

July 5th, 2022

To Whom It May Concern:

On behalf of OutRight Action International, please accept this submission in response to the 2022 Australian Capital Territory (ACT) government draft bill concerning variation in sex characteristics and restricted medical treatment. Established in 1990 and headquartered in New York, OutRight Action International is a leading international organization dedicated to human rights advocacy on behalf of lesbian, gay, bisexual, transgender and intersex (LGBTIQ) people. For more than 30 years we have documented, defended, and advanced human rights for LGBTIQ people around the globe. We make this submission in collaboration with Kimberly Zieselman, an experienced intersex human rights activist and former leader of interACT, the premier intersex advocacy organization in the U.S., whom OutRight has contracted to further inform and advance our work on behalf of global intersex communities.

OutRight's position on the rights of persons born with variations in their sex characteristics (often referred to as intersex) is grounded in international human rights law. States' legal obligations vis-a-vis the rights of LGBTIQ people are articulated by the Yogyakarta Principles, a set of principles developed by a team of human rights experts in 2007 on the application of international human rights law in relation to sexual orientation and gender identity, and the Yogyakarta Principles +10 (YP+10), which supplements the original principles, including through an articulation of international law in relation to differences in sex characteristics.¹

OutRight calls for an end to medically unnecessary interventions performed on intersex children prior to their ability to meaningfully participate in these life-altering decisions. States should uphold Principle 32 of the YP+10 regarding the right to bodily and mental integrity, which states:

¹ The Yogyakarta Principles: Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity, March 2007, http://yogyakartaprinciples.org/wp-content/uploads/2016/08/principles_en.pdf (accessed June 29, 2022); The Yogyakarta Principles Plus Ten: 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, November 10, 2017, http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5 yogyakartaWEB-2.pdf (accessed June 29, 2022).

No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.

The Principle calls on states to pass legislation that protects everyone, including all children, from all forms of forced, coercive or otherwise involuntary modification of their sex characteristics.

We join the chorus of intersex-led organizations and human rights groups worldwide that have condemned the deeply harmful surgeries and other efforts to "normalize" these children, efforts that have no proven medical benefit. Because of the serious physical and mental harm they cause, these procedures have been rejected by United Nations experts on health, torture, and women's and children's rights, the World Health Organization, Amnesty International, Human Rights Watch, and Physicians for Human Rights, among others. People whose bodies transcend arbitrary standards of sex classification must be the driving force behind any contemplated interventions on their bodies. OutRight strongly opposes any efforts that devalue healthy differences and the bodily autonomy of intersex people.

We are delighted to have an opportunity to provide our expert feedback on the 2022 ACT government draft bill concerning variations in sex characteristics and restricted medical treatment. We applaud the work of the ACT government and the many stakeholders responsible, especially intersex advocates, for creating such a meaningful draft compliant with necessary human rights protections. OutRight Action International fully supports the aim to ban "restricted medical treatments" (as defined in the bill) on children with intersex traits until they are old enough to decide treatments for themselves, with exceptions for emergency and urgently necessary procedures.

The passage of this law will firmly position the ACT government as a global leader in the protection of intersex people's human rights. Only Malta, Portugal, Germany and Iceland have passed similar reforms. We recognize and appreciate that the proposed draft bill builds upon the 2017 Darlington Statement, a joint statement by Australia and Aotearoa/New Zealand intersex community organizations and independent advocates.² The law also implements

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² Darlington Statement, 10 March 2017, https://darlington.org.au/statement/ (accessed 1 July 2022).

recommendations of the landmark 2021 Australian Human Rights Commission report on the rights of intersex people.³

As requested, the following are our responses to the specific questions about which the ACT government is seeking feedback:

1. OutRight supports the general principles listed in Sec.10 of the draft legislation as guidance for the committees in forming positive decisions and healthcare outcomes for intersex people. The principles thoughtfully and appropriately support an intersex person's right to bodily autonomy and decision making.

We would like to offer an edit to principle (c) on page 8 by adding an additional important factor that should not influence decisions about undertaking restricted medical treatment, namely; (iv) the feelings, comfort, or emotional needs of the parent(s) or caregiver(s).

Reasoning related to parents' emotional needs, including arguments related to parental bonding with infant children, is sometimes tragically used as a justification to perform unnecessary, harmful and irreversible medical procedures on intersex babies.⁴

- 2. We believe the definitions used for sex characteristics and variation in sex characteristics on pages 31-32 are suitable and conform with widely accepted and utilized definitions, including the definition used by the United Nations.⁵
- 3. We believe that the list of intersex variations on page 5 of the "Explanation of Bill" is appropriately inclusive and thorough, and in alignment with commonly accepted definitions of variations in sex characteristics. *Specifically, we support the inclusion of hypospadias, congenital adrenal hyperplasia and XXY variations.* These three specific categories are

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³ Australian Human Rights Commission, *Ensuring Health and Bodily Integrity: Protecting the human rights of people born with variations in sex characteristics in the context of medical interventions*, 18 October 2021, https://humanrights.gov.au/intersex-report-2021 (accessed 1 July 2022).

⁴ Gillam et al describe the possibility of a "child... not [being] accepted by parents in the chosen sex of rearing, leading to impaired bonding; ... of social or cultural disadvantage to child, for example, reduced opportunities for marriage or intimate relationships or reduced opportunity for meaningful employment and capacity to earn an income; [and] of social isolation, restrictions or difficulties, for example caused by embarrassment or social stigma associated with having genitalia which do not match the gender in which the person lives." Gillam, L.H., J.K. Hewitt, and G.L. Warne, Ethical principles for the management of infants with disorders of sex development. Horm Res Paediatr, 2010. 74(6): pp. 412-8.

⁵ UN Office of the High Commissioner for Human Rights, UN Free and Equal, "Fact Sheet: Intersex," https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf (accessed 1 July 2022).

sometimes erroneously not considered intersex traits despite being some of the variations in sex characteristics that are most commonly the subject of human rights violations on intersex people.

- 4. To the best of our knowledge and expertise, we do not believe there are medical treatments other than those listed in Sec. 7 that might inadvertently be captured as "restricted medical treatment" under this bill.
- 5. The bill establishes an Expert Panel in Sec. 25 to Sec. 32, providing for one panel member from each of the listed categories to form a five-member committee to make decisions about treatment plans. We believe to the best of our knowledge and expertise that the categories listed (medicine; ethics; human rights; variation in sex characteristics; and psychosocial support) provide the range of experience, skills and expertise needed. We particularly applaud the specific requirement in Sec. 26 (4) that at least one person with a variation in sex characteristics be appointed to the expert panel. We do note, however, that there are remaining questions around the Expert Panel selection process and duration of terms.
- 6. To the best of our knowledge and expertise, we believe that the process for creating a general treatment plan outlined in Sec.15 to Sec.19 will support appropriate information gathering, consultation and decisions for establishing a general treatment plan as described in the bill. In particular, we applaud the enumerated requirements that an approved general medical treatment plan be consistent with the principles articulated in Sec.10 and that it be established in consultation with the Minister responsible for the Human Rights Act of 2004 (Sec.17(1)(a)(iii)).
- 7. To the best of our knowledge and expertise, we believe that the parameters for what an individual treatment plan application needs to include and the process for how committees should consider these plans, as articulated in Sec.20 Sec.23, is appropriate and in the best interest of the protected intersex person. We support the requirement that the plan be consistent with the principles articulated in Sec.10 and in consultation with the protected person (if practicable).
- 8. We believe that Sec.12 does adequately describe "informed consent" and what is required for it, in the context of a person with variations in sex characteristics consenting to a restricted medical treatment. Importantly, the articulated definition of "required information" in Sec.12(2) includes key factors such as (iii) the likely advantages and disadvantages of deferring or not undertaking restricted medical treatment, including, if appropriate,

Established in 1990 ECOSOC Accredited information about other kinds of treatment (such as psychological care). We also applaud that the "required information" to meet the standard of informed consent, under Sec.12(2)(b), includes contact information for organizations that assist people with intersex variations and facilitate the sharing of knowledge and experience between intersex people and their families.

Finally, the bill drafters note they are considering including language on providing better psychosocial care for intersex individuals and their families, as well as peer support. We strongly urge that these provisions be expressly included in the legislation, as global intersex communities have expressed the vital importance of both psychosocial care and peer support, as evidenced by decades of qualitative data.

In conclusion, we support the draft legislation and respectfully encourage the ACT government to consider our additional recommendations enumerated above. We hope all Australian jurisdictions will undertake similar legislative reform to protect intersex people's human rights and that the Australian pediatric medical community will develop a national standard of care for intersex individuals that affirms human rights.

Sincerely,

Kimberly Zieselman, JD

Consultant, Global Intersex Rights

Kinborky Zieselman

OutRight Action International

Maria Sjödin

Acting Executive Director

OutRight Action International

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