



Intersex Aotearoa

Thematic Report to the United Nations Committee on the Rights of the Child, August 2022.

I. Intersex Aotearoa (New Zealand) – Advocacy Organisation

1. Intersex Aotearoa (IA) is a not-for-profit charitable trust that provides education, lobbying, advocacy and support focused on the health and wellbeing of intersex people, or those with variations of sex characteristics (VSC). Intersex Aotearoa is the only intersex-led national organisation informed by community consultation and lived experience. Expertise includes providing high level advisory roles, consultation methodologies, implementation and practice guideline creation. Intersex Aotearoa is the operational name for Intersex Trust Aotearoa New Zealand.

2. The Incentive Working Group (IWG) is led by Intersex Aotearoa in collaboration with representatives from the University of Waikato, the New Zealand Human Rights Commission, healthcare representatives and academics. IWG seeks to contribute to the demedicalisation of intersex bodies in Aotearoa, New Zealand, through public presentations, research, lobbying and education.

3. IA acts as the primary intersex voice in multiple high-level government and non-government consultations, including developments within the Ministry of Health (MOH), Ministry of Education, Department of Internal Affairs, Ministry of Justice, Statistics New Zealand, the Cross Party Rainbow Network and consultations on hate speech. Key relationships for IA continue with the Human Rights Commission, the Mental Health and Wellbeing Commission and the Health Quality and Safety Commission.

Although a working group (Clinical Reference Group) was set up in 2017 to focus on the healthcare of people with intersex variations aged 0 to 18 years, the work programme could not be carried out due to the challenges of bringing together medical perspectives and human rights perspectives on this area of healthcare.

4. Since the Committee's last review of New Zealand in September 2016, IA has been involved in significant developments including:

- November 2016: A roundtable hosted by the Human Rights Commission made recommendations which resulted in the development of the Clinical Reference Group (CRG), and a second Roundtable in 2017.
- August 2017: The CRG was established to focus on the healthcare of people with intersex variations aged 0 to 18 years. The work programme could not be carried out due to the challenges of bringing together medical perspectives and human rights perspectives on this area of healthcare.
- IA was part of the creation of the *Darlington Statement* March 2017, a regional Australasian initiative, updated in 2018 and 2020.¹ This statement sets out an agenda for change that is relevant to the present report with respect to intersex children, but the document traverses lifetime issues.
 - October 2018: IA co-hosted the 29th ILGA World Conference, held in Wellington.
 - August 2021: In response to a petition for intersex healthcare reform, Hon Dr Ayesha Verrall met with IA staff members, and supported intersex-led advice and regular meetings with MOH.

¹ Australian and Aotearoa/New Zealand Intersex Organisations “Darlington Statement” (10 March 2017) Darlington Statement <<https://darlington.org.au/statement/>>.

- September 2021: An on-going working group with MOH was established with members from IA and IWG meeting once a month to advise and participate in any future developments of rights-based intersex healthcare development.
- October 2021: Intersex Awareness Day statement by Associate Minister Verrall committing to rights-based intersex healthcare reform.
- May 2022: Labour Government announced its 2022 Budget spending to include intersex healthcare reforms.

5. Intersex awareness raising, education and training programmes continue to be developed by IA to be provided where possible within healthcare training environments, healthcare services, the sexual and family violence sector and sexual health providers.

6. A multi-year intersex peer support programme is being developed by IA, the first of its kind in Aotearoa, to provide peer support for those with intersex variations and their families, and train intersex peer workers.

II. New Zealand Government Response since 2016

7. The New Zealand Government has taken some initial steps to address issues regarding intersex children since its fifth periodic review by the Committee on the Rights of the Child (The Committee)². The Clinical Reference Group that was established to review the healthcare of intersex people aged 0 – 18 years did not complete that task.

8. Further legal and policy change is necessary to respond to The Committee’s concerns and to give effect to the recommendations made in 2016, so as to realise the right of the intersex child to be free from violence and to ensure their right to free and full development in dignity as provided for under the CRC.

9. IA and other allied experts recommend that the following issues and concerns must be addressed to implement the rights of the intersex child in New Zealand.

III. Remaining Concerns and Recommendations

The present report has been written by IA, with input from the IWG.

This section of the report is organised into several subsections. The first two address the questions posed in the list of issues prior to submission of the sixth periodic report of New Zealand (LOIPR)³ and the remaining subsections address other intersex related aspects since The Committees last review.

A. Harmful Practices

10. The LOIPR asks what measures have been taken to: *“Develop and implement a rights-based health-care protocol for intersex children to ensure that no child is subjected to unnecessary surgery or treatment and that the child’s free, prior and informed consent is obtained for necessary interventions and educate medical and psychological professionals on the negative consequences of unnecessary medical interventions on intersex children.”*

² Office of the High Commissioner on Human Rights (OHCHR) *Concluding observations on the fifth periodic report of New Zealand* (CRC/C/NZL/CO/5 2016).

³ Committee on the Rights of the Child *List of issues prior to submission of the sixth periodic report of New Zealand* (CRC/C/NZL/QPR/6 2020).

11. No substantive steps have been taken to develop or implement a rights-based health-care protocol. There has not been adequate work to define which surgical and medical interventions raise human rights concerns, and there is no agreement on this between health professionals, advocates and the State. There is no evidence of improved approaches to informed consent or to the education of health professionals on the negative consequences of medical interventions that raise human rights concerns.

12. The steps that have been taken are the establishment of a Clinical Network and Clinical Reference Group (2018 – 2020), meetings between the MOH and intersex advocates (2021 – 2022), a public statement made by Associate Minister of Health, Hon Verrall (2021), and government funding for the MOH to begin addressing this issue (2022).

13. At our recommendation, the NZ Government set up a working group in 2021 comprising the MOH, IA, key advocates and IWG members to advise on the development of intersex healthcare reforms. In 2022, the Government announced that it would set aside NZD 2.5 million to support a rights-based approach to health care for intersex New Zealanders. We welcome this commitment but seek further clarification on what work will be undertaken – and with whom – to progress intersex-rights-based health and well-being.

14. None of these steps have brought us closer to substantive change.

16. The Committee also recommended that New Zealand: “*Extend free access to surgical interventions and medical treatment related to their intersex condition to intersex children between the age of 16 and 18*”⁴

17. Further detail is also required as to whether – or how – the Government will action the Committee’s recommendation to extend free access to surgical interventions and medical treatment to young New Zealanders.

18. Although we welcome the recent steps taken by the Government to realise the right of the intersex child to be free from violence and to ensure their right to free and full development in dignity as provided for under the Convention, we are of the view that the legal and policy change needed to respond to The Committee’s concerns and to give effect to the recommendations made in 2016, is lacking.

19. The provision of adequate health care **includes providing people with the information they need, in a way that works for them, so they can make informed decisions and manage their health** as required by law.⁵ This role is described as **meeting health literacy** needs.⁶ Informed consent requires all critical information sharing to be provided for families and the child.⁷ To truly achieve informed consent, all information must be shared, including: alternative approaches, opting out, the psycho-social “normative” motivations for surgical interventions, potential risks, the need for further surgeries, and any and all physical/ mental lasting impacts on infants, children and youth

B. Data Collection

17. The LOIPR includes a request for data on: “*The number of intersex children who have undergone surgery or treatment related to their sexual characteristics*”⁸

18. To date, those data sets have not been provided. Our own investigation of data made available by the New Zealand Ministry of Health’s website reveals that, every year, children and young people undergo

surgery to

⁴ Office of the High Commissioner on Human Rights (OHCHR), above n 2, at [25(e)]. ⁵ *Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996*.

⁶ National Ethics Advisory Committee *National Ethical Standards for Health and Disability Research and Quality Improvement* (Ministry of Health, 2019) at ss 7-Informed Consent.

⁷ *Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland)* [2015] UKSC 11 (UKSC); *Rogers v Whitaker* (1992) 175 CLR 479 (HCA).

⁸ At [38(b)].

address non-life-saving issues in relation to intersex variations, with no clear change or downward trend in the numbers. This is a clear indication that the recommendations of the Committee have not been taken up.

19. Data should be collected and made available, making it explicit how many minors undergo gonadectomy in the context of a variation in sex characteristics, and how many undergo surgery on their sexual and reproductive organs under circumstances where that surgery could be delayed until the person is old enough to meaningfully consent.

20. The Committee recommended that New Zealand develop a comprehensive mechanism for the data collection and an information system on all areas of the Convention to facilitate analysis of vulnerable child populations, such as intersex/ira tangata children. To date, this has not been done, despite this being a key area of focus and commitment made by the CRG.

21. The Government should engage IA and IWG in determining how best to collect and organise data giving priority to Māori data, sovereignty and to individual and collective privacy.

22. As the Government body charged with giving effect to the Convention on the Rights of the Child, the Children's Commissioner must be provided with resources to effectively gather data and work with the key organisational bodies, including IA, to ensure intersex children can achieve free and full development and achieve their potential.

C. Redress

23. The Committee asked the New Zealand Government to: Develop a rights-based child health care protocol for intersex children.

*Promptly investigate incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions to provide redress to victims of such treatment, including adequate compensation;*⁹

24. IA and IWG are not aware of any progress in this area. The Clinical Reference Group that was set up to review clinical practice never set out to address these points. Our conversations with the MOH to date have made it clear there is no intention to adopt legal provisions or consider redress or compensation.

25. Intersex was deemed 'out of scope' for both the [Conversion Practices Prohibition Legislation Bill 2022](#)¹⁰ and Female Genital Mutilation Amendment Bill 2020. Minister Kris Faafoi committed to addressing the Human Rights Act 1993 (NZ) to ensure that Intersex is a protected status within the Act.¹¹

26. Investigating and rectifying past medical interventions is an important move forward for the

community.¹² **D. Right to Identity and Freedom from Discrimination**

27. *The Committee recalls its previous recommendation and recommends that the State party ensure full protection against discrimination on any ground, including by: ... “[s]trengthening its measures to combat negative attitudes among the public as well as other preventive activities against discrimination and, if*

⁹ OHCHR, above n 2, at [25(c)].

¹⁰ It is now formal legislation (*Conversion Practices Prohibition Legislation Act 2022*), see: <https://www.legislation.govt.nz/act/public/2022/0001/latest/whole.html>

¹¹ “Question 8—Glen Bennett to the Minister of Justice” (16 February 2022)

<<https://vimeo.com/678478013>>. ¹² Australian and Aotearoa/New Zealand Intersex Organisations, above n 1, at [10].

*necessary, taking affirmative action for the benefit of children in vulnerable situations, such as [...] intersex children ...*¹³

28. As noted in “Right to Identity,” Māori children have a right to preserve their indigenous identity.

29. The child’s right to preserve their Māori identity, including the embodiment of *ira tangata*¹⁴ and how that is provided for and accepted within *te ao Māori* (Māori world view) and according to *tikanga* (customary law). The importance of *tuakiritanga* (identity) is critical in an indigenous context. *Whakapapa* (genealogy) is the *mauri* (life force) that defines Māori existence. These are fundamental aspects that enable Māori full *mana motuhake* (self-determination) over their rights and privileges as *tangata whenua* and as provided for under international law.¹⁵

30. The New Zealand Government has not put any specific measures in place to uphold the right to identity or to protect intersex children (or adults) against discrimination, and this can be understood as a violation of *Te Tiriti o Waitangi/The Treaty of Waitangi* by the Crown.

B. Best Interests of the Child

31. The Committee encouraged New Zealand to develop procedures and criteria to provide guidance to all relevant professionals for determining the best interests of the child in every area and for giving it due weight as a primary consideration¹⁶. New Zealand law stipulates that the welfare and best interests of a child in their particular circumstances ‘must be the first and paramount consideration’¹⁷. We do not see clear evidence that procedures and guidance informed by the best interests of intersex people have been developed.

32. When it comes to intersex children, what is in their ‘best interests’ is still viewed in light of how they would participate in society as their assigned gender. Though we do not advocate for a child to be assigned ‘Intersex’ at birth, the child should be aware of being intersex from a strengths-based position, and have services and choices available for that child accordingly.

34. The early developmental stages of a child’s life have been widely proven to be sensitive to traumatic experiences, affecting both mental and physical development, a matter that State Parties are obliged to ensure to the maximum extent possible under Article 6 of the Convention.

35. Life preserving surgical interventions will be in the best interests of the intersex child. It is in the best interests of the intersex child to limit all cosmetic surgical interventions until the child is competent to give informed consent.

D. Education, leisure, and cultural activities

36. The Committee recommended building and upgrading education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all, and recalling its previous recommendation.¹⁸

37. In the context of the rights of the intersex child, this means that the Government must improve relationship and sexuality resources in primary and secondary education to include age-appropriate examples of variations of sex characteristics as a natural aspect of development. Intersex inclusion within school curriculum should enable intersex young people and their peers to recognise that intersex is a normal part of human development.

¹³ OHCHR, above n 2, at [15(b)].

¹⁴ Ira Tangata is a Māori phrase indicating Intersex from a Māori world view.

¹⁵ United Nations Declaration on the Rights of Indigenous Peoples, GA Res 61/295 (adopted 13 September 2007, signed 13 September 2007, entered into force 13 September 2007).

¹⁶ OHCHR, above n 2, at [16].

¹⁷ Care of Children Act 2004, section 4 (NZ).

¹⁸ OHCHR, above n 2, at [37].

38. The Government must continue its work to ensure that education from pre-school through secondary school is free of discrimination and interphobia, non-violent, inclusive and an effective learning environment for intersex children.

III. Recommendations

39. In light of the ongoing concerns and lack of substantive change since the last periodic review, we make the following recommendations.

A. Data collection:

40. We call for public disclosure of accurate data on all medical interventions intended to modify the sex characteristics of children, and the disclosure of historical data.¹⁹

B. Harmful medical practices:

41. We call for advisory bodies to develop appropriate human rights-based, lifetime intersex standards of care with full and meaningful participation by intersex community representatives, Māori representation and human rights organisations.²⁰

42. Multidisciplinary teams must operate in line with transparent, human rights-based standards of care for the treatment of intersex people. Multidisciplinary teams and hospitals must include human rights specialists, child advocates and independent intersex community representatives. Peer support must be integrated into multidisciplinary medical approaches.²¹

43. We call for improved and ongoing education of health, welfare and allied professionals in issues relating to intersex, including human rights issues. This includes agreeing to a working definition of 'intersex' that includes all variations of sex characteristics, without medical or pathological exclusion.²²

44. We call for the extension of free access to surgical interventions and medical treatment related to their intersex condition to intersex children between the age of 16 and 18, under the provision

of their informed consent.²³

C. Redress

45. We call for prompt investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions to provide redress to victims of such treatment, including adequate compensation.²⁴

D. Equity, Identity and Resourcing

46. Intersex-led organisations must be resourced to develop patient rights and human rights toolkits for intersex people and their families, with particular focus on developing materials and approaches sensitive to the needs of whanau Māori²⁵. These should be resourced and distributed by Government to healthcare medical colleges and relevant councils as part of any staff training and development.

47. We call for the inclusion of intersex content in relationship and sexuality education in primary and secondary school curriculums.

¹⁹ See, Australian and Aotearoa/New Zealand Intersex Organisations, above n 1, at [29]. ²⁰ At [17].

²¹ At [23] & [44].

²² At [31].

²³ Office of the High Commissioner on Human Rights (OHCHHR), above n 2, at [25(e)]. ²⁴ At [25(e)].

²⁵ See, Australian and Aotearoa/New Zealand Intersex Organisations, above n 1, at [27].

48. We call for equitable access to social and welfare services for people with intersex variations, especially including ira tangata.²⁶

²⁶ At [38].