sex chromosome variations, see Carmack, Notini and Earp (n 10); Morgan Carpenter, ‘Intersex Human Rights, Sexual Orientation, Gender Identity, Sex Characteristics and the Yogyakarta Principles plus 10’ (2021) 23(4) *Culture, Health & Sexuality* 516; David Andrew Griffiths, ‘Shifting Syndromes: Sex Chromosome Variations and Intersex Classifications’ (2018) 48(1) *Social Studies of Science* 125.

<sup>29</sup> For a discussion of this see Carpenter, ‘Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data’ (n 8); Morgan Carpenter, ‘Intersex Human Rights in a Time of Instrumentalization and Backlash’ in Sofia Gruskin, Anthony Tirado Chase and Pardis Mahdavi (eds), *Human Rights at the Intersections: Transformations through Addressing New Challenges* (I.B. Tauris, 2022); Cary Gabriel Costello, ‘Intersex and Trans\* Communities: Commonalities and Tensions’ in Stefan Horlacher (ed), *Transgender and Intersex: Theoretical, Practical, and Artistic Perspectives* (Palgrave Macmillan US, 2016) 83.



Thus, we believe that all people, including people with ‘contested’ traits, have a right to give personal informed consent to irreversible medical interventions to the maximum extent possible. While we respect a diversity of views about nomenclature, and personal preferences, we also note that, implicit in ideas about the exclusion of people with ‘contentious’ traits from definition of intersex and DSD is a problematic belief in the ‘otherness’ of people with traits that are more typically included.

It is our view that all people, irrespective of their sex characteristics or diagnosis, should be protected by this legislation. Such a view obviates possibilities for gaming definitions or nomenclature, and recognises that we all share a right to make our decisions about our own bodies to the maximum extent possible. We recognise that the ACT government is concerned about the costs of implementation and the vitally important need to consult populations that would be impacted by such an approach. For the sake of clarity, in our view this includes male circumcision where this takes place before the individual can personally give informed consent. We also believe that reforms to protect people with innate variations of sex characteristics are urgent, and any expansion of the scheme to protect other populations could serve to indicate the success of the legislation.

Nevertheless, our view is that a narrower approach must provide protections for all people who have innate sex characteristics that don’t fit medical and social norms for female or male bodies, and that create risks or experiences of stigma, discrimination, and harm. All people with such traits should have the benefit of access to legislative protections and independent oversight.

Further, in providing for general treatment plans, the legislation provides an elegant method for facilitating high frequency, low risk procedures, where these are well-evidenced, while also providing for effective oversight and transparency.

## **Clause 2, on commencement**

We recognise that preparations for commencement will be challenging, but we would prefer for commencement to occur before one year after enactment. We ask that the delay in commencement be explained in the explanatory memorandum for the bill.

Recognising the impermissibility of retrospective criminal laws, we recommend that the government provide for reporting arrangements relating to restricted practices dating from the time of publication of the consultation draft legislation in May 2022. This would introduce early transparency, albeit without penalties. The intent is to ensure that there is no spike in procedures prior to commencement. Evidence relating to numbers of some Medicare item codes shows a spike in some procedures in the year 2004-2006, around the time of the clinical workshop that led to a clinical ‘consensus statement’ on nomenclature and certain practices.<sup>30</sup> This indicates that uncertainty about the perceived legitimacy of future practices might impact current practices.

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<sup>30</sup> Morgan Carpenter, ‘The “Normalisation” of Intersex Bodies and “Othering” of Intersex Identities’ in Jens Scherpe, Anatol Dutta and Tobias Helms (eds), *The Legal Status of Intersex Persons* (Intersentia, 2018) 445.

## **Clause 6, on objects**

Please consider the scope of this clause, including whether or not references to “protected persons” in this clause should instead refer to “people with variations in sex characteristics”.

In part (c) we recommend that the government ensure alignment between language in the Objects and language in clause 10 on General principles.

## **Clause 7, on the meaning of restricted medical treatment**

We recommend consideration of the following issues:

- Adding an explanation of the purpose behind inclusion of temporary procedures. In our view, this is intended to avoid injury and trauma arising from procedures such as dilation. We note that hormonal treatments are intended to cause permanent changes, and puberty blockers are intended to suspend pubertal development.
- The government should consider regulating all temporary procedures, recognising that they can be managed through general medical treatment plans. Alternatively the legislation could remove any distinction between permanent and temporary procedures.
- The exception applying to the prevention of suffering or significant pain or distress risks being open to abuse where clinicians and parents may anticipate the possibility of future stigmatisation and suffering, or replicate existing rationales that refer, *inter alia*, to family distress, familial and community integration, future marital or relationship prospects, and potential gender dysphoria. Restricted medical treatments are not an appropriate response to these issues. We recommend that the term ‘distress’ be removed.
- In line with comments by Steph Lum and by Relationships Australia, we recommend that exceptions to the requirements for individual and general treatment plans are separated out from the meaning of restricted medical treatment in a separate clause. This will significantly improve clarity about the meaning of restricted medical treatment, enable better application of the general principles in clause 10, better facilitate provisions for record keeping on emergency procedures, and align with the common law doctrine of emergency. Emergency treatment can only be invoked when an individual is unable to exercise their autonomy.
- We recommend adding reporting requirements for procedures that occur under an exemption. This is necessary in our view to ensure transparency and the success of the legislation.

## **Clause 8, on protected persons**

We note that ‘variation in sex characteristics’ is not defined in the draft legislation, and so the definition of a protected person relies on capacity for decision-making and on having a trait that is not defined in legislation. We recommend the construction of an umbrella definition for ‘variation in sex characteristics’ in legislation below, in our comments on the dictionary.

## **Clause 9, on decision-making and capacity**

We note that these provisions are based on those in the Mental Health Act. We warmly welcome the inclusion of measures aimed at promoting supported decision-making.

We recommend that the evolving capacity of protected persons aged under 18 be taken into consideration.

We recommend that the relationship between clause 9 and Gillick competency be articulated, noting that the legislation goes beyond Gillick and implements an understanding of children and youth as rights-holders. This articulation should recognise that Gillick competency operates, as intended, as a shield for clinicians and not a tool for children and youth seeking to exercise their rights and autonomy.

## **Clause 10, on general principles**

We are strongly supportive of the articulation of a set of principles by which we can test the merits of applications and the operation of the legislation. We believe that such general principles should be applied to applications in relation to all persons with variations of sex characteristics.

To reflect the importance of these general principles to the operation of the proposed legislation, and to eliminate order effects, we recommend that current clause 10 be moved to immediately follow clause 6 on the objects of the legislation.

We note that the decision-making principles refer in many instances to current and past considerations for medical treatment that are grounded in gender stereotypes and social and cultural norms. In some cases, reference is made to “function” in order to make a rationale grounded in gender stereotypes and social and cultural norms appear objective. By their nature, these are not purely clinical considerations and they exemplify a situation of medical overreach<sup>31</sup> that gives rise to the necessity for the proposed legislation. We also note evidence that parents are educated by clinicians, and so may have limited ability to make decisions independently.<sup>32</sup> In this regard, it is the role of these principles to establish the parameters for acceptable treatment options that meet fundamental human rights norms.

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<sup>31</sup> Lih-Mei Liao, ‘Western Management of Intersex and the Myth of Patient-Centred Care’ in *Interdisciplinary and Global Perspectives on Intersex* (Springer International Publishing, 2022) 241.

<sup>32</sup> Stefan Timmermans et al, ‘Does Patient-Centered Care Change Genital Surgery Decisions? The Strategic Use of Clinical Uncertainty in Disorders of Sex Development Clinics’ [2018] *Journal of Health and Social Behavior* 1; O’Connor (n 3).

Regarding the specific general principles:

Principle (a) states:

*“a person has a right to bodily and mental integrity, autonomy and self-determination irrespective of their sex characteristics”*

This comprises a general principle applicable to all. We believe this is appropriate and helpful as the leading principle.

Principle (b) states:

*“a variation in a person’s sex characteristics must not be assumed to cause harm to the person”*

This statement recognises that bodily diversity should not be seen as necessarily broken or in need of modification or “fixing”. This assumption underpins current and past medical practices. However, in its current form we are concerned that the sentence is a falsifiable statement. Some forms of congenital adrenal hyperplasia (CAH) can cause harm and people with salt wasting CAH benefit from early investigation and treatment to pre-empt an adrenal crisis. Certain other traits also have the capacity, in some instances, to be associated with harm.

Principle (b) should instead be framed as an assumption that the trait should not be assumed to be a source of stigma or discrimination. We suggest the following statement for consideration:

*“a variation in a person’s sex characteristics is a natural facet of human diversity and must not be the basis for discrimination or stigma towards the person”*

Principle (c) states:

*decisions about undertaking restricted medical treatment on a protected person should not be influenced by any of the following considerations:*

*(i) conforming with perceived norms of appearance or function;*

*(ii) reducing the risk of discrimination or stigmatisation;*

*(iii) financial considerations*

We recommend adding “reducing the risk of gender dysphoria”, and considerations relating to “potential marital or other relationships prospects”.<sup>33</sup> These are current and past rationales for medical interventions that are grounded in social and cultural norms but that remain treated as if they are objective and neutral norms.

We are concerned about three existing statements within principle (c).

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<sup>33</sup> Carpenter, ‘The “Normalisation” of Intersex Bodies and “Othering” of Intersex Identities’ (n 30).

Firstly, the reference to function is too broad. An influential conception of health and the role of medicine articulated by Christopher Boorse conceives of the purpose of medicine as restoring or achieving “normal function”.<sup>34</sup> Such a view is controversial. It depends, for example, on a particular evolutionary origin story for homosexuality, and a framing of disease that does not, actually, coincide with a perceived need for medical treatment.<sup>35</sup> Alternative conceptions of the role of the medicine also exist. Irving Zola, for example, conceives of medicine as an instrument for social control, achieved through “‘medicalizing’ much of daily living” where “medical involvement in social problems leads to their removal from religious and legal scrutiny” and the source and treatment of such “problems” are individualised; located in individuals and not elsewhere.<sup>36</sup> Nevertheless, clinical concepts of normal function and the role of medicine typically operate without close examination of their meaning or impact.

In our view, these concerns nevertheless mean that restricting procedures aimed at ensuring conformity with perceived norms of function risks interrupting a broader set of procedures than necessary. In our view, it is the role of gender stereotypes and social and cultural norms in relation to restricted treatments that are matters of concern.

For example, perceived functional norms that are actually based on gender stereotypes and cultural norms include:

- in relation to masculinising interventions is expressed in the view that boys need to be able to stand up to urinate (in order to be boys) is a gendered norm, and a cultural norm, rather than a genuine functional norm
- in relation to feminising interventions is expressed in the views that young infants and girls need a vagina in order to be capable of penis-in-vagina sexual intercourse
- the belief that menstruation is unacceptable in a child with atypical external genitalia.

In contrast, valid functional norms include:

- the need to support adrenal function where necessary, to ensure the health of an individual
- the need to ensure ability to urinate, to ensure the health of an individual.

We note that these valid functional norms relate to the physical health of the individual and so qualify as exempt from restriction, while the functional norms grounded in gender stereotypes are not. This is appropriate. However, these illustrations are not exhaustive. We recommend greater clarity in expressing this principle such that it relates to particular rationales that may be described as functional.

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<sup>34</sup> Christopher Boorse, ‘On the Distinction between Disease and Illness’ (1975) 5(1) *Philosophy & Public Affairs* 49; Christopher Boorse, ‘Health as a Theoretical Concept’ (1977) 44(4) *Philosophy of Science* 542; Christopher Boorse, ‘A Rebuttal on Health’ in James M Humber and Robert F Almeder (eds), *What Is Disease?* (Humana Press, 1997) 1 <[http://link.springer.com/chapter/10.1007/978-1-59259-451-1\\_1](http://link.springer.com/chapter/10.1007/978-1-59259-451-1_1)>.

<sup>35</sup> Christopher Boorse, ‘A Second Rebuttal On Health’ (2014) 39(6) *Journal of Medicine and Philosophy* 683, 693.

<sup>36</sup> Irving Kenneth Zola, ‘Medicine as an Institution of Social Control’ (1972) 20(4) *The Sociological Review* 487.

Secondly, we support the reference to “financial considerations”, but it gives rise to consequences outside the scope of the proposed legislation. Financial considerations are a genuine concern impacting access to healthcare, and the ability to avail of the right to health. At present, the Medicare Benefits Schedule includes some codes for paediatric feminising procedures that lack direct analogues for adults.<sup>37</sup> This means that youth may potentially be unable to access treatment as adults, when they are no longer protected persons, as those that are restricted before they are old enough to personally consent.

The ACT government should consider engaging with the federal Department of Health and Aged Care to ensure that MBS codes are reformed to ensure consistency with the proposed legislation.

Thirdly, the reference to stigmatisation and discrimination should be described clearly in the explanatory memorandum to relate it to concepts of bullying, but also to familial and social integration. Clinical rationales include unevidenced suggestions that surgeries improve bonding between parents and child,<sup>38</sup> and this seems to us to be evidence of stigmatisation and its consequences within the family unit. Restricted medical treatments are never an appropriate response to these issues.

Principle (d) states:

*“to the greatest extent possible, a person with a variation in sex characteristics should make decisions about any restricted medical treatment”*

This is a general principle that is applicable to all, and this seems appropriate. The principle should refer to treatment on the person’s own sex characteristics, and it should be reordered higher in the list of principles, perhaps following existing principle (a).

Principle (e) states:

*“any view or wish expressed by a protected person in relation to their sex characteristics or proposed restricted medical treatment is the most important consideration”*

In our view, this principle should refer to a “freely expressed” view. Further, as “the most important consideration”, this principle should be reordered high in the list of principles, perhaps following existing principle (a) and existing principle (d). Consideration should be given to the language expressing prioritisation, and whether or not it might be appropriate to refer to the “single most important consideration”.

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<sup>37</sup> Carpenter, ‘Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data’ (n 8).

<sup>38</sup> Peter A Lee et al, ‘Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care’ (2016) 85(3) *Hormone Research in Paediatrics* 158 (‘Global Disorders of Sex Development Update since 2006’); Lynn Gillam, ‘Ethical Principles for the Management of DSD’ in John M Hutson et al (eds), *Disorders/Differences of Sex Development: An Integrated Approach to Management* (Springer, 2020) 179 <[https://doi.org/10.1007/978-981-13-7864-5\\_15](https://doi.org/10.1007/978-981-13-7864-5_15)>.

Principle (f) states:

*whenever possible, decisions about undertaking restricted medical treatment on a child with a variation in sex characteristics should be deferred to allow the child to make decisions when they have decision-making capacity*

We note that the meaning of the reference to a child is not currently defined in the proposed bill. Children might be regarded as a subset of protected persons, but it would be helpful for this to be specified.

We believe that this principle should include consideration of the evolving capacity of the child. In line with recommendations by Relationships Australia, we recommend that a note be included referring to the Convention on the Rights of the Child and explaining its relationship to the bill.

For consistency, the reference to decisions by a child should refer to a “freely expressed” view or wish.

Principle (g) states:

*when deciding the most appropriate restricted medical treatment for a protected person, priority should be given to a treatment that leaves as many decisions about their sex characteristics as possible for the person to make if and when they have decision-making capacity*

consideration should be given to the hierarchy in prioritising principles here.

Principle (h) states:

*a protected person should be assisted, as far as practicable, to take part in the decision-making about any restricted medical treatment.*

This principle raises a policy question about mechanisms to support supported decision-making, which are not yet clearly articulated in the draft legislation. We see this as an application of general principle (a).

### **Additional principles:**

We recommend adding a principle that expresses the human right of people with variations of sex characteristics to health, without discrimination. In our view this is a necessary balance to help ensure access to treatment by both protected persons and formerly protected persons. For example, we draw attention to our earlier remarks on financial considerations and Medicare Benefits Schedule paediatric-only item codes.

### **Alternative approaches:**

We are supportive of proposals by Relationships Australia that group principles thematically, describing or conferring decision-making rights and explaining how these are given effect (paragraphs a, d and f); describing how decisions should be made (paragraphs

b, c, e, h, where b and c are applicable to all persons with variations of sex characteristics); and describing what kind of decisions should be made (paragraph g).

We are also supportive of a proposal by Equality Australia for an overarching test to put the interests of the person with a variation of sex characteristics at the centre of a decision-making. We recommend the definition of a test that does not presume a particular decision by the panel.

We also note proposals to define clauses thematically in relation to all persons with variations of sex characteristics, all protected persons and protected persons aged under 18. We note that the bill primarily relates to protected persons.

### **Clause 11, on general obligations**

We recommend that the bill distinguish carefully between persons with variations of sex characteristics, and protected persons.

We recommend that the government ensure that reporting obligations to the expert panel are required for all treatment plans, including individual treatment plans, including acceptable post-facto reporting timeframes for medical treatments.

Applicants and other parties to the application process should be relieved of their liabilities and obligations to ensure patient confidentiality for the sole purpose of informing the panel.

### **Clause 12, on requirements for informed consent**

In part one, the meaning of “sufficient information” is unclear. Who determines what is sufficient? We recommend replacing this term with “required information”, and explaining requirements in government guidance for stakeholders.

In subclause (2) (ii), we recommend adding the impact on fertility, and on sexual function and sensation.

In subclause (2) (iii) in the phrase “the likely advantages and disadvantages of deferring or not undertaking restricted medical treatment, including, if appropriate, information about other kinds of treatment”, we recommend consideration of whether or not the word “if” should be inserted as alternatives to non-life preserving treatment should generally be available.

In this subclause, we recommend replacing “information about other kinds of treatment (for example, psychosocial care)” with “information about other kinds of care, support (including peer support) and treatment”.

In subclause (2) (c), we recommend that ministerial authority should be constrained by the bill’s objects and general principles.



The bill should establish that, even in respect of treatment carried out under a general treatment plan, that a person undertaking restricted medical treatment must obtain informed consent as described in this clause, and in line with the evolving capacity of any protected person who is under 18.

### **Clauses 13 and 14, on offences**

We note that the proposed penalties for unauthorised deferrable medical interventions on people with variations of sex characteristics are significantly less than those for female genital mutilation specified in the Crime Act 1900 (ACT). In relation to female genital mutilation, the penalty for performing this act is 15 years (with no penalty units), while the penalty for jurisdiction shopping is 7 years. The reasons for this disparity between offences is not clear.

In our view, the application of penalties for female genital mutilation is often racialised in ways that exclude cosmetic procedures that take place on non-racialised women with their personal consent.<sup>39</sup> That is, a distinction between permissible and criminalised procedures relies on the background of the person seeking a procedure as well as their consent.

Women with variations of sex characteristics may be at risk of practices commonly understood to be female genital mutilation even while other girls and women with variations of sex characteristics are at risk of unnecessary modifications to their genitals, including practices described as ‘enhancing’ genital appearance,<sup>40</sup> that are currently exempt from criminalisation as female genital mutilation. Thus deferrable medical interventions on people with variations of sex characteristics and procedures that modify the appearance or function of female genitalia are not clearly distinguishable. Consideration should be given to standardising offences.

We are supportive of comments by Relationships Australia in relation to penalty rates and implications for professional regulators and insurance providers.

We recommend adding a civil law penalty for failing to receive informed consent from a person with decision-making capacity in order to provide a remedy for individuals subject to treatment without informed consent.

### **Clauses 16 to 18, on general treatment plans**

In paragraph 16 (2) (b) we believe that general medical treatment plans should be constrained by both the general principles in clause 10 and the objects in clause 6.

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<sup>39</sup> Arianne Shahvisi, ‘“FGM” vs. Female “Cosmetic” Surgeries: Why Do They Continue to Be Treated Separately?’ [2021] *International Journal of Impotence Research*; Clare Dyer, ‘FGM: Surgeons Who Do Cosmetic Genital Surgery May Risk Prosecution’ (2019) 367 *BMJ* I6094.

<sup>40</sup> Carpenter, ‘Intersex Variations, Human Rights, and the International Classification of Diseases’ (n 9); Bock (n 9).

In clause 17 we recommend adding consultation with the Chief Medical Officer, and we recommend increasing the specificity of subclause 17 (2) to include reference to community organisations such as IHRA.

In paragraph 18 (6) (b) we recommend that any revisions should be fully explained and publicly disclosed by the committee.

The legislation should make provision for the sunseting, review and updating of general treatment plans. These might include provisions for automatic review, or requests by protected persons, persons with bodies with an interest in the care of protected persons, or expert panel members. Consultation arrangements for new plans should also apply to changes to plans. We believe that some consideration should be given to the possibility of vexatious requests.

### **Clauses 20 to 23, on individual treatment plans**

In clause 20, and given the provisions in this bill to enable supported decision-making, it would be consistent to add the protected person as a potential applicant. We recommend adding protected persons as applicants, and adding provisions to ensure that steps have been taken to determine a child's wishes and views, and steps taken to assist a child to participate in decision-making.

We also recommend improving the clarity around applications from persons with parental responsibility and persons with an interest in care of an individual.

In clause 20, we recommend adding requirements for applicants to include data on previous medical interventions, and any previous applications for relevant treatment in the ACT or elsewhere. This provision should anticipate the enactment of similar legislation in other jurisdictions.

In clause 20 we also recommend the addition of a process to review or terminate an individual treatment plan, or limit their duration. We note that limitations to specific procedures is implied by the scope of the plan content, and we seek to ensure continuity across individual treatment plans, and the drafting of treatment plans that anticipate treatments across a childhood and across a lifespan.

In paragraph 22 (2) (a), we recommend ensuring that, to the maximum extent possible, the protected person should be consulted. This is consistent with the evolving capacity of the child and provisions facilitating supported decision-making.

In paragraph 22 (2) (b), we recommend enumerating individuals with knowledge of the protected person (e.g. carers, interpreters, support).

We also recommend adding provisions to ensure the admissibility of information from past cases, similar cases, and evidence brought before the committee. The intention is to ensure consistent decision-making, promoting certainty about treatment decisions, and promote the development of expertise within the panel.

We note a drafting error where paragraph 22 (2) (b) contradicts subclause 22 (3) in relation to the necessity of disclosure or non-disclosure of the identity of a protected person.

Provision should be made for the sunseting of individual plans, and the review of individual plans.

Time limits should be set for consideration of an individual treatment plan by a committee.

In paragraphs 23 (1) (d) and (e), individual treatment plans should include detailed information about prior and proposed treatments, including the provision of evidence for a proposed treatment and for alternative treatments.

### **Part 5, on expert panels**

We support the proposals for an expert panel, recommending that a panel ensure the operation of the legislation in consistency with both objects and general principles, and the publication of annual reports that protect the privacy of individual persons that are the subjects of treatment plans.

We want the process to be as lightweight and accessible as possible, and inquisitorial rather than adversarial. Applicants should be supported by an individual appointed by the president or expert panel to assist them with the process, analogous to a counsel assisting, and in order to ensure that the process is inquisitorial and non-adversarial. By this, we mean that the panel members should be actively engaged in processes to ascertain facts and examine evidence.

The legislation should take account of the possibility that expert panel members may, in future, be members of similar panels in other jurisdictions.

In our comments on clause 20 we recommend that persons making applications for individual treatment plans include data on previous medical interventions, and any previous applications for relevant treatment in the ACT or elsewhere. The panel should be able to take into account in its decision-making any previous decisions made in relation to relevant individual treatment plans, and any relevant decisions made by panels in other jurisdictions.

The proposed legislation should make provision for a specified term of office for the president and expert panel members, while also enabling reappointment.

The proposals should give consideration to whether or not proceedings might be subject to freedom of information applications.

Panel members should be required to act impartially, and declare any conflicts of interests. Panel members should also be required to bring to bear their specialist expertise when making decisions in relation to general and individual treatment plans.

The president or the expert panel should have the power to appoint or recommend qualified persons who can support decision-making. The president or expert panel should be able to ensure that such persons act with impartiality in the best interests of the protected person.

In paragraph 25 (1) (b) we recommend defining “relevant people” more broadly to include community stakeholders.

In paragraph 26 (1) and (3), we believe that the legislation should set out more criteria for appointing the president. We recommend that the president have demonstrable expertise in human rights.

We are somewhat sympathetic to proposals to reduce the number of categories, and to the amalgamation of medicine and ethics (i.e. medicine and bioethics). However, we also note a tendency to prioritise medical expertise and not bioethical or allied health expertise, risking the appointment to a pool of members of individuals with bioethical and allied health expertise but their non-utilisation in situations where a sole medical/ethical/allied health expert is appointed to a panel. We note that convenings of medical experts during some discussions on possible legislation to protect the human rights of people with variations of sex characteristics have, in some cases, deliberately excluded bioethics expertise. Similarly, we advise against conflating psychosocial and psychological expertise with medical expertise.

We recommend that panel appointees include individuals with expertise in child rights and in disability rights. We believe that an expert in disability rights should have strong expertise in relation to capacity and supported decision-making.

In general, we prefer a panel rather than a president making decisions.

### **Clause 31, on annual reports**

We recommend expanding annual reporting to include reporting on:

- emergency and other exempt procedures on protected persons
- past procedures, including those prior to commencement of the Act and those in other jurisdictions, as documented in applications for individual treatment plans
- implementation of individual treatment plans and general medical treatment plans, including procedures that take place on persons aged under 18 with personal consent

### **Clause 33, on medical records**

We recommend ensuring that protected persons have access to:

- their own records
- information on any emergency and other exempt treatments

- historical records, prior to commencement of the proposed legislation.

## **Part 6, on notification and review of decisions**

Noting the overarching exemption for procedures that are urgent or life-saving, we recommend that any treatments be stayed or withheld while they are pending review outcomes.

In clause 37, we recommend that the president and panel should explain their decisions clearly. Any dissenting views by panel members should also be clearly explained.

All decisions should be notified to anyone with parental or carer responsibility, as far as is practicable.

As the expert panel is an expert body, there should be no review by a third party on the basis of merits by any less expert body. We support views that propose the operation of the expert panel in ways that are similar to those of other expert bodies and ACAT, including:

- Appointment of a larger pool of experts
- A smaller consensus panel for individual decisions
- A larger internal review, decided by a majority
- Followed by a limited review on merits including consideration of errors of law, or failures to consider relevant questions, including failure to consider relevant evidence
- Decision-making may be remitted back for internal review
- A final appeal might be made to the supreme court or ACAT on legal grounds

## **Part 7, on regulation-making powers**

We recommend that, when making, amending and revoking regulations, the government be required to consult with persons and institutions described in clause 17.<sup>41</sup> We note that we also recommend expanding the list of persons and institutions to explicitly include community organisations such as IHRA.

We recommend that operation of ministerial regulating powers be constrained to ensure the furthering of the objects and principles of the legislation.

## **Dictionary, on definitions**

In our view, leaving a definition of ‘variation in sex characteristics’ appears surprising in a bill that is named using this term. Lack of legislative definition provides no safeguards into the future and creates risks of gaming or neglect.

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<sup>41</sup> Clause 17 refers to consultations in respect of general medical treatment plans

We strongly favour inclusion of a legislative umbrella definition of ‘variations of sex characteristics’ that can be expanded via an enumeration of specific traits via regulation.

A legislative umbrella definition should provide a reference to current and historical umbrella terms, in acknowledgement that clinical terms are undergoing a shift from nomenclature based on histology, clusters of symptoms and eponyms to nomenclature based on genetics.

A legislative umbrella definition might include reference to “traits known using the terms intersex, disorders of sex development, disorders of sexual differentiation, differences of sex development, and including traits currently or historically known using such terms”.

This umbrella definition should note that it is expanded via regulation. Regulation should include the names of specific traits and diagnoses, as they are currently known.

In the proposed regulation, we recommend addition of the diagnosis ‘hyperandrogenism’. This diagnostic term is used to refer to atypical virilisation in women, where virilisation is problematised and treated. In our view, people with this diagnosis are entitled to the protections afforded by the proposed legislation in the same manner as other people with variations of sex characteristics.

## **Additional amendments**

Finally, we note that ACT legislation and regulation includes references to intersex that do not meet community expectations and that, in the case of regulation relating to birth registrations, we explicitly opposed as an organisation.<sup>42</sup>

These include references in the Births, Deaths and Marriages Registration Act 1997, Casino Control Act 2006, Children and Young People Act 2008, Confiscation of Criminal Assets Act 2003, Corrections Management Act 2007, Crimes Act 1900, Crimes (Child Sex Offenders) Act 2005, Crimes (Forensic Procedures) Act 2000, Discrimination Act 1991, Drugs of Dependence Act 1989, Intoxicated People (Care and Protection) Act 1994, and Terrorism (Extraordinary Temporary Powers) Act 2006. Some of these laws reference a definition in the Legislation Act 2001 that is not fit for purpose.

In relation to the Discrimination Act, a cross-reference to the Legislation Act persists despite the replacement of previous references to discrimination against intersex people with new references to discrimination on the ground of sex characteristics.

In the case of the Births, Deaths and Marriages Registration Act 1997, references to intersex provide for different kinds of medical gatekeeping when no medical gatekeeping should be required.

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<sup>42</sup> See, *inter alia*, Morgan Carpenter, ‘The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change’ (2016) 24(47) *Reproductive Health Matters* 74; Morgan Carpenter, ‘The “Normalization” of Intersex Bodies and “Othering” of Intersex Identities in Australia’ (2018) 15(4) *Journal of Bioethical Inquiry* 487.

All other cases relate to intimate body searches and detainment procedures. In our view, these situations impact people with innate variations of sex characteristics, where those stigmatised sex characteristics give rise to particular risks and vulnerabilities, or uncertainties about treatment alternatives by institutional bodies or staff. In our view, special consideration should be available to everyone who might be vulnerable to stigmatisation or discrimination because of their sex characteristics.<sup>43</sup>

We strongly recommend that the ACT government amend manage these through provisions included in this legislative package, to help ensure a coherent and consistent understanding of the population.

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<sup>43</sup> We note that these occurrences in legislation of the word intersex are accompanied also by the word transgender, and so vulnerabilities and risks on the basis of gender identity should also be considered.