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SUBMISSION TO:

The Australian Human Rights Commission Consultation on Protecting the human rights of people born with variations in sex characteristics in the context of medical interventions

September 2018

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About ACON

ACON is New South Wales' leading health promotion organisation specialising in HIV prevention, HIV support and lesbian, gay, bisexual, transgender and intersex (LGBTI) health. Established in 1985, our mission is to enhance the health and wellbeing of our communities by ending HIV transmission among gay and homosexually active men, and promoting the lifelong health of LGBTI people and people with HIV. We present this submission as strong allies of the intersex community and recognise that other organisations and groups that are peer led by intersex people should be central to discussions and policy processes relating to their health and wellbeing.

The authors of this document strongly support the recommendations outlined in the Darlington Statement and the Yogyakarta Principles+10, documents which have been developed through peer consultation with people who identify as intersex. These documents highlight the importance of seeking input and advice from intersex people on all issues that relate to them, and request that intersex people are not tokenized or co-opted.

General Comments

ACON acknowledge the human rights of intersex people and respect the intersex human rights movement. We acknowledge the distinctiveness and the diversity within the intersex community, and the unique needs to this community through our public affirmation of the Darlington Statement[1].

We recognise that "intersex persons are not united by a shared identity, sexual orientation or gender identity, but instead by common experiences of stigma, discrimination and violence due to innate sex characteristics" [2].

ACON are responding to the Australian Human Rights Commission's consultation on protecting the human rights of people born with variations in sex characteristics in the context of medical interventions as supporters of intersex persons, and their human rights to bodily autonomy and consent to medical interventions.

Our submission will address the following key points:

- Any medical interventions should meet international human rights laws and non-compliance requires sanctions
- Independent oversight is needed for decisions pre and post medical interventions
- Data should be collected about medical interventions
- Resources and funding for peer support and systemic advocacy by intersex-led organisations is needed at a government level
- All people should have the right to consent to medical interventions, and when consent is being given, it should be informed only by physiological health concerns and not psychosocial or social impacts

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[1] ACON. 2018. *Intersex People*, Sydney, Australia, https://www.acon.org.au/who-we-are-here-for/intersex-people/.

[2] Carpenter M, Hart B. 2018. *Background paper: making a submission to the Australian Human Rights Commission consultation on protecting the human rights of people born with variations of sex characteristics in the context of medical interventions*, Intersex Human Rights Australia, AIS Support Group Australia.

Terminology

For the purpose of this submission we will use the term 'people with variations in sex characteristics' to describe the population focus of this consultation in line with the Australian Human Rights Commission's Consultation Paper[3]. This terminology is inclusive of populations who are 'intersex' or have 'intersex variations' and may be used interchangeably for the purpose of this submission.

Background

The current absence of national guidelines on medical interventions for people born with variations in sex characteristics means that people from infancy through to adolescence are subject to unnecessary medical interventions which often have lifelong impacts on health outcomes. Justification for medical interventions is typically based on societal norms aiming to 'normalise' genitalia to appear more male or female for the purpose of rearing a child in a binary gender.

Surgeries performed on people with variations in sex characteristics can have lifelong impacts such as issues with reproduction and at times sterilisation, decreased sexual function, result in lifelong hormone replacement therapy, ongoing complications from surgery which require further surgeries or medical interventions throughout their lifespan, and "psychological damage due to an incorrect imposition of gender"[18].

There are only two very rare instances where medical interventions are required on infants born with variations in sex characteristics and these are: when a baby is born with internal organs on the outside of the body, and where a place needs to be made for urine to leave the body[4]. Any other surgery on infants to align bodies to look more classically 'male' or 'female' are considered cosmetic surgery, *and are not medically necessary*[4].

Medical interventions should meet international human rights laws

"All human beings are born equal in dignity and rights…regardless of our sex characteristics" – Zeid Ra'ad Al Hussein, UN High Commissioner for Human Rights, 2015[5]

Medical interventions on people with variations of sex characteristics that are not performed for the purpose of physiological health outcomes are regarded by international human rights bodies and intersex-led organisations as unnecessary, inhumane, and a violation of human rights.

In 2013 The Senate Community Affairs References Committee (Senate Committee) released a report on the involuntary or coerced sterilisation of intersex people in Australia[6]. The Senate Committee recommended "that all medical treatment of intersex people take place under guidelines that ensure

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[3] Australian Human Rights Commission. 2018. *Protecting the human rights of people born with variations in sex characteristics in the context of medical interventions: Consultation paper,* Sydney, Australia.

[4] Dr Stred S E. 2017. *US: End irreversible surgeries on intersex infants,* Human Rights Watch, https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us.

[5] United Nations High Commissioner for Human Rights. 2015. 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.

[6] The Senate Community Affairs References Committee. 2013. *Involuntary or coerced sterilization of intersex people in Australia,* Commonwealth of Australia, Canberra, Australia.

treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral or normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons"[6].

The recommendations made by the Senate Committee were supported by the Committee on Economic, Social and Cultural Rights in June 2017, and by the UN Human Rights Committee in November 2017[3]. The UN Human Rights Committee made a "clear recommendation to end irreversible medical treatment that is not absolutely medically necessary"[7] and identified that infants and children subjected to medical interventions "which are often based on stereotyped gender roles and are performed before they are able to provide fully informed and free consent"[8] violate basic human rights such as freedom from discrimination, protection from torture and experimentation, right to liberty and security, privacy, and equality before the law[7]. These practices fail to uphold and respect people's right to "physical integrity and ability to develop their gender identity"[9].

The United Nations have highlighted that these medical interventions are "counter to the absolute prohibition of cruel, inhuman, and degrading treatment, and as compromising the human rights to physical integrity and health"[15]. Physicians for Human Rights (PHR) further identify that "from a medical ethics perspective, carrying out an irreversible and medically unnecessary surgery before a child is old enough to consent violates internationally recognised informed consent requirements, and violates the obligation to do no harm"[15].

ACON believe any medical interventions should meet international human rights laws, and non-compliance with such laws require sanctions. In 2018 Malta amended existing legislation that bans medical interventions that aren't medically necessary on people who are unable to provide consent to add, "penalties for non-compliance, equivalent to penalties for female genital mutilation."[2] Violations on human rights must be held accountable by law.

All Australians are entitled to the human right to the highest attainable standard of physical and mental health (Article 12, International Covenant on Economic, Social and Cultural Rights)[10], and the protection of bodily integrity. There is a need to develop a rights-based clinical framework centred on the right of people with variations in sex characteristics to not "undergo medical interventions for social and cultural reasons"[11].

Right to consent to medical interventions

"Irreversible medical treatment, particularly surgery, should only be performed on people who are unable to give consent if there is a health-related need to undertake that surgery, and that need cannot be as

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[7] Intersex Human Rights Australia. 2017. *UN Human Rights Committee calls for recognition of right to bodily integrity*, https://ihra.org.au/31742/unhrc-iccpr-recommendations-2017/.

[8] UN Human Rights Committee. 2017. *Concluding observations on the sixth periodic report of Australia,* https://static1.squarespace.com/static/580025f66b8f5b2dabbe4291/t/5a04a67fec212d19b0559311/1510254213175/INT_CCPR_COC_AUS_29445_E.pdf.

[9] Intersex Human Rights Australia. 2015. *Human rights and intersex people*, https://rm.coe.int/ref/CommDH/IssuePaper(2015)1/Infographic.

[10] Department of Foreign Affairs. 1976. *International covenant on economic, social and cultural rights*, Commonwealth of Australia, Canberra, Australia, http://www.austlii.edu.au/au/other/dfat/treaties/1976/5.html.

[11] Carpenter M. 2016. *The human rights of intersex people: addressing harmful practices and rhetoric of change,* Reproductive Health Matters, pg. 74-84.

effectively met later, when that person can consent to surgery." – Silvan Angius, Member of the Bureau of the European Committee for Social, Cohesion, Human Dignity and Equality (on human rights and intersex people)[12]

Current practice of performing medical interventions for psychosocial purposes on infants or children with variations in sex characteristics does not meet what constitutes as ethical and legal fully informed consent to medical procedure guidelines in Australia.

The NSW Ministry of Health Policy Directive *Consent to Medical Treatment – Patient Information 2005* states "all patients have a choice as to whether or not to undergo a proposed procedure, operation or treatment…and be provided with sufficient information about the condition, investigation options, treatment options, benefits, possible adverse effects or complications…in order to make their own decision about undergoing an operation, procedure or treatment"[13]. This policy also applies in the context of decision-making for minors, parents and guardians must be provided adequate information to inform decisions. Informed consent is required in all cases of invasive medical treatment except in cases of emergency or necessity where a person is unable to provide consent and their life is at risk or to prevent serious injury[13].

The pressure put on parents to assign a 'gender conforming' sex at birth during birth registration procedures places "an overwhelming burden on parents of intersex babies to make quick decisions"[9], this pressure is often amplified further by medical practitioners who are trying to appease parental distress, and fail to inform parents that these procedures are experimental and scientifically unproven to alleviate psychosocial distress related to the child's gender later in life.

Medical interventions on infants and children with variations of sex characteristics performed for cosmetic purposes to make anatomy appear more male or female are irreversible, invasive, and are not a necessity for improved physiological health outcomes. This position is supported and recognised by international human rights bodies. In 2017, the UN Human Rights Committee called for Australia to "end irreversible medical treatment, especially surgery, on intersex infants and children, who are not yet able to provide fully informed and free consent, unless such procedures constitute an absolute medical necessity"[14].

The position to stop medical interventions on infants and children with variations in sex characteristics is further gaining support by clinicians globally. In October 2017, PHR called to end "all medically unnecessary surgical procedures that seek to alter gonads, genitals, or internal sex organs of children born with atypical sex characteristics, until the child is old enough to participate meaningfully in decisions about their body and health"[15].

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[12] Agius S. 2015. *Human rights and intersex people,* Issue Paper, Council of Europe, Council of Europe Commissioner for Human Rights.

[13] NSW Ministry of Health. 2005. *Consent to medical treatment – Patient information,* Policy Directive, NSW Government, https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2005_406.pdf.

[14] UN Human Rights Committee. 2017. *Concluding observations on the sixth periodic report of Australia,* CCPR, https://static1.squarespace.com/static/580025f66b8f5b2dabbe4291/t/5a04a67fec212d19b0559311/1510254213175/INT_CCPR_COC_AUS_29445_E.pdf.

[15] Physicians for Human Rights. 2017. *Unnecessary surgery on intersex children must stop*, Press Release, http://physiciansforhumanrights.org/press/press-releases/intersex-surgery-must-stop.html.

In July 2017, three former U.S. surgeons general released a statement reporting "there is insufficient evidence that growing up with atypical genitalia leads to psychosocial distress" and "evidence does show that the surgery itself can cause severe and irreversible physical harm and emotional distress"[16].

The Committee on Bioethics of the Council of Europe identify that "there is evidence of harmful results of such interventions, including 'genital dysfunction, scarring, loss of sexual feeling, loss of fertility, chronic pain, and the wrong gender assignment – with irreversible excision of genital and gonadal tissues", and further note that there is no evidence to support benefits of such surgeries to the child[12].There is no existing medical evidence base to support practices that 'gender normalise' infants or children with variations in sex characteristics via surgical interventions, and thus no reason to exempt medical interventions in these circumstances from appropriate decision-making processes that ensure informed consent is received under existing Australian healthcare policies.

Independent oversight is required in decision-making

"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" – Intersex Human Rights Australia, 2018[17]

Cases that determine medical interventions of people with variations in sex characteristics who do not have the capacity to consent must be "properly ventilated and considered, including the lifetime health, legal, ethical, sexual and human rights implications"[19], and this must be done by an "independent, effective human rights-based oversight mechanism(s) to determine individual cases…bringing together human rights experts, clinicians and intersex-led community organisations"[19].

We support the Senate Committee's recommendations that "oversight of these decisions is required" (5), "that all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court (6)," and that these administrative tribunals be adequately funded and resourced (8)[6].

In 1992 the High Court of Australia considered "whether a parent could consent to a hysterectomy and ovariectomy to be performed on 14-year-old child with an intellectual disability" (known as Marion's case), and found that "court authorisation is required for a medical procedure that requires invasive, irreversible and major surgery, and is not for the purpose of curing a malfunction or disease"[18]. While this case does not concern a child with variations of sex characteristics, the same level of authorisation should be sought in decision-making on medical interventions that do not serve a purpose of addressing physiological health outcomes, and which result in lifelong impacts on a person's ability to live a fulfilling life.

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[16] Elders, JM. Satcher D. Carmona R. 2017. *Re-thinking genital surgeries on intersex infants,* Palm Center: Blueprints for sound public policy, https://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf.

[17] Intersex Human Rights Australia. 2018. *Shadow report submission: Australia,* Newtown, Australia, https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/AUS/INT_CEDAW_NGO_AUS_31448_E.pdf

[18] Australia Human Rights Commission. 2009. *Surgery on intersex infants and human rights*, https://www.humanrights.gov.au/sites/default/files/content/genderdiversity/surgery_intersex_infants2009.pdf.

In 2017, the Family Court of Australia authorised "cross-sex" hormone treatment for an intersex child who had previously been prescribed testosterone at the age of approx. 12 or 13 to commence puberty (known as Kaitlin's case), regardless of the child's identification as 'female'[17]. When prescribed testosterone treatment, Kaitlin understood that this would assist her body to align with her female gender identity, upon learning this was not the case she was non-compliant with testosterone treatment. Kaitlin should never have been prescribed testosterone treatment, treatment of which violated her right to bodily autonomy and fully informed consent.

Cases such as Kaitlin would never have had to go through costly court procedures had the family's case been reviewed by an independent oversight consisting of intersex human rights experts, intersex-led organisations and clinicians.

The Senate Committee further highlight disturbing concerns at the distinctions "made by Australian courts between 'therapeutic' and 'non-therapeutic' medical intervention" where "treating cancer may be regarded as unambiguously therapeutic treatment, while normalising surgery may not. Thus basing a decision on cancer risk might avoid the need for court oversight in a way that a decision based on other factors might not"[6].

Medical interventions that are not based on physiological health outcomes but rather societal fears of future poor psychosocial development due to having a variation in sex characteristics, is not adequate justification for decision-making and requires appropriate oversight mechanisms. Independent oversight is needed for decisions pre and post medical interventions.

Lack of appropriate data collection

"Children who are born with intersex variations are still subjected to physically and psychologically painful surgeries, hormones, and other medical interventions in order for them to fit narrow ideas of 'female' and 'male'" – *Australian Psychological Society*[25]

Australia does not collect routine data on medical interventions performed on infants and children with variations in sex characteristics that is publicly available which can be used for research and advocacy purposes. We support the position of the Darlington Statement in that there is a need for "regular public disclosure of accurate summary data on all medical interventions to modify the sex characteristic of children, and disclosure of historical data"[19].

Typically, cases are only heard about in Australian media coverage when children and their families present to Family Court. For example in the case of Carla in 2016, in which the Family Court authorised the removal of the gonads of a 5-year-old intersex child[20]. The procedure resulted in sterilisation of the child. At the age of 3, Carla had already undergone cosmetic surgery on her genitals to make them appear more 'female'.

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[19] Intersex Human Rights Australia. 2017. *Darlington Statement,* Darlington, https://ihra.org.au/darlington-statement/.

[20] Topsfield J. 2018. *Inquiry into human rights of intersex people,* The Canberra Times, https://www.canberratimes.com.au/politics/federal/inquiry-into-human-rights-of-intersex-people-20180915-p503xg.html.

We further support the recommendation (13) made by the Senate Committee that "the Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients"[6].

Malta is currently the only country in the world to introduce legislation in 2015 banning medical interventions on infants and children with variations in sex characteristics that are not medically necessary[21]. This reform was celebrated by intersex human rights bodies internationally as a significant human rights achievement for people with variations in sex characteristics. We know that data informs public policy and legislation, and without such evidence on Australian intersex populations it is near impossible to influence changes in Australian public policy reform to achieve equality in health outcomes for this population.

The Global Disorders of Sex Development Consortium (2016 Update) identifies "there is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of disorders of sex development (DSD) surgery…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 stigmatisation"[22].

Given that there is no national or global medical consensus into the benefits and outcomes of medical interventions performed on infants or children with variations in sex characteristics that are not medically necessary due to a lack of evidence, we call for the Commonwealth to invest in research in this field, and to publicly disclose accurate summary data on all medical interventions on infants and children with variations in sex characteristics. We further support the need for such research to be community-led, and in collaboration with Australian intersex human rights bodies.

Need investment in peer support and peer policy advice

"I nearly died of septicaemia as a teenager, due to my genital surgery, I missed so much school I actually had to drop out entirely. It changed my whole life. Immense emotional impact to this day. I suffered PTSD and depression, and attempted suicide. I have struggled to get or keep jobs and felt trapped in a cycle of being outside of the normal social systems… I will never feel good about the surgical changes I was made to endure at an age too young to know better" – Sarah, woman with intersex condition PAIS, Intersex: Stories and Statistics from Australia[23]

There is a need for government investment and resourcing in existing peer support organisations for people with variations in sex characteristics and their families, and the development of new peer support systems and services to build the capacity of these communities. We support the Darlington Statement in recognising "the fundamental importance and benefits of affirmative peer support for people born with variations of sex characteristics," and that the "stigmatisation of intersex characteristics has resulted in a legacy of isolation, secrecy and shame"[19].

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[21] Intersex Human Rights Australia. 2015. *We celebrate Maltese protections for intersex people,* https://ihra.org.au/28592/we-celebrate-maltese-protections-for-intersex-people/.

[22] Lee PA. Nordenstrom A. Houk CP. Ahmed SF. Auchus R. Baratz A. Baratz Dalke K. Lia LM. Lin-Su K. Looijenga LHJ. Mazur T. Meyer-Bahlburg HFL. Mouriquand P. Quigley CA. Sandberg DE. Vilain E. Witchel S. Global DSD Update Consortium. 2016. *Global disorders of sex development update since 2006: Perceptions, approach and care,* Hormone Research in Paediatrics, 85: 158-180.

[23] Jones T, Hart B, Carpenter M, Ansara G, Leonard W, Lucke J. 2016. *Intersex: Stories and statistics from Australia,* Open Book Publishers.

"People born with intersex conditions experience trauma and stigma that have not been fully recognised by the medical and therapeutic professions…histories of surgery and silence have left children and families unable to address many of the traumas associated with intersexuality, including stigma, shame, surgical complications, and potential questions about sexual and gender identity"[24].

We further support the recommendations of the Senate Committee that "intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases (12)", and this information "be a mandatory part of the health care management of intersex cases (11)"[6].

Australians with variations in sex characteristics have identified a number of concerns contributing to poor mental health such as "feeling isolated by stigma or discrimination, family rejection, school bullying from peers and teachers, loss of romantic relationship or tension in relationships on the basis of the variation or related fertility issues, lacking positive social reinforcement, being unable to trust others or disclose to them, and anger or depression over broader socio-cultural rejection"[23].

Evidence further links poor mental health and wellbeing of people with variations in sex characteristics to "the impact of having undergone medical interventions including having undergone a traumatising or unwanted surgery, and grieving the physical parts or sense of autonomy that were lost…for example, Frida had harmed herself when she discovered the cover-up of past genital surgeries that she had unknowingly undergone"[23]. When individuals were asked about their experience with mental health services, some identified that psychologists or healthcare providers "took 'the parent's side' or the doctors' perspective on treatment or other issues rather than supporting their client"[23].

The Australian Psychological Society (APS) state "having an intersex variation is not a mental health issue…mental health issues can emerge as a result of unnecessary surgeries and hormone treatments that may be imposed on infants and young people throughout childhood and adolescence"[25]. The complex issues for people with variations in sex characteristics such as learning of their history of medical interventions, violations of human rights to informed consent and bodily autonomy, and future lifelong health outcomes e.g. sterilisation, limited sexual functioning or possible ongoing surgeries to treat surgical complications, require appropriate peer support to navigate these experiences.

We support the Darlington Statement in calling for "public, government, and philanthropic support for funded, affirmative peer support" and that "peer support must be integrated into human rights-based multi-disciplinary medical approaches, teams and services"[19]. People with variations in sex characteristics and their families need to have "access to funded, independent counselling and peer support"[2].

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[24] Istar Lev A. LCSW & CASAC. 2006. *Intersexuality in the family: An unacknowledged trauma,* Journal of Gay & Lesbian Psychotherapy, Vol. 10(2).

[25] Australian Psychological Society. 2018. Information sheet: Children born with intersex variations, https://www.psychology.org.au/getmedia/2d12b9c7-4a99-4c0b-9ee2-7079c6be3ba8/Children-born-with-intersex-variations.pdf.

Recommendations

- Introduce Federal legal protections for people with variations in sex characteristics from medically unnecessary medical interventions, with sanctions for non-compliance.
- Develop a rights-based clinical framework which centres on the right of people with variations in sex characteristics to not undergo medical interventions for psychosocial, cultural or other purposes that are not physiological health concerns, and the right to fully informed consent.
- Develop clinical guidelines on the deferral of medically unnecessary medical interventions on infants and children with variations in sex characteristics until they are able to provide fully informed consent.
- Develop an oversight mechanism to oversee decisions pre and post medical interventions consisting of Australian intersex human rights bodies, community-led organisations and clinicians, which allows for appropriate consideration of cases and access to peers. This mechanism must be appropriately resourced and funded by the Commonwealth.
- The Commonwealth to invest in research that includes a long-term prospective study of clinical outcomes for intersex patients. Research to be community-led and in collaboration with Australian intersex human rights bodies.
- The Commonwealth to publicly disclose accurate summary data on all medical interventions performed on people born with variations in sex characteristics.
- Improve data collection mechanisms for people with variations in sex characteristics to reflect this proportion of the population in national population data, and in state-wide healthcare provision settings.
- Public, government and philanthropic support for funded, affirmative peer support.
- Peer support be integrated into human rights-based multi-disciplinary medical approaches, teams and services.
- Commonwealth investment into peer support organisations and into the development of new peer support systems and services to build the capacity of people with variations in sex characteristics and their families.