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**For intersex human rights, information, and peer support**

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## **Submission to the Australian Human Rights Commission: Sexual Orientation, Gender Identity and Intersex Rights Snapshot Report**

### **1. Contents**

1. Contents .....	1
2. OII Australia and this submission .....	2
3. Intersex variations .....	2
4. How well SOGII rights are respected and protected in Australia.....	3
Home lives .....	4
Work lives .....	5
Healthcare issues .....	5
Community issues .....	6
Parents .....	6
5. Examples of legislation, policies and practices by government that unduly restrict SOGII rights.....	7
Failure to act on human rights violations in medical settings .....	7
Flawed implementations of third gender recognition .....	10
Funding actions and focus.....	12
Failure to recognise birth sex assignment in sport .....	13
6. What is being done, and what more should be done, to promote a culture of respect for SOGII rights.....	14
Health policy issues .....	14
Health service issues.....	15
Education and awareness raising policy and services .....	15
Sex and gender recognition policy .....	15
Policy on redress .....	15
Community development.....	15

## 2. OII Australia and this submission

Organisation Intersex International Australia Limited (“OII Australia”) is a national body by and for people with intersex variations. It promotes the human rights and bodily autonomy of intersex people in Australia, and provide information, education and peer support. OII Australia is a not-for-profit company, with Public Benevolent Institution status. This submission, like almost all other advocacy and service delivery activities by OII Australia, is wholly a product of volunteer input. Its focus is on intersex issues, the trailing “I” in SOGII.

The submission was written on behalf of OII Australia by Morgan Carpenter, president of the organisation, in consultation with members, board, and broader constituency. Contact: Morgan Carpenter, President, OII Australia, [morgan@oii.org.au](mailto:morgan@oii.org.au), +61 405 615 942.

## 3. Intersex variations

People with intersex variations are born with atypical physical sex characteristics. Many intersex variations exist; intersex is a spectrum or umbrella. A German researcher states they “comprise a heterogeneous group ... with at least 40 different entities of which most are genetically determined. An exact diagnosis is lacking in 10 to 80% of the cases”.<sup>1</sup> It can mean a different number of sex chromosomes; different physical responses to sex hormones; or different developmental hormone balances and anatomies. It includes many varied kinds of bodies, experiences and identities.

As a group, intersex people face a range of health and human rights issues, and deep-seated stigma, caught between two contrasting visions of who and how we should be. On the one hand, this includes medical interventions in infancy and childhood, explicitly intended to make intersex bodies conform to social norms for a specific sex or gender.<sup>2</sup> On the other hand, we increasingly face misgendering, through expectations to identify as a third gender or sex, to transgress gender norms. Generally, people with intersex variations may face some of the same stigma faced by trans people, particularly if we change our sex classification, but we also face stigma and failures to recognise our birth sex assignment.

A shift in terminology from LGBT to LGBTI over recent years has not been matched by an increase in understanding of intersex, nor action by non-intersex organisations on intersex issues. We are aware of multiple education programs that have framed intersex as a gender identity issue, as if all people with intersex variations share the same gender identity. We’ve also seen many cases of intersex (and trans) issues framed as issues of sexual orientation.

Over the last year, OII Australia has shifted our use of language slightly. While we still talk of intersex people, we also frequently talk about people with intersex variations. We do this to make three points.

Firstly, people with intersex variations are not an homogeneous group; we have many different kinds of innate sex characteristics, and different kinds of body. Current medical research and protocols, including research funded by institutions such as the National Health and Medical Research Council, intrinsically disorders this human diversity as “disorders of

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<sup>1</sup> Hiort, in University of Glasgow. “Proceedings of the 4th International Symposium on Disorders of Sex Development.” In Proceedings of the 4th International Symposium on Disorders of Sex Development. Glasgow: University of Glasgow, 2013. [http://www.gla.ac.uk/media/media\\_279274\\_en.pdf](http://www.gla.ac.uk/media/media_279274_en.pdf).

<sup>2</sup> Senate, Community Affairs References Committee, and Rachel Siewert. Involuntary or Coerced Sterilisation of Intersex People in Australia. Canberra: Community Affairs References Committee, 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).

sex development” or “DSD”. This new language reasserted medical authority in the light of successful intersex activism that cast our issues as human rights, and is strongly contested.<sup>3</sup>

Secondly, talk of intersex people frequently focuses on presumed identity issues; it often forgets that we have multiple gender identities. An identity focus ignores the diversity of those identities, and in particular it ignores intersex women and men. It denies us agency to make our own choices about our gender identities. We need greater understanding and welcoming of our diversity. While we supported federal guidelines on sex and gender recognition, we did so in acknowledgement that the guidelines recognised our diverse gender identities. Unfortunately, the implementation and interpretation has been less respectful, and we have modified our position.

Finally, we are caught between the languages of DSD and individual diagnoses, wielded by clinicians, the language of intersex, embraced by most community organisations (including both community-led organisations in Australia), and novel terms created elsewhere. The misuse of terminology, and construction of more and different abstract terminology creates a “hermeneutical injustice”: it prevents someone with lived experience from making sense of their own experience. Miranda Fricker describes a SOGII-related example of “hermeneutical injustice” thus:

*the difficulty of making sense of homosexual desire as a legitimate sexual orientation in a cultural-historical context where homosexuality is interpreted as perverse or shameful.*<sup>4</sup>

For people with intersex variations, this hermeneutical injustice is at its most profound in the culture of secrecy that applied to intersex diagnoses from the 1950s to, at least, the start of this century. In that silence, it gave people with intersex variations no words to describe our sutures, scars and lack of sensation, and no words to understand the commonalities we share across the diversity of intersex experiences.

That hermeneutical injustice is exacerbated by a spotlight on identity issues, in particular a spotlight on non-binary gender identities; instead, we need this word to continue to describe our experiences of the body.

Hermeneutical injustice is perpetuated by changes in clinical language. That distinct clinical language itself erects a barrier to alternative treatment paradigms based on respect for personal autonomy; and also a barrier to the new legal protections afforded by the Sex Discrimination Act.

#### **4. How well SOGII rights are respected and protected in Australia**

International attention to issues facing people with intersex variations is rapidly increasing, including 4 February Concluding observations of the UN Committee on the Rights of Child (CRC) for Switzerland. The Committee commented:

*43 ... (b) In line with the recommendations on ethical issues relating to intersexuality by the National Advisory Commission on Biomedical Ethics, ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support.*<sup>5</sup>

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<sup>3</sup> Davis, Georgiann. ““DSD is a perfectly fine term”: reasserting medical authority through a shift in intersex terminology”, in *Advances in Medical Sociology*, Vol. 12, 2011, p. 178. DOI: 10.1108/S1057-6290(2011)0000012012

<sup>4</sup> Fricker, Miranda. “Forum on Miranda Fricker’s Epistemic Injustice: Power and the Ethics of Knowing.” *Theoria*, no. 61 (2008): 69–71.

<sup>5</sup> United Nations Committee on the Rights of Child (4 February 2015) Concluding observations on the

The Committee also noted “the lack of redress and compensation” for Swiss survivors.

In Malta, a Gender Identity, Gender Expression and Sex Characteristics (GIGESC) Bill, that will create a right to physical integrity, passed its second reading on the same day.<sup>6</sup>

Nevertheless, respect and protection of the rights of people with intersex variations is mixed within Australia. The 2013 amendment to the Sex Discrimination Act was a huge advance in the rights of people with intersex variations, but public and institutional awareness is poor, and our own investigations suggest that few major institutions have acknowledged that “intersex status” means something different in intent and scope to the independent attributes of “gender identity” and “sex”.

Clinical practices do not appear to have changed since the passing of the amendment to the Sex Discrimination Act, nor publication of the Senate committee report on involuntary or coerced sterilisation.

Much intersex advocacy work necessarily focuses on ending surgical and hormonal interventions on infants and children that still continue today, but adults who have experienced medical interventions, particularly prior to the 2006 clinician statement and the contemporaneous commitments to end secrecy-based approaches to healthcare remain islanded by newer developments.

We have asked our members and the broader community for their experiences about how their rights are respected, and responses follow. A number of examples predate current legal protections.

## Home lives

- Trauma, with an impact on intimacy and home lives:

*The scar constantly reminds me how different I am. It's often the first thing a lover sees when I get naked too. Sometimes I just don't want to talk about it so it has stopped me getting too intimate with people.*

*Psychological issues with trust, intimacy, low-self esteem, authoritarian systems.*

*I haven't had a long term relationship since a set of post-diagnosis surgical interventions.*

*Ongoing drug use.*

*It has a serious impact on us in terms of our sexual health, our relationships, being able to reproduce, and being different. One of the things that they say to us is that we need to have our gonads removed because we are different— 'We want to make you look normal.' Of course, part of the whole sterilisation thing is that you have pretty big surgery and scars, so they are making you different!*

- Diminished sexual function and sensation:

*I really can't talk about this.*

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combined second to fourth periodic reports of Switzerland (advance unedited version), CRC/C/CHE/CO/2-4, [http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/CHE/CRC\\_C\\_CHE\\_CO\\_2-4%20ADVANCE%20UNEDITED%20VERSION\\_19492\\_E.doc](http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/CHE/CRC_C_CHE_CO_2-4%20ADVANCE%20UNEDITED%20VERSION_19492_E.doc)

<sup>6</sup> Parliament of Malta (2015) Gender Identity, Gender Expression and Sex Characteristics Bill, <http://www.parlament.mt/billdetails?bid=494&l=1&legcat=13>

## Work lives

- An impact of trauma and stigma on work lives:

*I have been un/underemployed for the last 14 years. Before I was out, secrecy and shame made me feel like I was living a double (triple) life... eventually I just quit the idea of engaging with the 'system' at all.*

*I started several small businesses and volunteered a lot.*

*In the end I operated my own business and even there difficulties with customers and 'whispers' became severe.*

- Stigma and discrimination:

*harassing me in a dreadful way to make me look like a pervert.*

*I had a co-worker who was very interested in finding out private details about my body. He was constantly asking questions of other people in the building about what was going on with me. After investigating, he finally confronted me in public in front of several other co-workers. "I know what's up with you!", he said. "You're a hermaphrodite!" I found that word offensive and his behaviour invasive and uncomfortable. When I complained about it to my supervisor, she said that I had to understand that people would have questions and that it was understandable... I felt tense and upset walking into the building and very uncomfortable using the men's toilets. There was a thing gap between the door and the cubicle wall. This guy was so abusive and harassing: he would try to peek into the gap, just to see my body parts.*

- Unwanted disclosure:

*I was deeply humiliated in front of a number of the staff.*

*I migrated to Australia with my employer. Close to the start of discussions with my employer about the relocation process, I felt I had to disclose some of my medical history to my employer's migration agent. Some of that included a history of stuff that just doesn't happen to typical guys, and history of trauma and reactive depression. A full medical history is a necessary part of the visa application process, and I was concerned about the implications. The migration agent required me to disclose that data to the employer, on the basis that it could affect the offer of a position to me in Sydney. It could have affected that offer – and it could also have affected my existing role in the business.*

*I was working for a company in another state and the manager heard from one of the staff that there was "something funny about me". The manager called me into his office and demanded to know what the "funny" was. I told him. He demanded that I then stand up in front of all the staff at an all-staff meeting the next morning to apologise for being different.*

## Healthcare issues

- Unwanted medical attention:

*When I was 11, I remember lying to my friends about going on a holiday and instead I went to hospital. I remember lots of people in white jackets standing around watching as another man put his fingers inside my vagina whilst talking about me like I wasn't there. They fixed me up and I went home and made up lies about how much fun I had had on my holiday.*

*Medical interference and mismanagement that was focused primarily on gender normalisation and not on my needs.*

- Inadequate medical funding and access:

*I had inadequate information on hormones, I felt used as a lab rat.*

*I avoid going to the doctors as much as I can.*

*I had a stand-up row in my medical insurer's office because they wouldn't refund any costs for a mammogram screening because I'm a guy.*

- Secrecy; difficulties both in naming their own experiences and framing them as systemic issues.
- A lifetime of post-sterilisation hormone treatment, including legacies of osteoporosis.
- Repeat surgeries, including surgeries to correct failed earlier surgeries.
- Infertility issues.
- Inadequate follow-up by clinicians:

*the consequences of those medical interventions are felt but treatments are unknown as no substantive long term follow ups have been done.*

- Absent or inadequate psychological support.
- Pressure into rapid decision-making.

## Community issues

- Lack of respect for any changed gender identity, but also lack of respect for birth sex assignment:

*refusal by people to refrain from using pronouns that I have explicitly requested they do not do so.*

*Prejudice, pointing, subtle dis-inclusion, It's kind of endless. I would say I am made aware of my differences in an uncomfortable way about once a day and in a way that is unnerving about once every couple of months.*

- An outsider empathy with LGBT persons and community; stigma being associated with LGBT communities without a sense of belonging.
- A sense of belonging in LGBT spaces, but also an experience of heteronormative surgical interventions (designed to promote heterosexual intercourse) while not being heterosexual.
- Lack of understanding of intersex; inadequate community support:

*social events and health resources are not all that friendly for Intersex people. I never feel like I really fit anyplace.*

## Parents

The peer support work of OII Australia is necessarily private, and not publicly visible. Within just the first month of 2015, we have been approached by 4 new families, with circumstances that we cannot disclose, except to note that parents are deeply concerned about their children, but also vulnerable, and that includes a vulnerability to stigma arising from disclosure.

Lih-Mei Liao, a clinical psychologist at London's main clinic working with people with intersex variations, and Margaret Simmonds of the UK AIS Support Group, comment concisely on the relationship between parents and clinicians:

*Social science research in DSD suggests that interactions between doctors and parents are at risk of preventing the latter from carrying out their duty of care towards their children, that 'parents are not given the chance to imagine their children's lives in any way except in need of immediate correction' (Feder, 2002, p. 313). Doctors may well believe that parents have all along been equal partners in decision-making regarding gender assignment and elective genital surgery, but detailed studies with medical experts have failed to identify clear examples of parental participation (Kessler, 1990, 1998). The ethical integrity of medically non-essential genital surgery on infants is significantly challenged by a combination of factors: the emotional vulnerability in parents, the lack of well-developed collaborative processes and the evidence of poor adult outcomes of surgery<sup>7</sup>*

They also about the pressures faced by psychologists in any role within a clinical system still focused on medical interventions:

*because psychological interventions would invariably be influenced by an ideology of self-acceptance, it is not immediately obvious how this might fit with the centrality of 'corrective' medical interventions (Liao & Boyle, 2004) and, increasingly, the race to discover molecular 'pathology' that causes the 'aberrations'.<sup>7</sup>*

This peer reviewed paper, and our own collective experience, highlight the need for implementation of the Senate report on involuntary or coerced sterilisation and, in particular, implementation of recommendations for rights-based treatment protocols, funded peer/community support, and external scrutiny.

## **5. Examples of legislation, policies and practices by government that unduly restrict SOGI rights**

### **Failure to act on human rights violations in medical settings**

Legal frameworks, including those on Female Genital Mutilation, still permit surgical interventions on girls with ambiguous genitalia, despite rejecting such interventions on other girls.<sup>8</sup> However, exempt medical interventions are justified using social and cultural rationales which are otherwise prohibited; Victorian guidelines include cultural rationales such as “marriage prospects” as a psychosocial rationale for surgical intervention.<sup>9</sup>

The government has not responded to a cross-party 2013 Senate Community Affairs Committee report on “Involuntary or coerced sterilisation of intersex people in Australia”, that made 15 recommendations to change clinical practices, provide adequate scrutiny and develop a human-rights basis for medical interventions.<sup>2</sup> Without implementation of this report, the rights of the child, the right to privacy, and rights to property are all unduly restricted. Australia’s obligations regarding the convention against torture, and other cruel, inhuman and degrading treatment, and the convention on the rights of people with disabilities are each of grave concern.

For a full half century from the 1950s, an “optimal gender model” adopted by clinicians saw the enactment of a belief in nurture, and the malleability of human identity: the genitals of intersex infants were aligned with sex of rearing; to ensure they and their partners don’t have gender issues. Secrecy was the norm, maintained into adulthood, sometimes throughout life, to ensure “normal” physical and psychosocial development.<sup>10</sup> Other people were often told that they would never meet anyone else with the same variation.

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<sup>7</sup> Liao, Lih-Mei, and Margaret Simmonds. “A Values-Driven and Evidence-Based Health Care Psychology for Diverse Sex Development.” *Psychology & Sexuality* 5, no. 1 (January 2, 2014): 83–101. doi:10.1080/19419899.2013.831217.

<sup>8</sup> Australia, and Attorney General’s Department. *Review of Australia’s Female Genital Mutilation Legal Framework - Final Report*. Attorney General’s Department, May 24, 2013. <http://www.ag.gov.au/Publications/Pages/ReviewofAustraliasFemaleGenitalMutilationlegalframework-FinalReportPublicationandforms.aspx>.

<sup>9</sup> Victoria, State of Victoria, and Department of Health. *Decision-Making Principles for the Care of Infants, Children and Adolescents with Intersex Conditions*. 50 Lonsdale Street, Melbourne: Victorian Government, February 2013. <http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions>.

<sup>10</sup> Swiss National Advisory Commission on Biomedical Ethics NEK-CNE. *On the Management of Differences of Sex Development. Ethical Issues Relating to “intersexuality”*. Opinion No. 20/2012. 2012 20. Berne, 2012. [http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf).

Elements of this are still true: secrecy is supposed to have ended in 2006, but specialist clinicians still believe that boys need to stand up to urinate, and larger clitorises need to be surgically reduced.<sup>11</sup> These concerns relate to the individual's position in a family and in society, and to social expectations of the individual's role and performance in those environments.

A key 2006 clinician paper defined "psychosocial" therapeutic rationales as including "minimizing family concern and distress", and "mitigating the risks of stigmatization and gender-identity confusion".<sup>12</sup>

The main relevant Australasian clinician organisation still supports and recommends infant surgery to:

*allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing.*<sup>11</sup>

Clinicians have been reporting improvements in surgical methods since at least 1995<sup>13,14</sup> despite limited evidence, and evidence to the contrary.<sup>15</sup> Nevertheless, the Royal Children's Hospital Melbourne stated in a submission to the 2013 Senate inquiry that:

*we acknowledge that outcomes related to current approaches remain to be established.*<sup>16</sup>

The Senate reports:

*there is no medical consensus around the conduct of normalising surgery.*<sup>2</sup>

Controversy is portrayed by clinicians as a dispute over surgical timing and degree of ambiguity,<sup>11</sup> rather than the necessary debate about patient autonomy, free and fully informed consent, non-discrimination and access to remedies – principles articulated in a 2014 WHO/UN interagency statement on eliminating forced sterilisation.<sup>17</sup>

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<sup>11</sup> Australasian Paediatric Endocrine Group, Jacqueline Hewitt, Garry Warne, Paul Hofman, and Andrew Cotterill. 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. Australasian Paediatric Endocrine Group, June 27, 2013. <http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>.

<sup>12</sup> Houk, C. P., I. A. Hughes, S. F. Ahmed, P. A. Lee, and Writing Committee for the International Intersex Consensus Conference Participants. "Summary of Consensus Statement on Intersex Disorders and Their Management." PEDIATRICS 118, no. 2 (August 1, 2006): 753–57. doi:10.1542/peds.2006-0737.

<sup>13</sup> Cheryl Chase (1998), Surgical Progress Is Not the Answer to Intersexuality, in: Alice Dreger (ed.) (1999), Intersex in the Age of Ethics: 148–159.

<sup>14</sup> Intersex Society of North America, "Hermaphrodites With Attitude, Fall/Winter 1995-96," *Hermaphrodites With Attitude*, Fall/Winter 1996 1995, <http://www.isna.org/files/hwa/winter1996.pdf/>

<sup>15</sup> Creighton, Sarah M. "Long-Term Outcome of Feminization Surgery: The London Experience." *BJU International* 93, Supplement 3 (2004): 44–46.

<sup>16</sup> Royal Children's Hospital Melbourne. *Submission of the Royal Children's Hospital Melbourne to the Senate Inquiry Into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development*. Submission. Australasian Paediatric Endocrine Group, July 10, 2013. <http://www.aph.gov.au/DocumentStore.ashx?id=84e279b0-e824-4d4a-9aba-080b11077117&subId=16195>.

<sup>17</sup> World Health Organization, and OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO. *Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An Interagency Statement*, 2014. [http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1).



We have seen no quantitative data on surgeries for intersex variations within Australia; indeed, material put to the 2013 Senate inquiry suggests that inadequate data is recorded, just as there is no long-term follow up. Creighton et al documents that the UK has recorded an increase in clitoris surgeries on under-14s over the period since 2006. They also document that,

*Rather depressingly for those who advocate a more prudent orientation, recent publications in the medical literature tend to focus on surgical techniques with no reports on patient experiences.<sup>18</sup>*

Clinician claims of the necessity of surgery for when clitorises are too big, or when boys must stand to urinate, are not grounded in clear evidence but rather are accompanied by “particular concern” for post surgical sexual function and sensation.

We have seen claims of surgical necessity juxtaposed against claims that there is no evidence of successful child development without such interventions.<sup>20</sup> This is unscientific when neither proposition has a clear evidence base. Further, it is the scalpel that has excised alternative data sets. In relation to clitoral surgeries, similar surgical interventions on non-intersex girls are overwhelmingly considered to be abhorrent – and without any sound medical basis.<sup>41, 8</sup>

The existing evidence base is subject to sample bias, and selection bias, with researchers interpreting the results of their own treatment paradigms. The following two statements, for example, refer to exactly the same study in Melbourne, published in 2005 by Warne et al in the paper, “A long-term outcome study of intersex conditions”.<sup>19</sup> The contrasting language shows subjectivity in the analysis, and the necessity of outside perspectives and scrutiny.

“Good” self-assessment by Melbourne research team:

*A long-term outcome study of 50 patients aged 18–32 years who had been treated in Melbourne when they were children showed that mental and physical health outcomes were as good for most of the DSD patients as for those in two control groups; however, there was a small minority of patients whose gender identity as adults was a source of such profound discomfort that they felt compelled to undergo treatment to change it.<sup>20</sup>*

“Distressed” external perspective by German research team:

*In the study by Warne et al. (2005), the persons with DSD were similarly as distressed as a comparison group of chronic somatically ill persons. Even though the rates of psychological distress are not directly comparable to our measures, the results similarly indicate markedly increased distress in persons with DSD. (For comparison, German prevalence rates of significant psychological distress in chronically somatic ill persons range from 43% to 50%, see Harter, 2000).<sup>21</sup>*

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<sup>18</sup> Creighton, Sarah M., Lina Michala, Imran Mushtaq, and Michal Yaron. “Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same?” *Psychology and Sexuality* 5, no. 1 (January 2, 2014): 34–43. doi:10.1080/19419899.2013.831214.

<sup>19</sup> Warne, G., Grover, S., Hutson, J., Sinclair, A., Metcalfe, S., Northam, E., et al. (2005). A long-term outcome study of intersex conditions. *Journal of Pediatric Endocrinology and Metabolism*, 18, 555–567.

<sup>20</sup> Warne, Garry, and Jacqueline Hewitt. “Disorders of Sex Development: Current Understanding and Continuing Controversy.” *Medical Journal of Australia* 190, no. 11 (June 1, 2009): 612–13. doi:190(11): 612-613.

<sup>21</sup> Schützmann, Karsten, Lisa Brinkmann, Melanie Schacht, and Hertha Richter-Appelt. “Psychological Distress, Self-Harming Behavior, and Suicidal Tendencies in Adults with Disorders of Sex Development.” *Archives of Sexual Behavior* 38, no. 1 (February 2009): 16–33. doi:10.1007/s10508-007-9241-9.

The Senate inquiry and multiple several studies demonstrate the subjective nature of assessments of “normality” in genitals:

*3.100 What little research exists regarding 'adequate' or 'normal' genitals, particularly for women, raises some disturbing questions. A British team of Jillian Lloyd and others measured variations in the dimensions of female genitalia in a small group of 50 women aged between 18 and 50 who did not have any medical condition affecting their genitals. Even in this very small sample, there was enormous variation in the size of genitalia, with the largest clitorises 700 per cent longer, and over 300 per cent wider, than the smallest; the largest labia minora 500 per cent longer, and 700 per cent wider, than the smallest; and with the longest vagina twice the length of the shortest.<sup>129</sup> Despite this range, a recent reference work on surgery on intersex patients in infancy refers simply to creating 'a clitoris that is in the right position and of the right size', without any elaboration, or discussion of what that size might be.<sup>130</sup> The committee received no information indicating whether or not this natural variation in genital size and shape is taken account of in areas such as the application of the Prader scale, or how medical specialists learn about the diversity of appearance of genitals or how they define 'normal' in their clinical practice.*

*3.101 Studies such as that by Lloyd and others indicate that there is enormous natural variation in the anatomy of sex. However, this is not necessarily reflected in the medical response to that variety. A group of Dutch researchers surveyed 164 physicians regarding their views about the desirable size of a woman's labia minora, by assessing their 'willingness to refer for, or perform, a labia minora reduction'. The doctors were divided into three groups: plastic surgeons, general practitioners, and gynaecologists, and shown pictures of female genitalia with different sized labia. The researchers found that all the doctors regarded smaller labia minora as ideal, and male doctors were more likely to recommend surgery than female, regardless of specialisation.<sup>2, 22</sup>*

Similar research exists in relation to men’s genitals and treatment for “hypospadias”.<sup>23</sup>

### **Flawed implementations of third gender recognition**

Defining intersex as a third classification for infants and children with intersex variations, as is the case in ACT,<sup>24</sup> places children at risk. Persons so assigned have lesser rights, and will face stigma and outing in school and other environments, and we oppose such classification, without the voluntary and informed consent of the person so classified, as a human rights abuse.

In discussions with representatives of the ACT government we have received disappointingly divergent responses from the health minister and attorney general, demonstrating a lack of connectivity between policy on birth certificates and policy on intersex (“DSD”) infant healthcare that is of grave concern.<sup>25</sup>

We are not in a situation where parents and infants can make a decision in favour of a third classification, free of stigma, or even simply within a neutral context. Stigma associated with

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<sup>22</sup> The Dutch study is: W Reitsma, MJ Mourits, M Koning, A Pascal, B van der Lei (2011) *No (wo)man is an island - the influence of physicians' personal predisposition to labia minora appearance on their clinical decision making: a cross-sectional survey*, in *The Journal of Sexual Medicine*, 2011 8(8):2377-2385, doi: 10.1111/j.1743-6109.2011.02321.x

<sup>23</sup> Alice Dreger (13 February 2014) *Do You Have to Pee Standing Up to Be a Real Man?* at Pacific Standard, The Science of Society, <http://www.psmag.com/navigation/health-and-behavior/pee-standing-real-man-73133/>

<sup>24</sup> See ACT Birth Registration Statement, form 201-BRS at <http://www.legislation.act.gov.au/af/2014-46/current/pdf/2014-46.pdf>

<sup>25</sup> Personal communications with then chief/health minister and attorney general, 2013-2014.

physical differences is already a key argument used to support surgical and hormonal interventions on infants and children, as described above. Liao and Simmonds describe this vulnerability clearly. Similarly, Morgan Holmes writes about clinician perspectives on the selective termination of fetuses with sex chromosome differences, such as XXY (often diagnosed as Klinefelter syndrome) and X0 (Turner syndrome):

*Dorothy Wertz's research shows that 49% of genetic professionals, and 48% of primary care physicians would favour selective abortion of fetuses with Klinefelter Syndrome. Meanwhile, 42% of genetics professionals and 37% of primary care physicians, favour selective abortion of fetuses with Turner Syndrome [35]. To give a sense of how these outcomes compare with the only even remotely close circumstance on the chart of potential identifications, I should point out that only 3% of genetics professionals and 3% of primary care physicians would favour selective abortion of a fetus who was not the sex desired by the parents... In addition, Wertz shows that the number of genetic professionals and primary care physicians who would terminate for Klinefelter or Turner syndrome are significantly higher than the numbers for schizophrenia, alcoholism or Alzheimer's. In a separate test for other measures and with other health care providers, only about 12% would focus on the positive aspects for Klinefelter syndrome and only about 16% would do so with Turner syndrome<sup>26</sup>*

We are aware that both IVF and pregnancy testing are used to prevent intersex births in Australia, with evidence of pregnancy termination for XXY and CAH.<sup>27</sup>

In a review of the ethics of genetic selection against intersex traits, Behrmann and Ravitsky comment on sex, gender, and sexual orientation:

*these concepts are actually intertwined on many levels. Parental choice against intersex may thus conceal biases against same-sex attractedness and gender nonconformity.<sup>28</sup>*

In the context provided by current clinical approaches, the ACT's third classification for infants and children is likely to exacerbate trends towards early surgical intervention and avoidance of intersex births.<sup>29</sup>

Conflating intersex with non-binary gender identities takes an essentialist approach to biology and leads to the misgendering of very many intersex people who identify as men or women, denying them their right to choose their own gender identity. Sometimes those sex assignments and gender identities are lifelong; sometimes they are hard won.

Ultimately, the creation of a novel classification called intersex, as has happened in ACT, is predicated on assumptions that identities and bodies need to match each other to be valid; that intersex bodies are a homogeneous third sex; that every body needs a corresponding identity classification. These are arguments that lead to surgeries on intersex infants to align genitals with sex of rearing. Such argumentation is also problematic for trans people: it leads in many States to requirements for trans people to be sterilised or otherwise modified to obtain gender recognition.

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<sup>26</sup> Morgan Holmes (2008) Mind the Gaps: Intersex and (Re-productive) Spaces in Disability Studies and Bioethics in Journal of Bioethical Inquiry doi: 10.1007/s11673-007-9073-2

<sup>27</sup> We provide some additional information here: <https://oii.org.au/25621/submission-ethics-genetic-selection-intersex-traits/>, the AIS Support Group Australia also presents information in: Androgen Insensitivity Syndrome Support Group Australia, and Anthony Briffa. *Discrimination against People Affected by Intersex Conditions: Submission to ACT Chief Minister*, February 15, 2003.

<sup>28</sup> Jason Behrmann and Vardit Ravitsky (2013) *Queer Liberation, Not Elimination: Why Selecting Against Intersex is Not "Straight" Forward* in the *American Journal of Bioethics*, 13:10, 51-53, <http://www.tandfonline.com/doi/full/10.1080/15265161.2013.828131>, accessed 11 September 2013.

<sup>29</sup> See also <https://oii.org.au/24097/flexible-or-open-birth-sex-assignments-have-no-impact-on-surgical-interventions/>

Framing intersex as a third or non-binary sex/gender classification impacts on public perceptions of intersex, and perpetuates hermeneutic injustices that prevent people from intersex variations from accessing community support.

Any third classification must be voluntary, with the informed consent of the person concerned.

While we supported 2013 federal guidelines on sex and gender recognition,<sup>30</sup> we did so in acknowledgement that the guidelines explicitly recognised our diverse gender identities, and changes to persons' sex assignments were voluntary.<sup>31</sup> Unfortunately, the implementation and interpretation has not adequately met those objectives, and we have modified our position accordingly.

Our modified approach is consistent with an emerging international consensus, including a 2013 declaration by the Third International Intersex Forum,<sup>32</sup> 2015 Maltese proposals for identification cards and passports,<sup>33</sup> and a 2014 international guide to good practice on recognition of trans rights, published by Open Society foundations.<sup>34</sup>

### Funding actions and focus

The NHMRC supports a well-funded Research Program in Disorders of Sex Development. In a 2015 funding round, the NHMRC has announced a \$5.5 million program grant for research on Disorders of Sex Development:

*Disorders of sexual development (DSDs) are surprisingly common, and often result in genital abnormalities, gender mis-assignment, infertility and psychological trauma. This Program will pool expertise in human genetics, molecular and developmental biology, to find genes important for sex development, identify gene defects that cause DSD, and study their functions. The Program team will work with clinicians to apply these findings to the accurate diagnosis and medical care of DSD in children.*<sup>35</sup>

The research program is also of utility in facilitating genetic de-selection via IVF and pregnancy terminations. The program framing does not admit a non-stigmatising, non-medicalised perspective on intersex diversity, consistent with the recommendations of the Senate Community Affairs Committee. Despite stressing concern about psychological trauma, the current NHMRC grant can be contrasted with a complete absence of funding for community-based programs to address trauma and stigma.

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<sup>30</sup> Australia, and Attorney General's Department. *Australian Government Guidelines on the Recognition of Sex and Gender*, 2013. <http://www.ag.gov.au/Publications/Pages/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.aspx>.

<sup>31</sup> See <https://oii.org.au/22636/welcome-guidelines-sex-gender-recognition/> and <https://oii.org.au/22663/third-sex-redux/>

<sup>32</sup> See at <https://oii.org.au/24241/public-statement-by-the-third-international-intersex-forum/>

<sup>33</sup> See February 2015 press report at [http://www.maltatoday.com.mt/news/national/49185/male\\_female\\_or\\_x\\_the\\_new\\_gender\\_options\\_on\\_identification\\_documents](http://www.maltatoday.com.mt/news/national/49185/male_female_or_x_the_new_gender_options_on_identification_documents)

<sup>34</sup> Byrne, Jack, Open Society Foundation, Open Society Foundations, Open Society Institute, and Open Society Public Health Program Public Health Program (Open Society Institute). *License to Be Yourself Laws and Advocacy for Legal Gender Recognition of Trans People*. New York: Open Society Foundations, 2014. <http://www.opensocietyfoundations.org/reports/license-be-yourself>

<sup>35</sup> Australian Government National Health and Medical Research Council, Program Grants for funding in 2015, [https://www.nhmrc.gov.au/files\\_nhmrc/file/grants/funding/2013/program\\_grants\\_outcomes\\_for\\_funding\\_2015\\_140217.pdf](https://www.nhmrc.gov.au/files_nhmrc/file/grants/funding/2013/program_grants_outcomes_for_funding_2015_140217.pdf)

With one sole and welcome exception in the National LGBTI Health Alliance, no LGBTI organisations, including youth and health promotion organisations, made submissions to the Senate inquiry on involuntary or coerced sterilization. This demonstrates a lack of understanding of intersex issues, community engagement and capacity. Intersex people are very often a distinct group of people with distinct needs, as highlighted by the content of this submission but also a 2014 international civil society statement on LGBTI rights.<sup>36</sup> Intersex-led organisations are better placed for service delivery for people with intersex variations, and have a track record in project delivery, but remain entirely unfunded.

### Failure to recognise birth sex assignment in sport

The Sex Discrimination Act's exemption from protection on grounds of intersex status in competitive sport<sup>37</sup> creates the potential for elite women athletes with intersex variations to be excluded from competition, even while IAAF evidence shows that there is no scientific basis for the exclusion of women athletes with intersex variations.<sup>38</sup>

Further, there is no evidence in medal tables to show that women with intersex variations, often subjected to humiliation as a result of sex testing,<sup>39</sup> compete unfairly.

Such athletes have not doped, nor have they cheated. The existence of this exemption demonstrates how people with intersex variations do not need to transition to have our bodies and gender identities treated as suspect. This is a particular issue for women with intersex variations who have been assigned and raised female since birth, and who identify as women; in many such cases there is no evidence of any variations in their sex characteristics until the point where they are subjected to sex testing.<sup>40</sup>

Despite this, there is international concern regarding four elite women athletes with the intersex variation 5-alpha-reductase deficiency, who were subjected to "partial clitoridectomies" and sterilisation in order to compete in sport.<sup>41</sup> This is very clearly a coercive context for those unnecessary yet irreversible medical interventions. Current legislation and practice permits such occurrences in Australia.

<sup>36</sup> Council for Global Equality. *Civil Society and Non-State Donor Recommendations from the Conference to Advance the Human Rights of and Promote the Inclusive Development for Lesbian, Gay, Bisexual, Transgender (and Intersex) Persons Washington DC, November 2014*. Council for Global Equality, December 2014. <http://globalequality.org/storage/documents/pdf/civil%20soc%20recommendations%202014-12-11-f.pdf>.

<sup>37</sup> See for a detailed critique: <https://oii.org.au/22142/submission-sda-intersex-status/>

<sup>38</sup> Stéphane Bermon, Pierre Yves Garnier, Angelica Lindén Hirschberg, Neil Robinson, Sylvain Giraud, Raul Nicolli, Norbert Baume, Martial Saugy, Patrick Fénelichel, Stephen J. Bruce, Hugues Henry, Gabriel Dollé, and Martin Ritzen (August 2014) Serum Androgen Levels in Elite Female Athletes, in *Journal of Clinical Endocrinology and Metabolism*, doi: 10.1210/jc.2014-1391

<sup>39</sup> Sheringham, Sam. "Genoveva Anonma: 'I Had to Strip Naked to Prove I Was a Woman.'" *BBC Sport*. January 14, 2015. <http://www.bbc.com/sport/0/football/30760929>.

<sup>40</sup> For example, Sengupta, Rudraneil. "Why Dutee Chand Can Change Sports." *Live Mint*, November 22, 2014. <http://www.livemint.com/Leisure/9P3jboG2G0ppTVB7Xvwj0K/Why-Dutee-Chand-can-change-sports.html> and Martínez-Patiño, María José. "Personal Account A Woman Tried and Tested." *The Lancet*, December 2005, 366–538.

<sup>41</sup> Jordan-Young, R. M., P. H. Sonksen, and K. Karkazis. "Sex, Health, and Athletes." *BMJ* 348, no. apr28 9 (April 28, 2014): g2926–g2926. doi:10.1136/bmj.g2926.

## 6. What is being done, and what more should be done, to promote a culture of respect for SOGII rights

*"I would like intersex people to be more involved in the establishing of some guidelines to ensure that intersex folk are not damaged by trying to fix them when they are healthy."*

*"I am concerned that hospitals do not refer people to intersex run peer support groups because they are afraid that new patients will find out how many mistakes they made in the past."*

We do not have sustainable capacity to effectively advocate for SOGII rights in Australia, nor do we have sustainable capacity to deliver peer support, information and awareness raising services. Our skills and expertise are in high demand, both domestically and internationally<sup>42</sup> as we have proven analysis and advocacy skills. We struggle in particular with demands for peer and family support.

Our board are a mixture of retired and current advocates, with repeated loss of spokespeople and other volunteers, who are constantly on the edge of burnout due to excessive demands, vicarious trauma and prior life experience, and no reward.

As time and circumstance permit, OII Australia is working in partnership with other rights-based and intersex-led organisations to improve peer support, social support, and also professional support for those activities. However, we cannot sustain the existing level of engagement.

In contrast, we see a well funded clinical research program on DSD and a diversity of well funded LGBTI organisations, many of whom have become intersex-inclusive by acronym, without any capacity or deliberate engagement on intersex issues.

More must be done to address the following gaps:

### Health policy issues

- Australian governments must implement the 2013 Senate Community Affairs Committee report on the "Involuntary or coerced sterilisation of intersex people in Australia". Implementation would be consistent with the 2015 concluding remarks of the UN Committee on Rights of the Child in observations on Switzerland.<sup>5</sup>
- Australia must develop and enact national uniform legislation prohibiting the sterilisation of children, regardless of whether or not they are intersex or not, in the absence of their prior, fully informed and free consent, except where there is a serious threat to life or health.
- Psychosocial rationales for surgical and hormonal interventions on persons with intersex variations must no longer be regarded as acceptable or therapeutic.
- Intersex women and girls must be subject to the same policy arrangements on Female Genital Mutilation as non-intersex women and girls, with no medical exemptions that permit interventions for social and cultural reasons such as future marriage prospects.
- Australian governments must develop clinical treatment protocols that meet international human rights obligations, covering healthcare from prenatal diagnosis through to adolescence, and with long term follow up; such protocols must be developed with community participation.

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<sup>42</sup> Occasional overseas work is voluntary and/or entirely funded by overseas human rights defenders.

## Health service issues

- Service delivery must include long term, peer and psychological support. This must be integrated with, but outside, the clinical environment.
- Services must provide particular support for parents and prospective parents, including those using genetic counselling services.
- Services must provide particular support for individuals who suffer epistemic injustice, a legacy of isolation, secrecy and shame.
- These recommendations are consistent with the 2015 concluding remarks of the UN Committee on Rights of the Child in observations on Switzerland.<sup>5</sup>

## Education and awareness raising policy and services

- Education policies must contain adequate recognition of the existence of intersex bodily diversity.
- Media and public awareness is poor and generally associates intersex with gender identity issues; no independent mainstream attention was paid to the human rights concerns raised by the Senate inquiry.
- Intersex-led services need funding to promote inclusion in education, and help develop greater public and media awareness.

## Sex and gender recognition policy

- To respect the diversity of intersex gender identities, and prevent possibilities of involuntary assignment to a third sex or gender classification, third classifications should be streamlined and labelled “X”, “indeterminate” or “non-specified”. A third classification should not include the term “intersex”.
- Our policy goal is a situation where sex or gender, like race and religion, should no longer appear on birth certificates, and where persons able to give voluntary and informed consent are, in the meantime, free to choose a gender marker through a simple administrative procedure.
- These policy recommendations are consistent with an emerging international consensus, including a 2013 declaration by the Third International Intersex Forum,<sup>32</sup> 2015 Maltese ID proposals,<sup>33</sup> and a 2014 international guide to good practice on recognition of trans rights, published by Open Society foundations.<sup>34</sup>

## Policy on redress

- In line with the statement of the Committee on the Rights of Child, we call for attention to issues of redress and compensation for persons who have undergone involuntary or coerced medical treatment.

## Community development

- Intersex-led organisations (OII Australia and AIS Support Group Australia) need to be resourced to contribute to policy development and service delivery in the above areas.

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