



Human Rights Commission
Te Kāhui Tika Tangata

Intersex Roundtable Report 2016

The practice of genital normalisation on
intersex children in Aotearoa New Zealand

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Intersex Roundtable Report 2016

The practice of genital normalisation on intersex children in Aotearoa New Zealand

- 1 Issues for people born intersex are complex and controversial. This reflects the extraordinarily wide range of conditions involved, their relative rarity and the lack of adequate long-term outcome data. Management of these conditions needs a comprehensive multidisciplinary team approach that supports the needs (both physical and psychological) of those affected and their families.
- 2 While substantial change in the care of intersex children has occurred over the past 20 years, ethical, medical and human rights concerns have been raised by intersex advocates, academics, the New Zealand Human Rights Commission and international bodies (including the United Nations Human Rights Council, World Health Organisation and the UN Special Rapporteur on torture) regarding practice in this area, with calls for recognition of bodily integrity and an end to treatments aimed solely at “normalising” sex.
- 3 Although no sexual orientation, gender identity and intersex issues were reflected in the UPR recommendations, the Government made it clear it intended to follow up on these issues as part of its commitment to ongoing engagement with civil society.

The Roundtable

Background

- 4 To facilitate Government’s commitment, the Intersex Trust Aotearoa New Zealand and the New Zealand Human Rights Commission co-hosted a Roundtable that brought together multiple stakeholders to address New Zealand’s current practice of genital normalisation on intersex children.
- 5 The Roundtable aimed to create an opportunity for sharing perspectives and information, provide a New Zealand context on Intersex/Disorders of Sexual Development (DSD) issues, review international good practice and initiatives and create a plan to progress action on these issues.
- 6 Participation was by invitation only and 30 people attended (Appendix 1, Participant List).
- 7 A comprehensive set of readings (Appendix 2) was distributed prior to the Roundtable and was available in hard copy on the day.
- 8 The first half of the day-long programme included presentations from diverse perspectives – intersex, family, tangata whenua, medical, Government agency (Ministry of Health), legal, midwifery, human rights, international, Pasifika, ethical, youth, members of parliament. (Available transcripts are attached as appendices.)

- 11 The afternoon involved two workshops; the first to flesh out the key issues arising from the morning's presentations and pre-Roundtable resources and the second to develop draft actions from these issues.

Roundtable Outcomes

- 12 The Roundtable prioritised five areas for action:

- i definitions and data,
- ii education and awareness raising,
- iii political will and resources,
- iv service delivery and support, and
- v legislative change.

i Definitions and data

An agreed definition of intersex is an essential precursor to the systematic gathering of national data and development of appropriate practices.

It was noted by the Roundtable, a clear understanding of the nature and extent of the issues facing intersex people across New Zealand is necessary for the development of comprehensive and evidenced-based policies and practice. It was agreed that a better understanding of the multiple dimensions of intersexuality was important for progress to be made toward dealing with the issues generated by current practice.

While this requires an agreed and workable definition of 'intersex', it was evident from the discussion there is not a current shared definition and there are several perspectives to consider to develop one.

'Intersex' is an umbrella term used in New Zealand¹ and internationally² to describe a wide range of natural bodily variations. 'Intersex' refers to people born with sex characteristics (including genitals, gonads, hormonal balance and chromosome patterns) that do not fit typical binary notions of male or female bodies. It has been in use for 60+ years and includes more than 30 conditions.

'Disorders of Sexual Development' (DSD) was a term developed in 2005 by a multidisciplinary meeting of medical and nonmedical experts to

encompass any congenital conditions associated with atypical development of chromosomal, gonadal, or anatomical sex.³

Subsequently, various commentators have taken the term 'DSD' to mean differences of sex development, or diversity of sex development, providing an alternative to the pathologising language of 'disorder'.⁴

The Roundtable agreed the most acceptable term would be self-identifying and driven by intersex people with medical input. It was also agreed labels should be used sensitively and should acknowledge cultural variations.

ii Education, awareness-raising and ongoing dialogue

A programme of education and ongoing dialogue is pivotal to developing increased understanding and informed practices about intersex people, their contexts and their experiences.

Not enough is known about intersex people and their experiences. It was agreed a comprehensive, multi-sectoral and interdisciplinary education programme (including bodily diversity) should be planned and rolled out consistently across New Zealand.

The programme would focus on multiple stakeholders including, but not limited to, intersex people and their families, health practitioners, medical training providers, school teachers and communities. It would build on shared language, understandings and approaches and be informed by stories from intersex people and families.

It was also agreed that dialogue amongst multi-sectoral groups should be ongoing toward developing agreed approaches and practices across varying perspectives and practices.

iii Resources and lack of political will

Government has a central role to lead and resource New Zealand's response.

There is a current lack of financial and information resources and capability to adequately respond to the issues for intersex

children and adults. Partly this is because of a seemingly lack of political will to address the issues involved in current practices of genital normalisation on intersex children.

Government has a central role to lead New Zealand's response. Other governments have taken steps in this direction and the United Nations is calling on States to take action, including prohibiting surgery and procedures on intersex children aimed solely at "normalising" sex.⁵ (Note, while some international discourse refers to prohibiting 'unnecessary' medical interventions on intersex children, it isn't clear yet what 'unnecessary' means in a NZ medical practice context.)

iv Service delivery/support

*Greater support should be available for intersex people and their families.*⁶

The Roundtable called for greater support for families and vulnerable groups and four goals were proposed:

- 1 Establish a national multi-disciplinary expert advisory group to address resourcing, legislation and ethical issues.
- 2 Establish a single family-centred national service with high quality, timely decision-making (similar to the model used by child oncology).
- 3 Ensure the availability of good quality and accessible whole-of-life care.
- 4 Undertake research.

v Legislative and policy change

Effective responses to intersex people and issues need to be mandated by legislative and policy change.

Legislative and policy changes identified by the Roundtable included,

- developing legislative safeguards for children
- testing the right to bodily autonomy/integrity and the right to refuse medical treatment against the Bill of Rights Act

- identifying documents that require amending to be congruent with intersex gender identity
- establishing an expert advisory group with a legislative framework to support its existence and functioning
- amending the Human Rights Act to clarify gender expression/gender identity/intersex status as a basis of non-discrimination and reviewing S21.

- 13 The Roundtable agreed the next step would be to establish an expert advisory group with an appropriate framework and terms of reference to support its existence and functioning. This was a common strategy for most of the issues raised by the Roundtable.

Other actions generated by the Roundtable needed further discussion but it was agreed they could be driven by a work programme developed from the expert advisory group. These included:

- development of agreed definitions of intersex and DSD conditions to enable enhanced data collection and consideration of the establishment of a national register
- developing a national (online or other) educational resource informed by individual, family and community narratives
- specific support services for intersex children and adults and their families, including consideration of a single, family-centred national service that ensures whole-of-life multi-disciplinary care and support care
- mandatory courses for related sector group training; and
- legislative and procedural safeguards for intersex children, including an ethical framework for funding and research requirements.

Next Steps

- 14 The Roundtable agreed that:
 - i An approach would be made to the Director General of Health to discuss the establishment of an expert advisory group with an appropriate framework and terms of reference to support its existence and functioning.
 - ii The final agreed Roundtable Report would be disseminated to the participants as a public document for use as a resource and advocacy tool.
 - iii The final agreed Roundtable Report would be disseminated to the Ministers of Justice and Health and to the Parliamentary cross-party LGBTI working group.
 - iv Roundtable participants would review their own strategies and actions.
 - v A follow-up Roundtable would be held in 12 months and would be an opportunity to review and report on progress made.

Committee on the Rights of the Child concluding observations on the fifth periodic report of New Zealand

As a result of the NZ CRC review, the NZ Government received five recommendations related to intersex children as an outcome of New Zealand's review under the United Nations Convention on the Rights of the Child.

- a 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;
- b 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;
- c 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;
- d Extend free access to surgical interventions and medical treatment related to their intersex condition to intersex children between the age of 16 and 18.

Resource Material

Advocacy

Dreger, A. (2015). Rejecting the Tranquilizing Drug of Gradualism in Intersex Care. alicedreger.com/DSD Human Rights 21 Nov 2015

Ethico-legal

Brauer, S. (2012). On the management of differences of sex development. Ethical issues relating to "intersexuality" Culture. Opinion number 20/2012. Bern: Swiss National Advisory Commission on Biomedical Ethics. www.nek-cne.ch

Government of Malta (2015). Gender Identity, Gender Expression and Sex Characteristics Act, Chapter 540. *"An Act to provide for the recognition of the gender of a person and regulate the effects of such a change, as well as the recognition and protection of the sex characteristics of a person."* <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1>

Mc Donald, E. (2015). Intersex People in Aotearoa New Zealand: The Challenges for Law and Social Policy. (2015)46 VUWLR Law and Social Policy

Ehrenreich, N. and Barr, M. (2005). Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices". Harvard Civil Rights-Civil Liberties Law Review, vol. 40, 72-140

Australian Community Affairs References Committee (2013). Involuntary or coerced sterilization of intersex, people in Australia. Canberra: Commonwealth of Australia. ISBN 978-1-74229-917-4. http://www.aph.gov.au/senate_ca

Human Rights

Baisley, E. (2016). Reaching the Tipping Point? Emerging International Human Rights norms Pertaining to Sexual Orientation and Gender Identity. Human Rights Quarterly. Vol 8 (1) pp 134-163

Human Rights Commission: Te Kahui Tika Tangata (2007). To be Who I Am: Kia noho au ki toku ano ao. Report of inquiry into discrimination experienced by Transgender People: He Purongo mo

te Uuitanga mo Aukatitanga e Pangia ana e nga Tangata Whakawhitiira. Wellington: Human Rights Commission

Human Rights New Zealand (2010). Rights of Sexual and Gender Minorities. HRNZ 19, 304-323. <https://www.hrc.co.nz/files/1914/2388/0525/HRNZ>

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United Nations (2015). Fact Sheet: Intersex. United Nations Human Rights. https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf

United Nations Human Rights (2015). Speak Up Stop Discrimination: Joint UN Statement Ending violence and discrimination against lesbian, gay, bisexual, transgender and intersex people). Office of the High Commissioner, United Nations. <http://www.ohchr.org/EN/Issues/Discrimination/Pages/JointLGBTIstatement.aspx>

Australian Community Affairs References Committee (2013). Involuntary or coerced sterilization of intersex, people in Australia. Canberra: Commonwealth of Australia. ISBN 978-1-74229-917-4 http://www.aph.gov.au/senate_ca

Inclusivity and Language

Ansara, Y. G. (2013). Health Information Sheet. Inclusive Language Guide: Respecting people of intersex, trans and gender diverse people. Newtown, Australia: National LGBTI Health alliance

Intersex and Allies – community statements

Statement from the: 'Don't leave out the I' workshop, ILGA Oceania Conference, Wellington, March 2016

InterAct youth (2016). Advocates for intersex youth. <http://interactadvocates.org>

The world 'oldest' intersex advocate – (21 November, 2015) USA psychotherapist Tiger Devore. Statement made after resigning from: Institutes of Health (NIH) for the DSD – Translational Research Network (DSD-TRN)

Intersex Trust Aotearoa New Zealand [ITANZ] (2015). Key points & priorities for ITANZ-HRC meeting (23 September, 2015) to discuss ITANZ submission to the Committee Against Torture (CAT) and inclusion within the National Plan of Action (NPA). Wellington: ITANZ

Medical

Lee, P. Nordenstrom, A. Houck, C., Ahmet, S. F. et al (2016). Consensus statement: Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics*. Doi:10.1159/000442975

Midwifery

American College of Nurse Midwives (2012). Position Statement: Transgender/Transsexual/Gender Variant Health Care. Silver Spring, MD. www.midwife.org

Canadian Association of Midwives (2015). A Statement on Gender Inclusivity & Human Rights. Quebec. www.canadianmidwives.org

Parental Advocacy

Magritte, E. (2012). Working together in placing the long-term interests of the child at the heart of the DSD evaluation. *Journal of Paediatric Urology*, 8, 571-575

Baratz, A. (2015) Parental choice on normalising cosmetic genital surgery. In response to: British Medical Journal article Normalising cosmetic genital surgery, *BMJ* 2015; 351

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LIAO, L. M. & SIMMONDS, M. 2013. A values-driven and evidence-based health care psychology for diverse sex development. *Psychology & Sexuality*, 5, 83-101

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ROEN, K. & PASTERSKI, V. 2014. Psychological research and intersex/DSD: recent developments and future directions. *Psychology & Sexuality*, 5, 102-116

Tangata Whenua

Kerekere, E (2015) Takatāpui: Part of the Whānau. Tiwhanawhana Trust and Mental Health Foundation. PDF

Videos

What It's Like To Be Intersex – YouTube
<https://www.youtube.com/watch?v=cAUDKEI4QKI>

Paediatric Surgeon Mika Venhola on INTERSEX
<https://www.youtube.com/watch?v=riNtxjntqZE>

INTERSEXION TRAILER – YouTube
<https://www.youtube.com/watch?v=RVmPJVPLP-U>

36 Revolutions of Change | Sean Saifa Wall | TEDxGrandRapids
<https://www.youtube.com/watch?v=9mvNmRlpfaM>

Websites

Advocates for Intersex Youth.
<http://interactadvocates.org>

Androgen Insensitivity Syndrome Support Group Australia Inc. www.aissga.org.au

AIS-DSD Support Group.
<http://aisdsd.org>

ESPE DSD Working Group – European Society for Paediatric Endocrinology. <https://www.eurospe.org/about/workinggroups/DSD.html>

EuroPSI: European Network for Psychosocial Studies in Intersex/dsd: <http://www.europsi.org>

Intersex Trust Aotearoa New Zealand.
www.ianz.org.nz

National LGBTI Health Alliance.
<http://lgbtihealth.org.au>

Appendix 1: Participant List

1	Angela Ballantyne	Senior Lecturer Bioethics, University of Otago
2	Anya Satyanand	Executive Officer, Te Ara Taiohi
3	David St George	Chief Advisor, Office of the Chief Medical Officer, Ministry of Health
4	Denise Steers	Psychologist/Researcher, University of Otago
5	Elisabeth McDonald	Associate Professor of Law, Victoria University, Wellington
6	Elizabeth Kerekere	Tiwhanawhana Trust / Assistant Research Fellow at the University of Otago Medical School, Wellington
7	Esko Wiltshire	Associate Professor, Paediatrics and Child Health, University of Otago
8	Fran Mouat	Paediatric Endocrinologist, Starship Children's Hospital
9	Fuimaono Karl Pulotu-Endemann	Academic/Medical Professional/Consultant/Fa'afafine
10	George Parker	Midwife/Researcher, University of Auckland
11	Helen Gardiner	Community Educator/Support & Advocacy
12	Jill Chrisp	Manager Policy & Advocacy, Human Rights Commission
13	Jackie Blue	Equal Employment Opportunities Commissioner (Shadow responsibility for LGBTI Rights Commissioner)
14	Jan Logie	MP, Green Party and co-chair LGBTI cross-party WG
15	Jeanie Douche	ITANZ Board Member/Midwife/Academic – researcher
16	John Hancock	Senior Legal Advisor, Human Rights Commission
17	Katrina Roen	ITANZ Board Member/Academic
18	Louisa Wall	MP, Labour Party and co-chair LGBTI cross-party WG
19	Mani Mitchell	ITANZ Executive Officer/Intersex person

20	Dame Margaret Sparrow	ITANZ Board Member/Retired Sexual Health Clinician
21	Moana Eruera	Snr Human Rights Specialist, Human Rights Commission
22	Neil Price	Paediatric Surgeon, Starship Children's Hospital
23	Paul Gibson	Disability Commissioner, Human Rights Commission
24	Paul Hofman	Paediatric Endocrinologist, University of Auckland
25	Richard Tankersley	LGBTI Rights Commissioner, Human Rights Commission
26	Robyn Maude	Director of Student Research and Senior Lecturer, School of Midwifery, Victoria University, Wellington
27	Rosslyn Noonan	ITANZ Patron
28	Spencer Beasley	Clinical Professor Paediatric Surgery, University of Otago
29	Stella Milsom	Endocrinologist, University of Auckland
30	Tommy Hamilton	ITANZ Board Member/Counsellor/University Lecturer

Appendix 2:

Presentations to the Roundtable

Presentations to the Roundtable were between 5 and 8 minutes long. Each presenter was asked to:

- 1 introduce their own perspective,
- 2 outline current work, practice and focus, and
- 3 indicate what they think needs to be done – key issues/actions

Perspective	Presenter	Organisation
1 Intersex	Mani Mitchell	ITANZ
2 Advocate	Helen Gardiner	Community Educator/Support & Advocacy
3 Tangata Whenua	Elizabeth Kerekere	Tiwhanawhana Trust
4 Medical	Esko Wiltshire	Associate Professor, Paediatrics and Child Health, University of Otago
5	David St George	Ministry of Health
6 Legal	Elisabeth McDonald	Associate Professor of Law, Victoria University, Wellington
7 Midwifery	Jeanie Douche	ITANZ Board Member/Midwife/Academic – researcher
8 Human rights	John Hancock	Human Rights Commission
9 International	Katrina Roen	ITANZ Board Member/Academic
10 Pasifika	Fuimaono Karl Pulotu-Endemann	Academic/Medical Professional/Consultant/Fa'afafine
11 Ethics	Angela Ballantyne	Senior Lecturer Bioethics, University of Otago
12 Parliament	Louisa Wall / Jan Logie	Members of Parliament Labour and Green and co-chairs LGBTI cross-party WG
13 Youth (international)	BuzzFeed video	

Presentation – Intersex

Mani Mitchell, Intersex Trust Aotearoa New Zealand

Kia ora Whānau

I am both humbled and struggling a little with my task today.

Humbled, and so appreciative to have you all here. Thank you.

Grateful to the Human Rights Commission (HRC) for helping make today happen and very aware of our over 15 years' collaboration and history. Struggling because of the weight of responsibility I carry to ensure the voice of intersex/DSD persons is heard today.

For the next few minutes I want to clearly take off my hat as a teacher, as a counsellor, as Executive Director of ITANZ, and as an artist, and stand before you as a damaged intersex person who has found their voice.

I have searched for weeks how to do this and am aware of the fact I have only a short amount of time to speak.

I have drawn inspiration from intersex youth. Two and a half years ago I was the sole clinical support person for the world's first ever retreat for intersex youth (youngest 15, oldest 26) in California, USA. It was the last day of our four days together. Our task was to decide what to do as a group to create a youth presentation to doctors and specialists who would be attending the CME day at the AIS-DSD support group conference (the world's largest intersex conference).

We started to go around the group and instead of ideas, what came from the group was trauma/horror stories of things (all within the last year) that had personally happened to them in medical settings. I am a member of the NZ ethics committee for counsellors and many of the stories I heard disturbed me greatly.

- Inappropriate touching/photography
- Clumsy, down-right unprofessional language
- Bullying – lack of obtaining informed consent
- Threats (withholding of treatment)

- People being told lies (about their condition or treatment options)
- Being mis-gendered.

I let the young ones talk. There were lots of tears, lots of hugging and, as each person told their story, I could see the sense of isolation and shame diminishing. We did some processing and talked about what we could do with the information and experience the group held.

Even as I write this I am still so moved by what that group did. It was their idea and they achieved it in a less than a 24-hour period. The next day, after a two-hour car ride, these amazing young people stood in front of a room full of medical people and acted out a series of stories. As a group, they picked what was the top five for them. They firstly acted the story as it had happened and then they replayed the story with how they would like that situation actually dealt with, including the words they needed to hear and the information they needed. At the end of that presentation there were few dry eyes in the room – mine included.

So, in honour of those brave inspirational young people, this is an adapted intersex story.

I was born early in the morning, my mother with a young nurse awaiting the arrival of a doctor. The young nurse announced to the world and my mother that I was a hermaphrodite, a language event my mother never recovered from, and the scars I carry still.

Replay: Ensure all practitioners who attend the birth of children have the skills and confidence to deal with the situation. No one needs to panic and everyone needs to celebrate the birth of the child.

The fact I was indeed intersex was extremely difficult for my parents. I am unsure how much information they got. What I do know that the situation was treated with great secrecy and shame. No-one ever talked to me directly. I learned from being a very little person to endure excruciatingly painful and

humiliating examinations without moving, without sound. I learned to hide and never talk about what had happened.

Replay: The critical players in the intersex narrative are parents. They need skilled, supportive help to learn that their child is fabulous, to meet other parents and to be supported to love their child as they are; help with knowing that their child is okay and learning about their child's difference. It is critical parents understand that their child is the agent of their own bodily autonomy. Life-threatening issues need to be addressed and all other surgery MUST BE LEFT until the child has the capacity to decide for themselves to have surgery or not.

Yes, a gender needs to be assigned, we live in a binary world, but as it is with ALL children that assignment is provisional and may, or may not, be confirmed as the child grows up. ONLY the child knows their gender. As some of you know, I was initially assigned male as a child and was changed to female aged one.

Replay: Intersex DSD people are as diverse (maybe more) than the rest of the population. We locate ourselves right across the spectrums of gender and sexual diversity.

For the record, I am non-binary and queer identified. Neither of the childhood gender assignments were 'correct'. Age 5 I went to school, told never to show anyone, terrified of being 'found out', full of shame and fear with zero self-agency or advocacy ability. No surprise I fell victim to a sexual predator. I would be 40 before I broke that secret.

The model we currently have does not work. We need kids who feel confident of who they are, able to say NO, and tell parents, especially, when not okay stuff is happening. Doctors MUST ask kids before touching them, especially their genitals, and accept that sometimes a child will say NO.

I did not have genital normalising surgery until I was 8. Doctors I have tried to talk to in the past have all assumed, because I am not angry or vocal, it was bad surgery. It was not cosmetically, the surgeon did a brilliant job. I live every day with the fact that the tender and precious exquisite heart of my sexual

being was taken from me. Damaged beyond repair because society was uncomfortable with how I looked. I live with that every day and like many of my intersex colleagues I do feel mutilated. It has had an impact on my life in a way that is very difficult to put into words.

Replay: Yes, having a body that's different needs to be supported. We don't deal with racism by turning everyone brown. We need age appropriate ways to help intersex/DSD people and their families/ whānau to feel okay about having bodies that are different.

All around the world we have examples of intersex people who have not had operations and who are able to, and do, talk about the fact that having a different body is not something horrible to be feared. We must support bodily autonomy.

Puberty for me was a nightmare, like lots of intersex people I don't have standard plumbing. I have a urogenital sinus; my vagina and urinary opening are deep inside my body. I learned as a fear-filled teenager I could not use tampons. I did not know why. Or, why sex was so unbearably painful. Or, why I got urinary infections all the time.

Replay: My mum was a nurse. I don't think she had any idea how different my body was. She thought I had been 'fixed' with the surgery. I needed, like all intersex people, information about my body. If our bodies, our endocrine system, whatever is different WE need that information. It's our body to learn about, understand that difference. We need medical people to stand beside us, to help us be well, the best well we can be and to listen. Really listen to us about the things that are important issues for us because they are not always the things that people so often focus and obsess about.

I could talk for much longer, I am not going to, other than to say please listen to our voices. Our pain, trauma, stories. See us not as defective, disordered, rather see us as precious, creative beings. Work with us, with our parents, those who love us, to be whole and even more amazing.

Thank you for listening.

Presentation – Tangata Whenua

Elizabeth Kerekere, Founder/Chair, Tiwhanawhana Trust (edited transcript)

*Ngati Oneone, Te Aitanga a Mahaki, Whānau a Kai,
Rongowhakaata, Ngāi Tāmanuhiri
Ngā mihi mahana ki a koutou katoa
He mokopuna nō Te Tairāwhiti e tū atu nei
Ko Elizabeth Kerekere tōku ingoa*

My role today is to speak from a Tangata Whenua point of view of intersex people. I will begin with some basic cultural values that many of you will be familiar with. Firstly, Māori culture is based entirely on whakapapa. On one hand whakapapa is about genealogy; where we come from; going back centuries and through to our future generations. But it is also our wider connectedness and relationships; how we work across whānau – across our different families. Through those connections we build responsibilities and accountabilities back to each other.

The core structure of our society is whānau, hapū and iwi. Whānau – which of course you know – means ‘extended family’ but it also means to ‘give birth’. Hapū – our sub-tribes – also means to ‘be pregnant’. And Iwi means ‘bones’ – our connection back to the earth. The placenta is ‘whenua’ or land, so that when a baby is born the placenta is planted back into the earth. That connects those babies spiritually back to their ancestors – where they come from and where they will go back to.

‘Tamariki’ is the Māori word for children. Tama is derived from Tama Nui Te Ra, the sun god, so ‘tama’ here refers to the divine spark. ‘Riki’ is short for ‘Ariki’ – a chief. This is the perception our people had of our children – our most revered and most treasured family members. Notwithstanding the impact of colonisation on the entire structure of Māori culture – and the deliberate attempts to dismantle all of that structure, which has resulted in the prevalence of child abuse in our communities. As I say, that might be part of Māori society but it is not at all part of Māori culture.

So, looking at the work that we do in the community. I founded Tiwhanawhana Trust in 2001, and we continue to be the only political Takatāpui⁷ group in the country. We work alongside many different organisations, because we understand that to uplift Māori with diverse sexes, genders and sexualities we need to uplift our whānau. A big part of that is reminding them of our cultural values. Because we know pre-colonisation our people had much more fluid expressions of sexuality and gender. Rose Pere, some of you may know and have heard speak. One of our most revered elders and writers and communicators, Rose spoke of our intersex people as a **taonga** (treasure). Our people recognised when they were born that intersex people had special lessons to teach us.

Part of what Tiwhanawhana does is work across many different sectors, around education, mental health, health, youth development, suicide prevention, violence – anything we can get involved with. We are particularly interested in issues related to diverse sexes, genders and sexualities and that is how we have developed a relationship with ITANZ. There is very little information about Takatāpui – especially who are intersex – so we undertook to create a base line resource. One of my projects was the Takatāpui: Part of the Whānau print and video resource, in collaboration with the Mental Health Foundation.

My PhD will also contribute to this, entitled ‘Part of the Whānau; The Emergence of Takatāpui Identity (2016)’. Tiwhanawhana does this partly to contribute to the Western body of knowledge that exists but also to build up mātauranga. It is this Māori knowledge that helps us when we are working with our people, because tikanga – the way that we do things in our culture – is based on ‘tika’, on what is right. And that is based on mātauranga. So, for us as takatāpui we need to build up that mātauranga and add to that tikanga so it broadens what is tika so that it is no longer considered acceptable to discriminate against anybody because of their sex, gender, sexuality or their bodily diversity.

Because as Rose Pere pointed out, intersex conditions are not new. When I think about intersex people I think of them as the embodiment of 'tipua'. Tipua were creatures in our culture who could change form and change their gender at will. Different tribes had different stories. For me intersex people and trans people have a way of embodying tipua in incredibly remarkable ways.

So, when we are working with whānau, we remind them that this is a natural, albeit rare, phenomenon. I believe it is part of our wairua. That our ancestors created our sexes, genders and sexualities. That we are only conduits of everything that comes through from our Gods and from our ancestors. Through them we stand in our own mana today.

Every time we interfere with the wairua and the bodily mana of a person, we impact on their ability to contribute to future generations. The wairua and the mauri that we are born with determines how we express ourselves and who we will be in the world in terms of our sex, gender and sexuality and whether that is a non-binary identity or a gender diverse identity. All of that needs to be encompassed. It is not about being normal. It is that we are all of ourselves. It is that we should be inviting the person to discover what it is our ancestors have to say and how we choose to be in the world. It is up to us to celebrate that, to love that, to be excited by that.

As I mentioned, the first takatāpui resource came out in November (2015). It is the fastest moving resource the Mental Health Foundation has and we have just gone out of print. Our next resource, in collaboration with RainbowYOUTH, focuses on supporting whānau who are struggling. We are talking with takatāpui youth, their parents and their grandparents to encapsulate how we create supportive whānau. We include intersex whānau, who are at a point of shock, not knowing what to do or who to listen to.

I believe in their hearts our whānau believe that they are protecting us. In this society, that is very binary, we need to find other ways to help calm and protect those whānau. We need to help those whānau realise they are still looking after their child by allowing that child to grow up, to live and be strong in who they are, with the body they were born with and to

whatever degree they decide to surgically or socially affirm their wairua and their identity in the future.

No reira, it is a great pleasure to be amongst you today and I am very much looking forward to the rest of the speakers. Tēnā rā koutou katoa.

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Presentation – Ethics

Angela Ballantyne, University of Otago Wellington

It is a privilege to be here, thank you for inviting me.

- 1 Methods in ethics.
 - a Reflective equilibrium – working between ethical principles and intuitions in various cases to try to achieve consistency.
 - b Treat like-cases alike and different cases differently. There are many differences between people and situations and actions, so this involves identifying the morally relevant similarities and differently. For example, it would prima facie be unjust to treat a murder and non-murder the same (ie to not punish the murder); and unjust to treat boys and girls differently (i.e. boys can go to school and girls can't). There is huge phenotypic variety amongst humans – race, sex, height etc. The question is where and when we should allocate moral value to these differences. Historically, both race and gender have been seen as morally relevant grounds to distribute civil and political rights (voting, owning property). Obviously race and gender differences still exist in NZ but we no longer think they are morally relevant grounds upon which to distribute these rights.
 - c Binary gender norms and definitions of 'normal genitalia' are social constructs and are therefore open to interrogation and debate; these norms are malleable and modifiable. Science increasingly shows that sex is a spectrum and a wide variety of phenotypes are naturally occurring – for example, different definitions of normal genitalia can see the rate of intersex vary from 1/100 to 1/4500. The question is what moral value we put on this naturally occurring difference.
- 2 While there are many ethical issues in relation to intersex, I am going to focus on an ethical framework for making decisions regarding the interests of children who are not autonomous and who cannot decide for themselves.
 - 3 Parental autonomy, harm and best interests. How do these principles apply to intersex?
 - a General life (outside of medicine) – Parents have wide scope of freedom to raise their children as they see fit; but in exceptional cases the police/ CYFS/Courts can intervene to prevent the parents inflicting harm on the children.
 - b Within medicine – Doctors have a professional obligation to determine which interventions have a sufficient safety and efficacy profile to be offered to parents. Parents can't demand treatment (I want a cosmetic nose job for my 5-year-old so he can get an acting role). Within these options, parents have wide autonomy to determine what is in their children's best interests. But again, in exceptional cases doctors can initiate legal proceedings to remove this decision-making capacity from parents to prevent the parents inflicting harm on the children. (e.g. Jehovah witness parents refusing a blood transfusion for their child).
 - c There is a high threshold to remove parental rights. Note that the parental rights and responsibilities (to make decisions for their children) are removed only in order to prevent serious harm to the child, not to force parents to optimise the child's best interests. (eg not to stop parents letting their kids watch lots of TV or drinking Coke in a baby bottle).
 - 4 From an ethics perspective, the first question is which interventions to treat intersex cause more than minimal harm to the child and should therefore be prohibited?
 - Superficially it can seem like there is consensus that life-preserving treatment and treatment to ensure correct organ functioning is necessary but cosmetic treatment is more controversial. But when we start looking at specific interventions we will find disagreement about what goes in

different categories. Is the capacity to have penetrative sex an example of 'fixing basic medical function' or 'cosmetic'? Again, this relates to social norms and the value we place on the capacity to have penetrative sex.

- Let me know focus on cosmetic interventions to prevent psycho-social harm. The harm arises from being different, stigma and discrimination.
- i WHO defines health as 'well-being' – this is broad and legitimately includes psychological and emotional wellbeing. Medical interventions to prevent psycho-social harm aren't outside the scope of medicine, such as cosmetic surgery for a child burn/trauma victim to 'normalise appearance' might be considered acceptable.
- ii There are three factors that would support a preference, but not an absolute rule, for waiting until the child is old enough to participate in decision making in cases of cosmetic treatment.
 - The degree of psycho-social harm is hard to predict as cultural norms vary between communities and families. As a previous speaker said, research suggests the amount of harm experienced by the child is more closely associated with parental attitudes and not with the underlying physiology. Also, physiological harm can come from providing the surgery as some intersex people say they felt violated and rejected.
 - There is increasing acceptance in NZ of diverse experiences of gender and sexuality (LGBTAIQ). We need to take account of trends and the trajectory towards more liberal attitudes. So not just the degree of stigma in 2015, but in 2030 when the child is an adolescent and in 2050 when they may be thinking about reproducing etc.
 - Sexuality and gender identity are deeply personal and often private aspects of the human experience. As other speakers have said, "how we want to be in the world" and "you in your own uniqueness".

iii In combination, these factors present strong reasons to avoid trying to predict in advance what the child will later want.

- Where there is not clear evidence of harm requiring the prevention of treatment, we need to consider substantive principles and ethical processes to support parents and protect children's best interests.
- i Ethicists in Melbourne (Gillam et al) have recently proposed seven principles to guide decision making for children with intersex.
 - Minimise physical risk and promote physical wellbeing
 - Minimise psycho-social risk and promote psychosocial well-being
 - Preserve potential for fertility
 - Promote capacity for satisfying sexual relations
 - Leave options open for the future
 - Consider the views and wishes of the child
 - Respect the parents' wishes (in balance with the other principles)
- ii Process. Many parents presented with decisions regarding intersex will be confronted, shocked, maybe panicked and will likely have little experience with this topic. They should be supported to ensure they make well-reasoned judgments about their children's best interests. Consider for example the support offered to people who contemplate egg and sperm donation. Forming a 'non-traditional' family through gamete donation is seen to raise many issues couples are unlikely to have previously thought about and would be unlikely to occur to them on their own.

There are compulsory stand-down periods and compulsory counselling in New Zealand designed to ensure appropriate time and support to make a good decision about providing or using gametes. Making decisions about atypical genitalia and gender are also outside the scope of everyday parenting considerations and may equally warrant a supportive decision-making process.

Presentation – Human Rights

John Hancock, New Zealand Human Rights Commission

Human Rights Dimensions

Slide 1: Reporting on New Zealand's progress re human rights obligations

- State parties must regularly report to the UN on progress made in implementing commitments under human rights treaties
- Law of Treaties (Vienna Convention)
- Treaties contain reporting protocols and procedures – ie. Art 44 UN Convention on Rights of the Child

Slide 2: UN Reporting Opportunities

- To Treaty bodies (ie UN Human Rights Committee) regarding individual treaties
- Day of Discussions/General Comments
- Universal Periodic Review – to UN Human Rights Council
- Studies undertaken by UN Special Rapporteurs

Slide 3: Potential Outcomes

- Treaty bodies – Concluding Observations eg. Ireland – 71st Session of CRC (11 – 29 January 2016)

Harmful practices

39. The Committee notes as positive the adoption of the Gender Recognition Act 2015 by the State party. It remains concerned, however, about cases of medically unnecessary surgeries and other procedures on intersex children before they are able to provide their informed consent, which often entail irreversible consequences and can cause severe physical and psychological suffering, and the lack of redress and compensation in such cases.

40. The Committee recommends that the State party:

- a 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;
 - b Undertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;
 - c Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity and on the consequences of unnecessary surgical and other medical interventions for intersex children.
- Provides considerable utility for advocacy, given obligation on Government to respond and address.

Slide 4: Human Rights Engaged

- Non-discrimination (universal)
- Right of child to exercise informed consent (Art 12 UNCRC)
- Protection from degrading treatment (Art 7 ICCPR, Art 37.1 UNCRC)
- Best interests of the child (Art 3 UNCRC)
- Right of child to “maximum extent” of development (Art 6.2)
- Right to physical/mental health (Art 12 ICESCR, Art 24 UNCRC)
- Measures to abolish harmful traditional health practices (Art 24.3 UNCRC)

Slide 5: Current Reporting Opportunities

International

- NZ CRC review – September 2016; supplementary submissions due 15 August 2016
- NZ ICESCR review – NZ report to ICESCR due May 2017 – List of Issues for NZ Government released 12 April 2016 – re measures to combat violence against transgender persons and children
- UPR – NZ third cycle report – due Oct 2018, review Jan/Feb 2019

Domestic

- National Plan of Action on Human Rights

Slide 6: General Comment No. 22 (2016) on the Right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights) – Advanced Unedited Version, 4 March 2016

Includes following observations

- Certain individuals and population groups that experience multiple and intersecting forms of discrimination that exacerbate exclusion in both law and practice, such as lesbian, gay, bisexual, transgender and intersex persons (LGBTI) and persons with disabilities, the full enjoyment of the right to sexual and reproductive health is further restricted. For the purpose of this General Comment, references to LGBTI persons include, in addition to lesbian, gay, bisexual, transgender and intersex persons, other persons who face violations of their rights on the basis of their actual or perceived sexual orientation, gender identity and sex characteristics, including those who may identify with other terms. For intersex persons, see Fact Sheet on Intersex, <http://www.unfe.org> https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf

- Non-discrimination, in the context of the right to sexual and reproductive health, also encompasses the right of all persons, including LGBTI persons, to be fully respected for their sexual orientation, gender identity and intersex status.
- It is also important to undertake preventive, promotional and remedial action to shield all individuals from the harmful practices and norms and gender-based violence that deny them their full sexual and reproductive health.

Slide 7: ICESCR General Comment 22 (contd)

Core Obligations on State Parties Include:

- To enact and enforce the legal prohibition of harmful practices and gender-based violence, including female genital mutilation, child and forced marriages and domestic and sexual violence including marital rape, while ensuring privacy, confidentiality and free, informed and responsible decision-making, without coercion, discrimination or fear of violence, on individual's sexual and reproductive needs and behaviours.
- To ensure access to effective and transparent remedies and redress, including administrative and judicial ones, for violations of the right to sexual and reproductive health.

ICESCR Violations include:

- Laws and policies that indirectly perpetuate coercive medical practices, including incentive or quota-based contraceptive policies and hormonal therapy, surgery or sterilisation requirements for legal recognition of one's gender identity.

http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=E%2fC.12%2fGC%2f22&Lang=en

Appendix 3: Midwifery Position Statement: Inclusive Partnerships with LGBTI Communities

(DRAFT 2 at September 2016)

(NOTE: This statement has been developed following, and as a result of, the Intersex Roundtable)

Background

Traditionally midwifery has been a women-centred profession, positioned for the moment upon the hetero-normative landscape of reproduction. This construction largely privileges women's reproductive rights over other vulnerable gendered identities such as lesbian, gay, bisexual transgender and intersex (LGBTI) citizens.

The last decade attests an explosion of discourses concerning discriminatory and harmful practices in health care settings, apropos of sex and gender. These include violations of reproductive rights and the right to bodily integrity (see Intersex Trust of Aotearoa New Zealand [ITANZ] 2015). The issue is part of a global trend that is gaining momentum (United Nations Human Rights 2007; Baisley, 2016). Midwives accordingly are at the forefront of working in partnership with LGBTI clients to provide a culturally safe and positive childbearing experience.

Moreover, respecting the autonomy of whanau to make full and informed decisions about their infants' care has its expression in the Code of Health and Disability Services Consumer Rights (Health and Disability Commissioner, 1996). Midwives have a pivotal role in supporting sex and gender variant families alongside protecting intersex infants' rights to bodily integrity until they are of an age to decide who they choose to become for themselves.

As new technologies come into play, LGBTI citizens have opened up new horizons for contemplating inclusive partnerships and new possibilities for being in childbirth. Midwives can make a difference by respecting the right of LGBTI communities to share in the same protection of reproductive rights as other New Zealand citizens. It is therefore timely that NZCOM on behalf of its members and in consultation with their LGBTI partners makes explicit its position on including and protecting the reproductive rights of LGBTI communities alongside the right to bodily integrity.

Consensus Statement

The NZCOM believes that midwives practise in a culturally safe manner throughout the childbearing experience. The tenets of cultural safety summon midwives to embrace diversity invoking them to critically reflect on their own (hetero)sexual assumptions and how these may impact on the care of LGBTI citizens they encounter in practice. It is at this juncture that Statements from the Canadian Association of Midwives (CAM, 2015) and American College of Nurse Midwives (ACNM, 2012) provide a platform for NZCOM to show its commitment to Human Rights and Social Justice by summoning the need for an all-inclusive maternity service in Aotearoa New Zealand.

Guidelines

- LGBTI communities have the right to a safe space in which to enjoy the full entitlement of their

reproductive rights, free from discrimination and stigmatisation throughout their childbearing experience.

- NZCOM shows its commitment to an all-inclusive maternity service through incorporating inclusive statements throughout its Philosophy, Competencies for Practice, Standards of Practice – Turanga Kaupapa and Code of Ethics.
- The language used in the care of LGBTI citizens is inclusive, taking into account the diversity and appropriateness of the terminology within the LGBTI community.
- In accord with NZCOM (2009) consensus statement on Informed Consent and Decision-Making, parents of intersex babies have the right to be fully informed and make informed decisions and give consent about their babies' care.
- Parents of intersex babies have the right to access and support from intersex peoples and families as an integral part of an informed decision making process.
- Intersex infants have the right to maintain physical integrity.
- Genital normalising surgery has lasting implications and should be deferred until the child is old enough to decide who they choose to be.
- NZCOM shows its commitment to Human Rights and social justice through its educational programmes including undergraduate and post graduate curricula, certification and policy statements such as the Vulnerable Children's Act.

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- 3 International Intersex Consensus Conference (The Chicago Consensus, 2005). <https://science.report/pub/59252>
- 4 LIAO, L.-M. & ROEN, K. 2014. Intersex/DSD post-Chicago: New developments and challenges for psychologists. *Psychology & Sexuality: Special Issue*, 5, 1-4
- 5 United Nations for LGBTI Equality Action (2015) encourages States to:
 - Prohibit medically unnecessary surgery and procedures on the sex characteristics of intersex children, protect their physical integrity and respect their autonomy.
 - Ensure that intersex people and their families receive adequate counselling and support, including from peers.
 - Prohibit discrimination on the basis of intersex traits, characteristics or status, including in education, health care, employment, sports and access to public services, and address such discrimination through relevant anti-discrimination initiatives.
 - Ensure that human rights violations against intersex people are investigated and alleged perpetrators prosecuted, and that victims of such violations have access to effective remedy, including redress and compensation.
 - National human rights bodies should research and monitor the human rights situation of intersex people.
 - Enact laws to provide for facilitated procedures to amend sex markers on the birth certificates and official documents of intersex people.
 - Provide health care personnel with training on the health needs and human rights of intersex people and the appropriate advice and care to give to parents and intersex children, being respectful of the intersex person's autonomy, physical integrity and sex characteristics.
 - Ensure that members of the judiciary, immigration officers, law enforcement, healthcare, education and other officials and personnel are trained to respect and provide equal treatment to intersex persons.
 - Ensure that intersex people and organisations are consulted and participate in the development of research, legislation and policies that impact on their rights.

https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf

- 6 'Family' is defined in its broadest sense and may not necessarily involve blood relatives
- 7 Takatāpui embraces all Māori with diverse sexes, genders and sexualities including whakawahine, tangata ira tane, lesbian, gay, bisexual, trans, intersex and queer.



Human Rights Commission
Te Kāhui Tika Tangata