



*Many of the participants at the Darlington retreat. Photo courtesy of Phoebe Hart.*

## **Darlington Statement: Joint consensus statement from the intersex community retreat in Darlington, March 2017.**

Joint statement by Australia and Aotearoa/New Zealand intersex community organisations and independent advocates, including the Androgen Insensitivity Support Syndrome Support Group Australia (AISSGA),<sup>1</sup> Intersex Trust Aotearoa New Zealand (ITANZ),<sup>2</sup> Organisation Intersex International Australia (OIIAU),<sup>3</sup> Eve Black, Kylie Bond (AISSGA), Tony Briffa (OIIAU/AISSGA), Morgan Carpenter (OIIAU/Intersex Day Project<sup>4</sup>), Candice Cody (OIIAU), Alex David (OIIAU), Betsy Driver (Bodies Like Ours), Carolyn Hannaford (AISSGA), Eileen Harlow, Bonnie Hart (AISSGA), Phoebe Hart (AISSGA), Delia Leckey (ITANZ), Steph Lum (OIIAU), Mani Bruce Mitchell (ITANZ), Elise Nyhuis (AISSGA), Bronwyn O'Callaghan, Sandra Perrin (AISSGA), Cody Smith (Tranz Australia), Trace Williams (AISSGA), Imogen Yang (Bladder Exstrophy Epispadias Cloacal Exstrophy Hypospadias Australian Community - BEECHAC<sup>5</sup>), Georgie Yovanovic.

### **Preamble**

- A. Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that are more diverse than stereotypical definitions for male or female bodies. For some people these traits are apparent prenatally or at birth, while for

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<sup>1</sup> <http://aissga.org.au>

<sup>2</sup> <http://ianz.org.nz>

<sup>3</sup> <http://oii.org.au>

<sup>4</sup> <http://intersexday.org>

<sup>5</sup> <http://beechac.com>

others they emerge later in life, often at puberty (see UN definition<sup>6</sup>). We recognise our diverse histories and use the word intersex inclusively, and acknowledging our right to self-determination.

- B. We observe that, despite the best efforts of intersex human rights defenders, discrimination, stigmatisation and human rights violations, including harmful practices in medical settings, continue to occur in Australia and Aotearoa/New Zealand.
- C. We observe the 2013 Senate Community Affairs References Committee report, *Involuntary or coerced sterilisation of intersex people in Australia*,<sup>7</sup> and the 2016 Family Court of Australia case, *Re Carla (Medical procedure)*.<sup>8</sup> We observe the *Concluding observations on the fifth periodic report of New Zealand* by the UN Committee on the Rights of the Child in 2016.<sup>9</sup>
- D. We recognise the international obligations of our countries, having signed the *Convention against Torture*, the *Convention on the Rights of the Child*, the *Convention on the Elimination of Discrimination against Women*, and the *Convention on the Rights of Persons with Disabilities*.
- E. We note that intersex peer support remains largely unfunded, advocacy funding remains precarious and limited, and intersex-led organisations rely on volunteers to address the many gaps in services left by other, well-resourced health, social services and human rights institutions.
- F. We acknowledge the kind support for this event from the National LGBTI Health Alliance,<sup>10</sup> Twenty10,<sup>11</sup> Astraea Lesbian Foundation for Justice,<sup>12</sup> and an anonymous donor.
- G. Recognising these issues, this gathering of Australian and Aotearoa/New Zealand intersex community organisations and individuals in March 2017, meeting on Gadigal Land in Darlington, Australia, acknowledges and respects the work of support organisations and human rights advocates over past years and acknowledges -
  1. The **Malta Declaration** of the Third International Intersex Forum in 2013.<sup>13</sup>
  2. That intersex people **exist in all cultures and societies**, throughout history, and that the existence of intersex people is worthy of celebration.

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<sup>6</sup> <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&langID=E>

<sup>7</sup> [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index)

<sup>8</sup> *Re Carla (Medical procedure) [2016] FamCA 7*

<sup>9</sup> [http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/NZL/INT\\_CRC\\_COC\\_NZL\\_25459\\_E.pdf](http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/NZL/INT_CRC_COC_NZL_25459_E.pdf)

<sup>10</sup> <http://lgbtihealth.org.au>

<sup>11</sup> <http://twenty10.org.au>

<sup>12</sup> <http://astraefoundation.org>

<sup>13</sup> <https://oii.org.au/24241/public-statement-by-the-third-international-intersex-forum/>

3. The **diversity of our sex characteristics** and bodies, our identities, sexes, genders, and lived experiences. We also acknowledge **intersectionalities** with other populations, including same-sex attracted people, trans and gender diverse people, people with disabilities, women, men, and Indigenous - Aboriginal and Torres Strait Islander, Tangata Whenua - and racialised, migrant and refugee populations.
4. That the word 'intersex', and the intersex human rights movement, **belong equally to all people born with variations of sex characteristics**, irrespective of our gender identities, genders, legal sex classifications and sexual orientations.
5. Our rights to **bodily integrity, physical autonomy and self determination**.
6. Our opposition to **pathologising terminology** such as "disorders of sex development", not only because such labels are inherently disordering, but also because this promotes the belief that intersex characteristics need to be "fixed".

### **Human rights and legal reform**

7. We call for the immediate **prohibition as a criminal act** of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent. We call for freely-given and fully informed consent by individuals, with individuals and families having mandatory independent access to funded counselling and peer support.
8. Regarding **sex/gender classifications**, sex and gender binaries are upheld by structural violence. Additionally, attempts to classify intersex people as a third sex/gender do not respect our diversity or right to self determination. These can inflict wide-ranging harm regardless of whether an intersex person identifies with binary legal sex assigned at birth or not.

Undue emphasis on how to classify intersex people rather than how we are treated is also a form of structural violence. The larger goal is not to seek new classifications but to **end legal classification systems** and the hierarchies that lie behind them. Therefore:

- a. As with race or religion, sex/gender should not be a legal category on birth certificates or identification documents for anybody.
- b. While sex/gender classifications remain legally required, sex/gender assignments must be regarded as provisional. Given existing social conditions, we do not support the imposition of a third sex classification when births are initially registered.
- c. Recognising that any child may grow up to identify with a different sex/gender, and that the decision about the sex of rearing of an intersex child may have

- been incorrect, sex/gender classifications must be legally correctable through a simple administrative procedure at the request of the individual concerned.
- d. Individuals able to consent should be able to choose between female (F), male (M), non-binary, alternative gender markers, or multiple options.
9. We call for **effective legislative protection** from discrimination and harmful practices on grounds of **sex characteristics**.
  10. We call on governments and institutions to **acknowledge** and **apologise** for the treatment of people born with variations of sex characteristics, and provide **redress and reparation** for people born with variations of sex characteristics who have experienced involuntary or coercive medical interventions. There must be no time limit on access to redress and reparation.
  11. We call for an end to **genetic discrimination**, including in insurance and employment.
  12. We call for all adults to have the **right to marry and form a family** irrespective of their sex characteristics.
  13. We note the difficulty that many intersex people have when **travelling**, including experiences of discrimination and harassment due to their bodily diversity, through the requirements of gendered documents, gendered screening and restrictions on travel with pharmaceutical prescription documents. We call on our governments to work with states, countries and international regulators to resolve these issues.
  14. We call for meaningful **participation** by, and **consultation** with, intersex people and community organisations in all issues and policies affecting us.

## Health and wellbeing

15. We acknowledge the **long-term physical and psychological implications of harmful and continuing medical practices**, and limited access to support and peers.
16. Current forms of **oversight of medical interventions** affecting people born with variations of sex characteristics have proven to be inadequate.
  - a. We note a lack of transparency about diverse standards of care and practices across Australia and New Zealand for all age groups.
  - b. We note that the Family Court system in Australia has failed to adequately consider the human rights and autonomy of children born with variations of sex characteristics, and the repercussions of medical interventions on individuals and their families. The role of the Family Court is itself unclear.

Distinctions between “therapeutic” and “non-therapeutic” interventions have failed our population.

17. We call for the implementation of advisory bodies to develop appropriate **human rights-based, lifetime, intersex standards of care** with full and meaningful participation by intersex community representatives and human rights institutions.
18. We call on the Australasian Paediatric Endocrine Group<sup>14</sup> and other medical/health bodies to stand alongside intersex-led community organisations to develop **human rights-based lifetime standards of care**.
19. We recognise that **intersex people have health and medical needs**, sometimes related to having an intersex variation, and sometimes not. We recognise that for people with an intersex variation, misconceptions and associated stigma can act as barriers to treatment. Current practices are often based on the needs of other populations.
20. We recognise access limitations in **rural, regional and remote** settings.
21. We call for **resourced access to necessary and appropriate health, medical and allied services and treatment**, including surgeries and hormone treatment, psychosocial, psychosexual and psychological support, and including reparative treatments. **Standards of care** must support reparative treatments, and must not require conformity with stereotypical and clinical norms for female or male bodies, women and men, nor impose inappropriate psychiatric eligibility assessments.
22. We call for the provision of alternative, independent, effective **human rights-based oversight mechanism(s)** to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations. The pros and cons for and against medical treatment must be properly ventilated and considered, including the **lifetime health, legal, ethical, sexual and human rights implications**.
23. Multi-disciplinary teams must operate in line with **transparent, human rights-based standards of care** for the treatment of intersex people and bodies. Multi-disciplinary teams in hospitals must include human rights specialists, child advocates, and independent intersex community representatives.
24. Some people need pap smears, some people need prostate examinations or mammograms, and some people need a combination of these. **National screening programs and computerised systems** must recognise the needs of people born with intersex variations.
25. We call for an end to the use of IVF and other forms of **genetic selection** to de-select variations of sex characteristics.

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<sup>14</sup> <http://apeg.org.au>

26. We call for **access to reproductive services** and fertility counselling for all intersex people, with protection of our reproductive autonomy, regardless of whether or not our capacity for fertility is considered to be in line with our legal sex.
27. Intersex-led organisations must be resourced to develop **patient rights and human rights toolkits** for intersex people and our families to improve access to healthcare, and ensure enjoyment of the highest attainable standard of physical and mental health.
28. Children with intersex variations require clear, **age-appropriate disclosure** of their intersex variations, and affirmative support, including peer support.
29. We call for regular **public disclosure of accurate summary data** on all medical interventions to modify the sex characteristics of children, and disclosure of historical data.
30. We call for more research, including **clinical, sociological and psychological research, led by community input**. Clinical research, including longitudinal research, requires true, non-medicalised controls.
31. We call for improved and ongoing **education of health, welfare and allied professionals** in issues relating to intersex bodies, including human rights issues.
32. Children with intersex variations should never be subjected to **medical photography** and display.
33. We call for respect for the **privacy, integrity, and security of our medical records**.
34. Recognising the difficulty that some intersex people have in accessing childhood medical records, we call for **full access to medical records**. Paediatric hospital records should be kept indefinitely. The medical records of people with whole-of-life medical issues should also be kept indefinitely.
35. We call for **access to sport** at all levels of competition by all intersex persons, including for all intersex women to be permitted to compete as women, without restrictions or discriminatory medical investigations.
36. Hormone treatment is required for a lifetime after sterilisation or in cases where gonads do not produce adequate hormones. However, people with intersex variations face **unnecessary costs and challenges in accessing and managing appropriate hormone treatment**. These include access to sex hormones, the unfair and undisclosed cost of treatment required as a consequence of unwanted medical interventions, accessing testosterone and estrogen at the same time, changing from one sex hormone to the other, accessing screening, and travel restrictions, including

travelling with medication and physical screening. We call for national and clinical standards to address these issues.

37. We call for the implementation of **adequate clinical transition pathways** from paediatric to adult services.

38. We call for equitable access to social and welfare services for people with intersex variations. The needs of people with intersex variations in **aged care, home care, state care, and disability services** require further investigation, with full and meaningful participation by intersex-led organisations.

## Peer support

39. We recognise the **trauma and mental health concerns** caused by the unnecessary medicalisation of intersex people, as well as stigmatisation of intersex characteristics that has resulted in a legacy of isolation, secrecy and shame.

40. We recognise the fundamental importance and benefits of **affirmative peer support** for people born with variations of sex characteristics.

41. Our peer support organisations and other peer communities need resourcing and support to **build communities and networks** inclusive of all intersex people. No intersex person or parent of an intersex child should feel they are alone, irrespective of their bodily variation or the language they use.

42. We recognise the needs and lived experience of **youth**, and of people coming from varied **cultural and faith backgrounds**. We recognise these experiences as valid and legitimate.

43. We recognise the fundamental importance and benefits of **peer support for parents, caregivers, and families** of people with variations of sex characteristics. We recognise the importance and benefits of **peer support for friends, partners, and others** who support intersex people in their day-to-day lives.

44. **Peer support must be integrated** into human rights-based multi-disciplinary medical approaches, teams and services.

45. We call for **public, governmental, and philanthropic support** for funded, affirmative peer support.

46. We acknowledge that intersex people are the **experts** on our own lives and lived experience. Intersex people are experts in understanding the long term effects of medicalisation and medical interventions.

## Allies

47. Intersex is distinct from other issues. We call on allies to actively **acknowledge** our distinctiveness and the diversity within our community, to **support** our human rights claims and **respect** the intersex human rights movement, **without tokenism**, or instrumentalising, or co-opting intersex issues as a means for other ends. “Nothing about us without us.”
48. We encourage all organisations and bodies that support the intersex movement to **recognise this Darlington statement**.
49. We call for intersex people, and the intersex human rights movement, **to be allies** to the LGBTQ, disability, Indigenous, anti-racist, and women’s movements.
50. We call on intersex people to recognise our own diversity, and call for **intra-community dialogue and mutual support**.

## Education, awareness and employment

51. We acknowledge that **stigma is often the result of misconceptions** about intersex which is compounded by a lack of education and awareness.
52. We recognise that the stigmatisation and pathologisation of people born with variations of sex characteristics **hinders self-acceptance, access to community, help-seeking, and accessing of services** including healthcare.
53. We acknowledge the impacts of stigma, trauma and unwanted medical interventions on access to **education** and on **employment**, and consequences that include high rates of **early school leaving, poverty, self-harm and suicidality**.
54. We call for the inclusion of accurate and affirmative material on bodily diversity, including intersex variations, in **school curricula**, including in health and sex education.
55. We call on education and awareness providers to develop content with intersex-led organisations, and promote delivery by intersex people.
56. We call on **employer groups, governments, institutions and trade unions to develop affirmative policies and practices** to support employees with intersex variations.
57. We call for policies in **educational institutions and employment** to recognise that some people born with intersex variations may benefit from **accommodations and reasonable adjustments**, including special needs requirements, workplace adjustments, job access assistance, and provisions for medical leave.



58. We acknowledge the **vital importance of positive stories and role models** and the existence of some positive media coverage of intersex people. We acknowledge that much media work unfortunately perpetuates the stigmatisation of intersex people and bodies. We call on the **media to work with intersex-led organisations** to improve their understanding of intersex people and our human rights issues.

59. We call for an **end to the stigmatisation and unnecessary pathologisation** of intersex bodies.

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