



Human Rights Commission
Te Kāhui Tika Tangata

Intersex Roundtable Report 2017

Ending the practice of genital normalisation
on intersex children in Aotearoa New Zealand

March 2018

Contact

Human Rights Commission InfoLine

0800 496 877 (toll free)
Fax 09 377 3593 (attn: InfoLine)
Email infoline@hrc.co.nz
TXT 0210 236 4253
www.hrc.co.nz
Language Line and NZ Sign Language
interpreters available

If you have a hearing or speech
impairment, you can contact the HRC
using the New Zealand Relay Service.
NZ Relay is a telecommunications service
and all calls are confidential.
www.nzrelay.co.nz

Tāmaki Makaurau – Auckland

Level 7, AIG Building,
41 Shortland Street, Auckland
PO Box 6751, Wellesley Street
Tāmaki Makaurau Auckland 1141
Waea Telephone 09 309 0874

Te Whanganui ā Tara – Wellington

Level 8, Vector Building
44-52 The Terrace
PO Box 12411, Thorndon
Te Whanganui ā Tara Wellington 6144
Waea Telephone 04 473 9981

Otautahi – Christchurch

Level 1, BNZ Centre
120 Hereford Street
Christchurch 8011
Waea Telephone 03 379 2015

Office of Human Rights Proceedings

Te Tari Whakatau Take Tika Tangata
Email ohrp@ohrp.org.nz
PO Box 6751, Wellesley Street,
Auckland 1141

Contents

Introduction	3
Progress since 2016 Roundtable	3
The 2017 Intersex Roundtable	4
Roundtable Outcomes	4
Agreed next steps and actions from the 2017 Roundtable	6
Appendix 1: Participant List	7
Appendix 2: Presentations to the Roundtable	8
Summary of Presentations	9
Appendix 3: Resource material	13
Appendix 4: New Zealand Child and Youth Intersex Clinical Network: Membership of the Clinical Reference Group	14

Introduction

- 1 There are significant outstanding human rights issues for intersex people in New Zealand, which have been identified and highlighted in reports to the United Nations (UN) and the Human Rights Commission (Commission) over a number of years.
- 2 While the Commission's 2006 Transgender Inquiry did not intend to encompass the experiences of intersex people, many made submissions during the process. These submissions were summarised and included in the final Inquiry report, alongside a recommendation for greater education and more dialogue around intersex issues. This resulted in two roundtable discussions in 2009 and 2010. This consultative process was reactivated in 2014 after New Zealand's second Universal Periodic Review and the New Zealand Government agreed to look further into human rights for persons with variations in sex characteristics.
- 3 The relationship between intersex individuals and the Commission dates back well over ten years and, as the National Human Rights Institution (NHRI) of New Zealand, the Commission considers intersex human rights a key component of its strategic work.
- 4 The Intersex Project partners (The New Zealand Human Rights Commission, The Intersex Trust of Aotearoa New Zealand, Tīwhanawhana Trust, and the University of Otago, Wellington) planned and executed the Intersex Roundtable that took place on 21 June 2017 in Wellington.
- 5 Key stakeholders were invited to participate and build on the work of the 2016 Intersex Roundtable. A full list of participants is detailed in Appendix 1.
- 6 The research, presentations, updates and recommendations from the 2017 Intersex Roundtable are documented in this report.

Progress since 2016 Roundtable

- 7 The focus of the 2016 Intersex Roundtable¹ was to bring together multiple stakeholders to address New Zealand's current medical practice of genital normalisation on intersex children and to build on earlier discussions at Roundtables in 2009 and 2010.
- 8 The 2016 Roundtable prioritised five areas for action which are detailed in the 2016 report:
 - i. Definitions and data
 - ii. Education and awareness raising
 - iii. Political will and resources
 - iv. Service delivery and support
 - v. Legislative change
- 9 The 2016 Roundtable agreed that:
 - The Director General of Health would be approached to discuss the establishment of an expert advisory group with an appropriate framework and terms of reference to support its existence and functioning.
 - The final agreed Roundtable Report would be disseminated to the participants as a public document for use as a resource and advocacy tool.
 - The final agreed Roundtable Report would be circulated to the Ministers of Justice and Health and to the cross-party Rainbow NZ Parliamentary Network.
 - Roundtable participants would review their own strategies and actions.
 - A follow-up Roundtable would be held 12 months later to review and report on progress made.

10 Following the 2016 Intersex Roundtable, the New Zealand Government received four intersex-specific recommendations from the UN Committee on the Rights of the Child in their concluding observations on the fifth periodic report of New Zealand (page 8, *Harmful Practices: 25: (b)(c)(d)(e)*):

- *Develop and implement a child rights-based health care protocol for intersex children, setting the procedures and steps to be followed by health teams, ensuring that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guaranteeing the rights of children to bodily integrity, autonomy and self-determination, and provide families with intersex children with adequate counselling and support;*
- *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;*
- *Educate and train medical and psychological professionals on the range of biological and physical sexual diversity and on the consequences of unnecessary surgical and other medical interventions on intersex children;*
- *Extend free access to surgical interventions and medical treatment related to their intersex condition to intersex children between the age of 16 and 18.*

11 The New Zealand government also received the following request (Article 16, para. 32) by the UN Committee Against Torture in the List of Issues Prior to Reporting (LoIPR) in the 60th session of the committee, 18th April – 12 May 2017:

Please comment on reports of premature surgery and other medical treatment to which intersex children are subjected (see the submissions of Intersex Trust Aotearoa New Zealand, and StopIGM.org and Zwischengeschlecht.org to the Committee against Torture in 2017). Please indicate the number of intersex children who have undergone sex assignment surgery during the reporting period.

The 2017 Intersex Roundtable

12 The 2017 Roundtable took place on 21 June 2017 in Wellington.

13 Building on the 2016 Intersex Roundtable, the recommendations of the UN Committee on the Rights of the Child and the request from the UN Committee Against Torture, the objectives for the 2017 Roundtable were to:

- Update on progress since the 2016 Roundtable
- Identify issues and strategies toward improving the quality of life for intersex people – children and family/whānau
- Build understanding and awareness of intersex issues

14 A variety of updates were presented by stakeholders on the progress made on intersex issues in the last 12 months, as detailed in Appendix 2. Presentations covered the fields of human rights, nursing, pediatric endocrinology, whānau advocacy, midwifery, medical education and legislative updates from parliament.

15 Participants shared copies of new publications and position statements with the group prior to the event and these have been compiled in Appendix 3.

Roundtable Outcomes

16 The following key themes emerged from the presentations and discussions at the 2017 Roundtable:

Bodily integrity

- The protection of, and advocacy for, bodily autonomy of intersex persons must remain central to discussions of ending the practice of genital normalisation on intersex children in Aotearoa New Zealand.

Human rights

- The connection between international human rights frameworks and the realisation of domestic human rights must be understood by all who are working to improve the lives of intersex people in Aotearoa New Zealand.

Collaboration

- More collaboration is needed across all sectors around the country working with intersex people with a focus on self-determination rather than prescriptive and differing advice. A national clinical network would provide a central point of communications and policy development.
- The work we do in Aotearoa New Zealand must be part of the global conversation about how to improve the lives of intersex people and their families/whānau.
- The voices of intersex people and their whānau must be central to policy development, legislative changes and medical developments. The Roundtable affirmed the saying “Nothing about us without us” in support of intersex voices in decision making and movement building.
- The voices of young people must be heard in these discussions if a child-centered approach is to be truly realised. This also builds succession planning into our advocacy and creates leadership opportunities for intersex people.

Decolonisation and breaking the gender binary

- Evidence presented in case studies at the Roundtable acknowledged that the enforcement and presumption of the gender binary and Western constructions of gender can be problematic. This presumption can be insensitive to cultural constructs and understandings.

Language

- The Roundtable agreed that consistent and strengths-based language is important when discussing the needs and identities of intersex people. The group encouraged the use of “sex variations” instead of “sex differences”.²

Data and research

- The Roundtable participants agreed that mandatory reporting is needed on the instances of medical interventions on intersex children in Aotearoa New Zealand. It was agreed that a national health database is needed to hold good data while providing appropriate privacy provisions. The database must be adequately resourced.

Education

- Continued collaboration is needed between tertiary education providers to raise the profile of the level of appropriate health care expected for intersex people and their whānau in Aotearoa New Zealand.
- Continued efforts are also needed to engage medical professionals and support services in ongoing professional development in this area.

National Clinical Network

- The Roundtable participants discussed the offer from the Ministry of Health to fund a national intersex clinical network through the Pediatric Society of New Zealand.
- The benefits and risks of this offer were discussed at length and a suggested framework for a network was agreed upon.
- Recommendations by the Roundtable on how the network could operate have now been approved by the Pediatric Society of New Zealand.
- The advertisement for expressions of interest, including details of the scope of the network, have been included as Appendix 4.
- Expressions of interest were sought through the Pediatric Society of New Zealand with the network’s first meeting scheduled for May 2018.

Agreed next steps and actions from the 2017 Roundtable

- 1 A multi sectoral National Clinical Network will be established through the Paediatric Society of New Zealand and funded by the Ministry of Health. The clinical reference group for the network will consist of twelve members who will be selected based on clinical and advisory experience in intersex health services. At least half of the group will be required to have medical experience, with established expertise in the management of intersex children and youth. The clinical reference group will have a multi-disciplinary approach to intersex health service delivery aiming to broadly represent the geographic regions of New Zealand. The network will:
 - Promote nationally coordinated intersex health services
 - Develop an infrastructure that supports quality services, safety, equity of health service provision, and best value of resources
 - Develop a system for the monitoring and auditing of services to inform continuous quality improvement to include best practice recommendations
 - Identify and liaise with national and international bodies with relevance to intersex services
 - Establish a plan that best supports a workforce education and development programme
 - Support and address some of the intersex recommendations to Government from the United Nations Committee on the Rights of the Child (2016)
- 2 All Roundtable participants commit to working towards the objectives of the Roundtable in their fields of expertise and influence

Appendix 1

Participant List

Apologies: Dr Esko Wiltshire, Angela Ballantyne, Paul Foster-Bell (MP)

Name	Role
Anita O'Boyle	Midwife Educator
Aych McArdle	Human Rights Researcher, Intersex Trust of Aotearoa New Zealand
Brendon Bowkett	Paediatric Surgeon
Craig Waterworth	Massey University
David St George	Chief Advisor – Integrative Care, Ministry of Health
Denise Steers	Psychologist/Researcher, University of Otago
Elizabeth Kerekere	Tiwhanawhana Trust
Fran Mouat	Paediatric endocrinologist, Starship Children's Hospital
George Parker	Women's Health Action
Georgia Andrews	Board member and intersex youth representative, Intersex Trust of Aotearoa New Zealand
Helen Gardner	Parent advocate
Jan Logie	Member of Parliament, Co-chair cross-party Rainbow NZ Parliamentary Network
Jeanie Douché	Board member, Intersex Trust of Aotearoa New Zealand/ Midwife/Educator
Jill Chrisp	Manager Policy and Advocacy, Human Rights Commission
Louisa Wall	Member of Parliament, Co-chair cross-party Rainbow NZ Parliamentary Network
Mani Mitchell	Executive Director, Intersex Trust of Aotearoa New Zealand/ intersex person
Margaret Sparrow	Board member, Intersex Trust of Aotearoa New Zealand
Pat Tuohy	Chief Advisor – Child and Youth Health, Ministry of Health
Paul Hofman	Paediatric endocrinologist, University of Auckland
Richard Tankersley	LGBTI Commissioner, Human Rights Commission
Stella Milsom	Endocrinologist, ADHB

Appendix 2

Presentations to the Roundtable

Presentations to the Roundtable were between 10 minutes long with 5 minutes for questions/discussion at the end.

Each presenter was asked to update the group on their work in the last year towards the goals of the 2016 Intersex Roundtable.

Expertise	Presenter	Organisation
Child and Youth Health	Pat Tuohy	Ministry of Health
Intersex	Mani Mitchell	Intersex Trust of Aotearoa New Zealand
Tangata Whenua	Elizabeth Kerekere	Tiwhanawhana Trust
Intersex	Georgia Andrews	Intersex Trust of Aotearoa New Zealand (Youth Rep)
Endocrinology	Dr Paul Hofman	Starship (Endocrinology)
Midwifery	Jeanie Douché	Intersex Trust of Aotearoa New Zealand
Parliament	Louisa Wall and Jan Logie	Co-chairs, cross-party Rainbow NZ Parliamentary Network
Pediatric surgeon	Brendon Bowkett	Pediatric surgeon
Medical Education and Policy Development	George Parker	Women's Health Action
Nursing	Craig Waterworth	Massey University
Parent Advocate	Helen Gardner	

Summary of Presentations

1 Dr Pat Tuohy, Chief Advisor (Child and Youth Health) to the Ministry of Health

- Dr Pat Tuohy represented the New Zealand government at the fifth periodic report of New Zealand to the UN Committee on the Rights of the Child (UNCRC) in Geneva 2016 where New Zealand was questioned on the rights of intersex children.
- Dr Tuohy addressed the recommendations of the UNCRC and noted that the changes needed will be a transitional process and won't be finished until society as a whole rejects the binary nature of gender that drives much of what health practitioners do in the field of intersex healthcare.
- The offer of adding an Intersex Clinical Network to the Paediatric Society of New Zealand Clinical Network group, funded via the Ministry of Health, was introduced. The practicalities of how such clinical networks have worked for other key health topics were explained. Dr Tuohy acknowledged that the establishment of this group would not meet all of the recommendations from the UNCRC but would be a good foundation for further work.
- The complex issues on working in consultation with parents around consent were highlighted. It was noted that both clinicians and whānau need access to education in this area. Mobilising support in communities would be key to achieving positive lifelong outcomes for intersex people.

2 Mani Mitchell, Executive Director of the Intersex Trust of Aotearoa New Zealand (ITANZ)

- Mani Mitchell provided an update to the Roundtable and their international and national advocacy over the last 12 months.
- Acknowledged the important relationship between the NZ Human Rights Commission and ITANZ, with special mention to the foundational support of Dame Margaret Sparrow, Sir Paul Reeves, and Rosslyn Noonan.
- Briefed the Roundtable participants on the United Nations Human Rights mandates and the issues faced by intersex people. Updates from the UN Committee on the Rights of the Child, the UN Committee Against Torture, the UN World Health Organization, and the UN High Commissioner for Human Rights were presented to the group.
 - Key updates from ITANZ's work over the last 12 months include:
 - Publication of the Astrea Foundation *We Are Real* report³.
 - A submission by ITANZ to the UN Committee Against Torture in preparation for New Zealand's review under the 7th periodic cycle. This resulted in a request by the Committee to New Zealand in their list of issues prior to reporting to comment on "*premature surgery and other medical treatment to which intersex children are subjected,*" and to "*indicate the number of intersex children who have undergone sex assignment surgery during the reporting period.*"⁴
 - The Sydney intersex retreat and the publication of the Darlington Statement.⁵

- The 4th World Intersex Forum and the publication of a joint media statement.⁶
- A training coordinated by the United Nations Development Programme and the Asia Pacific Forum for National Human Rights Institutions and partners. Held in Samoa in June 2017, this training focused on promoting and protecting human rights in relation to sexual orientation, gender identity and sex characteristics (SOGISC).

3 Dr Elizabeth Kerekere, Chair/Founder of Tiwhanawhana Trust

- Dr Elizabeth Kerekere presented information from her recently published PhD thesis (Kerekere, 2017), and explained the historically sacred position of intersex people within Te Ao Māori. She elaborated on her contention that intersex people are modern day ‘tipua’ – magical creatures who can change gender and form.
- Dr Kerekere highlighted the need for decolonisation of our health system for the care of intersex people in Aotearoa New Zealand.
- From a tangata whenua perspective, the role of whānau was discussed. The resources *Takatāpui: Part of the Whānau*⁷ and *Growing up Takatāpui: Whānau Journeys*⁸ were tabled for the Roundtable to distribute through their respective networks.
- The IDAHOBIT (International Day Against Homophobia, Biphobia, Intersexphobia and Transphobia) report was discussed and tabled for the Roundtable to read.⁹
- Dr Kerekere explained the need for a national rainbow strategy that centres around the needs of the most marginalised in Rainbow communities, particularly young people and those with diverse sex characteristics and genders.

4 Georgia Andrews, Youth Representative on the ITANZ board

- Georgia Andrews provided a youth perspective on international and national developments in intersex advocacy.

- Georgia highlighted the importance of clinicians connecting intersex patients to accurate information and to other intersex people through a diagnostic process.
- Georgia stressed the prevalence of intersex variations (1.7% of the population¹⁰) and the important link between enhanced wellbeing and intersex people connecting with each other.

5 Dr Paul Hofman, Paediatrician and Endocrinologist in the Starship Paediatric Diabetes and Endocrinology team

- Dr Paul Hofman updated the Roundtable on his role within the Starship team in the management of healthcare for intersex children.
- Detailed two case studies of intersex children born in Aotearoa New Zealand and the outcomes of different medical interventions.
- Detailed the evolution of “corrective genital surgery” in Aotearoa New Zealand and the various outcomes of these early interventions.
- Acknowledged concerns raised by intersex groups about management of intersex healthcare.
- Discussed further case studies of early intervention and posed the question, “Have we done the right thing by intervening early?”

6 Jeanie Douché, Board member of ITANZ and Adjunct Research Fellow at the Graduate School of Nursing, Midwifery and Health at Victoria University

- Jeanie Douché provided an update to the Roundtable on progress made in the field of Midwifery since the 2016 Roundtable.
- Acknowledged the important role Mani Mitchell and ITANZ have played in enlightening midwifery students about intersex babies and adults.

- Thanked the NZ Human Rights Commission for their role in bringing these Roundtables together.
- Discussed the findings of the 2016 study *Intersex Statistics and Stories from Australia* which points to the high rates of suicidality in intersex people compared with their non-intersex peers.
- Suggested language in this area needs to be inclusive of the diversity of intersex people, respect the rights of intersex people to self-identify, and avoid deficit-based models.
- Updated the Roundtable on the final position statement on inclusive partnerships for NZCOM membership.
- Presented a draft outline of a programme of study proposed for Bachelor of Midwifery programmes, Certification and Annual Practising Certificates (APC) for Registered Midwives. Working title for this course is “Sex and Gender Matters”.
- Detailed visiting lectureships completed with Mani Mitchell in collaboration with ITANZ.

7 Louisa Wall and Jan Logie, Members of Parliament

- Louisa Wall and Jan Logie updated the Roundtable of the cross-party Rainbow NZ Parliamentary Network’s commitment to make progress on issues facing intersex people in Aotearoa New Zealand.
- Acknowledged the importance of the Roundtable and the need for this work to be directed by those who identify as intersex.
- Committed to using legislative and other government functions to put protections in place for intersex people from unnecessary medical interventions and to guarantee access to appropriate health services.
- Emphasised the importance of breaking down the gender binaries in this work and beyond.
- Identified the progress made in Europe on the protection of bodily integrity of intersex people and that protections for intersex people come down to ensuring equality of citizenship.

- Believe that we need responsive systems that enable intersex people to make decisions for themselves and to be fully informed.

8 Mr Brendon Bowkett, Paediatric Surgeon

- Brendon Bowkett discussed the critical importance of accreditation and training of health board members and executives on issues facing intersex people in Aotearoa New Zealand.
- The need for increased psychological aspects of support and care were highlighted with a call for greater access to relevant support for intersex people and their whānau.
- Acknowledged the value of stories from intersex people in this work.

9 George Parker, Women’s Health Action consultant

- George Parker presented a discussion on equity and social justice issues as they link to access to appropriate healthcare.
- Norm-critical approaches and intersectional analysis were acknowledged as key elements in dismantling previous harmful approaches to intersex issues.
- Identified the need for further education in medical schools. George currently teaches the elective paper *Sex, Sexuality and Gender Identity* at the University of Auckland’s Medical School for third year undergraduate students. Only 20-30 out of 300 students are able to take this paper.
- George noted the impact this paper has had on students becoming change agents and engaging in activism in this space. The Roundtable agreed that papers like these should be mandatory curriculum requirements in medical training.

10 Craig Waterworth, Nursing lecturer at Massey University

- Craig Waterworth presented on a short course that has been developed on understanding and supporting intersex people.

The course content covers five central modules:

- Definitions and manifestations
- Psychological dimensions
- Clinical concerns
- Decision making principles
- How to practice as an ally

11 Helen Gardner, Parent advocate

- Helen Gardner, who has worked alongside families and caregivers of children with variations of sexual development, discussed the important role of parents/caregivers as primary healthcare providers for their children.
- Explained the impacts of a medical diagnosis on whānau that are not often talked about, such as fear, shame, and grief. The way medicalised language is used in this process impacts on the wellbeing of parents and can ultimately impact parent-child relationships.
- Suggested the following template for a first discussion by a physician with parents:

"You have a wonderful new baby. Congratulations. I can see your baby is just perfect. I'm pleased to be your family's physician and I'll be meeting with you regularly over the next few weeks and months to talk with you about your baby's health. Your baby has some health needs but they are not life threatening. In fact, we see these things quite a lot and we have a team of people here who can support you and will be happy to answer your questions."

- Helen presented key tips for medical professionals supporting intersex children and their whānau. These include:
 - Relationship development: active listening is an skill
 - Let your words be ones of empathy and hope
 - Reassure us: *"You have a simply beautiful child, and our team will support and help you work through this."*
 - Pass us as parents on to a member of a specialised team who has excellent people skills, an understanding of our child's medical condition, and who is warm and reassuring.
 - Ensure this coordinator provides us with basic written information to take home, as well as contact names and numbers we can ring if we have concerns.
 - Please avoid raising any big or frightening medical issues such as genital surgery for at least the first six months, unless there is medical urgency. The first months are mighty tough without this kind of pressure. If we do our own research and have questions, assure us that our baby's life is not at risk and that there are international guidelines for providing surgery at optimal times, if and when these are needed.
 - We need time to ask questions as well as listen. We need to be involved in decision-making and to be given choices. Remember: *"Nothing about us without us"*. This makes us feel valued, respected, and cared for.
 - Finally, please keep in mind that we are a family, and that how we are treated affects our child, and how our child is treated affects our family. Their health is our health. You cannot separate us. We belong together.

Appendix 3

Resource material

Key documents published since the 2016 Intersex Roundtable:

Refer to 2016 Roundtable *Resource Material* for earlier relevant publications.

- 1 4th International Intersex Forum – Media Statement. (2017, April 27). Retrieved from <https://oiieurope.org/4th-international-intersex-forum-media-statement/>
- 2 Astraea Lesbian Foundation for Justice. (2016). *We are Real: The Growing Movement Advancing the Human Rights of Intersex People*. New York: Astraea Lesbian Foundation for Justice.
- 3 Callens, N., Van Kuyk, M., van Kuppenveld, J. H., Drop, S. L., Cohen-Kettenis, P. T., Dessens, A. B., & Dutch Study Group on DSD. (2016). Recalled and current gender role behavior, gender identity and sexual orientation in adults with disorders/ differences of sex development. *Hormones and behavior*, 86, 8-20.
- 4 Carpenter, M. (2016). *The human rights of intersex people: addressing harmful practices and rhetoric of change*. *Reproductive Health Matters*. 24:47, 74-84. <http://dx.doi.org/10.1016/j.rhm.2016.06.003>
- 5 Darlington Statement (2017, March). Retrieved from <https://oii.org.au/darlington-statement/>
- 6 Guntram, L., & Zeiler, K. (2016). "You have all those emotions inside that you cannot show because of what they will cause": *Disclosing the absence of one's uterus and vagina*. *Social Science & Medicine*, 167, 63-70.
- 7 Jenkins, T. & Short, S. (2016). *Negotiating intersex: A case for revising the theory of social diagnosis*. *Social Science and Medicine*. 175, 91-98. <http://dx.doi.org/10.1016/j.socscimed.2016.12.047>
- 8 Kerekere, E. (2015). *Takatāpui: Part of the Whānau*. Auckland: Tīwhanawhana Trust and Mental Health Foundation
- 9 Kerekere, E. (2017a). *Growing Up Takatāpui: Whānau Journeys*. Auckland: Tīwhanawhana Trust and RainbowYOUTH
- 10 Kerekere, E. (2017b) *Part of the Whānau: The Emergence of Takatāpui Identity – He Whāriki*. Wellington: Tīwhanawhana Trust
- 11 Kerekere, E. & Byrne, J. (2017). International Day Against Homophobia, Biphobia and Transphobia 2017: Report for Panel Presentation on Human Rights Issues in Rainbow Communities. Presentation made by IDAHOBIT Coalition to Parliament 17 May 2017, Wellington, New Zealand.
- 12 Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., ... & Mazur, T. (2016). Global disorders of sex development update since 2006: perceptions, approach and care. *Hormone Research in Paediatrics*, 85(3), 158-180.
- 13 Lundberg, T., Roen, K., Hirschberg, A. L., & Frisé, L. (2016). "It's Part of Me, Not All of Me": *Young Women's Experiences of Receiving a Diagnosis Related to Diverse Sex Development*. *Journal of Pediatric and Adolescent Gynecology*, 29(4), 338-343.
- 14 Waterworth, C. (2017, May 10). From nurse education, clinical, or workforce issues through to healthy living, Nursing Review has it covered. Retrieved from <http://archive.nursingreview.co.nz/issue/april-2017-vol-15-2/natural-diversity-understanding-and-supporting-intersex-people/#.WmBT8FT1XVo>

Appendix 4

New Zealand Child and Youth Intersex Clinical Network: Membership of the Clinical Reference Group

Introduction

The Paediatric Society of New Zealand invites Expressions of Interest for membership of the Child and Youth Intersex Clinical Reference Group (CRG). The purpose of this Network is to provide clinical leadership to improve health practices, systems and approaches for intersex children and youth up to 18 years of age. This will be achieved through the appointment of a national, multi-disciplinary Clinical Reference Group (CRG) supported by the Secretariat. The CRG will provide advice on appropriate health services for intersex children and young people to the New Zealand Child and Youth Clinical Network Programme's (NZCYCN) Advisory Group, the Paediatric Society of New Zealand (PSNZ) and Ministry of Health (MoH). There is agreement for the Network to be established for a period of up to two years. Any extension of the defined period will need to be mutually agreed by all parties and conditional on MoH and PSNZ contract period.

The Network will:

- promote nationally coordinated intersex health services
- develop an infrastructure that supports quality services, safety, equity of health service provision and best value of resources
- develop a system for the monitoring and auditing of services to inform continuous quality improvement to include best practice recommendations
- identify and liaise with national and international bodies with relevance to intersex services
- establish a plan that best supports a workforce education and development programme

- support and address some of the intersex recommendations to Government from the United Nations Committee on the Rights of the Child (2016).

Selection to the CRG

Preference is for twelve CRG members to be selected based on clinical and advisory experience in intersex health services. At least half of the group will be required to have medical experience with established expertise in the management of intersex children and youth. The CRG will have a multi-disciplinary approach to intersex health service delivery aiming to broadly represent the geographic regions of New Zealand.

Clinical Reference Group Membership

Expressions of interest are requested from the following three areas:

1. Medical specialists

Priority will be given for medical professionals with expertise in the management of intersex children and youth from the following disciplines. Ideally the group will consist of:

- Paediatric surgeon (x1)
- Paediatric endocrinologists (x2)
- Adult endocrinologist (x1)
- Obstetrics/gynaecology (x1)

2. Intersex consumer advocates

Three intersex consumer advocates are requested.

- Two intersex representatives, one being a young intersex person
- An intersex family representative

3. Other members

The CRG will make up the total group number to a maximum of twelve members from the following backgrounds:

- Tangata whenua
- Pasifika health provider
- New Zealand College of Midwives
- Representative from the Human Rights Commission
- General paediatrics
- Academic specialist Primary care provider (e.g. GP, RN)
- MoH representation

Responsibilities

The CRG members will be responsible for:

- providing advice from their areas of expertise to other Network members
- responding to requests for information and advice from other Network members
- linking with own and related organisations and sectors taking responsibility for specific streams of work as allocated
- not disclosing any confidential information or making media statements on matters relating to the Network without the prior approval of the whole CRG and Chair

The CRG will develop a work plan with achievable deliverables based on the following activities:

- Develop a definition of intersex for New Zealand
- Create a national registry of intersex people

- Develop good practice guidelines
- Establish a centralised and coordinated health care system for intersex children and young people. Increase awareness of intersex health and people's related experiences through the development of targeted education programmes

To be considered for membership on the CRG of the Intersex Clinical Network, please provide a brief resume in support of your application with specific reference to your area of interest and relevant knowledge and skills.

It is expected that CRG members attend two (2) face-to-face meetings and two (2) additional conference calls each year and actively participate in email based collaboration regarding Network activities. The Terms of Reference for the Network can be obtained from the email address below.

Timeline

All EOIs to be received by the Clinical Network Secretariat before 5pm, Friday 22nd December 2017.

Please address your Expression of Interest to:

Expression of Interest for Clinical Reference Group membership

New Zealand Child and Youth Intersex Clinical Network

Paediatric Society of New Zealand

P O Box 22 234

Wellington

Email: denise@paediatrics.org.nz

Endnotes

- 1 New Zealand Human Rights Commission, *Intersex Roundtable Report 2016* (November 2016). https://www.hrc.co.nz/files/5914/8124/9497/HRC_Intersex_Roundtable.pdf
- 2 Asia Pacific Forum, *Promoting and Protecting Human Rights in relation to Sexual Orientation, Gender Identity and Sex Characteristics: A Manual for National Human Rights Institutions*. (2016). http://www.nhrcnepal.org/nhrc_new/doc/newsletter/APF_LGBTI_Manual_for_NHRIs_SOGI_and_Sex_Characteristics_Manual%20Final.pdf
- 3 Astraea Lesbian Foundation for Justice. *We are Real: The Growing Movement Advancing the Human Rights of Intersex People*. (2016). New York: Astraea Lesbian Foundation for Justice.
- 4 UN Committee Against Torture. *List of Issues Prior to Reporting (LoIPR)*. 60th session, Article 16, paragraph 32. (2017).
- 5 OII Australia. (2017). Darlington Statement. Retrieved from <https://oii.org.au/darlington-statement/>
- 6 OII Europe. (2017). 4th International Intersex Forum – Media Statement. Retrieved from <https://oiieurope.org/4th-international-intersex-forum-media-statement/>
- 7 Kerekere, E. *Takatāpui: Part of the Whānau*. (2015). Auckland: Tiwhanawhana Trust and Mental Health Foundation
- 8 Kerekere, E. *Growing Up Takatāpui: Whānau Journeys*. (2017). Auckland: Tiwhanawhana Trust and RainbowYOUTH
- 9 Kerekere, E. & Byrne, J. (2017). *International Day Against Homophobia, Biphobia and Transphobia 2017: Report for Panel Presentation on Human Rights Issues in Rainbow Communities*.
- 10 Asia Pacific Forum, *Promoting and Protecting Human Rights in relation to Sexual Orientation, Gender Identity and Sex Characteristics: A Manual for National Human Rights Institutions*. p65 (2016).



Human Rights Commission
Te Kāhui Tika Tangata