



INTERSEX HEALTH WEBINAR

**October 5, 2022
7-8pm**

**Information and Resources for Medical
Students**

Register at tengakaukahukura.nz



INTERSEX HEALTH WEBINAR

Te Ngākau Kahukura and Intersex Aotearoa will present information and research about intersex health and what it means to use a human rights framework in this context.

We will discuss language, patient-centred care, and access to community support. Our goal is to increase confidence for medical students on how to engage with intersex people/people with variations of sex characteristics and their parents/whānau. We will provide links for further reading, access to community resources, and time provided for questions after the presentation.

What we're talking about when we say 'intersex'

Intersex is an umbrella term that describes those who have **innate variations in their sex characteristics**. **There are up to 40 different variations known, occurring** in approx. **2.3% of the population**. Sex characteristics include a person's chromosomes, genitals, reproductive systems, gonads, hormone sensitivity and production. **Variations of sex characteristics** are considered **outside** of the **stereotypical norms of male and female bodies**.

Intersex variations are **innate = natural**.

Medical pathology may only deem some variations as intersex. Those that are medically “between sex”.

. For eg:

- 46, XX intersex
- 46, XY intersex
- True gonadal intersex

Terminology

Intersex, intersexual, **variations of sex characteristics (VSC)**, **disorders** of sex development, differences of sex development (DSD) **hermaphrodite**, atypical sex anatomies, **doubtful sex**. **Mutations**, conditions, **abnormalities... variations**.

'...Objections to the language of “disorders of sex development” began immediately after it was clinically adopted in 2006 and have continued to the present time.'
(Carpenter M, 2018)

5-alpha reductase deficiency, Androgen Insensitivity Syndrome (AIS), Aphallia, Clitoromegaly (large clitoris), Congenital Adrenal Hyperplasia (CAH), gonadal dysgenesis (partial & complete), hypospadias, Klinefelter Syndrome, micropenis, mosaicism involving "sex" chromosomes, MRKH (Mullerian agenesis; vaginal agenesis; congenital absence of vagina), ovo-testes (formerly called "true hermaphroditism"), Partial Androgen Insensitivity Syndrome (PAIS), Progestin Induced Virilization, Swyer Syndrome, Turner Syndrome

The Rainbow - LGBTQIA+

Understanding the difference between sex, gender and sexuality is key to the distinct groups that make up 'The Rainbow'.

The inclusion of the 'I' is an important part in the acronym, as intersex challenges social norms. **Intersex is not a gender identity or related to sexuality**, yet parallels of lived-experience can foster peer allyship.

The systems that feed into the discrimination of intersex people: **interphobia, transphobia, homophobia**, are the **heteronormative, patriarchal, and colonial everyday 'norm's** of our society. The defying of these norms connects the intersex movement to its peers within the rainbow, by calling for bodily autonomy and self-determination; the freedom to live as we are, without fear or shame or pathologisation.

However, the **majority of those with variations of sex characteristics would not perceive themselves as 'part of the rainbow'**.

History of medicalisation

..."intersex individuals have been pathologized by the medical profession's insistence on a strict binary model of sex, gender and sexuality; this is true in the past and in the contemporary context" (Davis et al., 2016; Meyerowitz, 2002)

- Prior to WW2 adults were the subject of medical interventions, and these adults often sought out treatment options themselves.
- between **1930 and 1955**, so-called 'sex change' operations were controversial, while **intersex surgeries were becoming routine, including the removal of healthy gonadal and genital tissue.**
- Post WW2 new surgical technologies emerged. In the late 1940s a new specialty – paediatric urology.
- 1955 **John Money** published guidelines **that recommended early surgical intervention on genitals that did not conform** to cultural ideas of **what male and female genitals should look like, and recommended consistent rearing in one corresponding 'gender'.**

What occurred is a blurring of medical intervention as a psychological support.

Yet these notions of support were based on a heteronormative conventions.

As one doctor writes of surgical interventions in the 1930's on patients with CAH:

"As a result of operative treatment it has been discovered that these patients show not only a general and immediate tendency to lose their acquired male characters, and revert to their normal feminine ones, but also to return to normal sexuality psychologically, when this has been abnormal before operation. (Broster et al., 1938: 5)"

- **The "problem" of intersex becomes** more and more **a childhood issue**, and the importance of swift and surgical responses are emphasised and strict delineation between male and female bodies is recommended.
- John Money – **used surgical intervention as a tool for psychological study.**
- The fragility of **childhood psychological development** is used as a **justification for early intervention.**
- **Parental anxiety** is also invoked as a threat to psychological development, and one which **surgery on the child can manage.**

Social norms prevail with new surgical technologies

"It is generally recognized that restoration of normal masculine micturition must, if possible, be achieved before the school age, say 5 to 8 years. For psychological reasons it is obviously important that the boy at school should pass urine like his fellows. (Higgins et al., 1951: 219) "

In hypospadias treatment, medical professionals were constructing standing-up urination as a new component of what a 'normal' child was. These same motivations drive nearly 200 surgical interventions a year in Aotearoa.

The literature from this time shows that many of these early pioneers of intersex pathologisation were **in fear that diverse bodies could lead to diverse sexualities**. As a response to queer fear **there is a belief that if you edit the body, you can edit the mind**.

Using heterosexuality as a measure; one that is linked to strict patriarchal and colonial notions of normality, bodies are structured into a binary of how to be male and female.

Yet, if 2.3% of the population have a variation of sex characteristics, what is "normal"?

What are the health concerns, not the social concerns?

“Surely, ...it will be familiarity rather than knowledge that finally takes away [intersexuals'] supposed 'strangeness.' (A Dredger, 1996) ”

Colonisation in Aotearoa

Many hapū and iwi have stories that tell of tupuna that can be understood now as having intersex variations. All members of the whānau were accepted as they are. The colonisation of Aotearoa alongside British settlers brought British values, norms and knowledge systems, as well as British social, cultural, political, legal, scientific and medical systems.

Tangata whenua are revitalising pre-colonial notions of embodiment: Dr Elizabeth Kerekere doctoral research on Takatāpui and Tu Chapman's journey as 'Ira Tangata' (podcast)

Intersex and transgender healthcare

Both **trans and intersex are still pathologised within a medical setting**, but in different ways. Medical interventions for trans individuals are approached with a caution that is not replicated in intersex interventions:

Even after years of criticism from intersex people, many providers are quick to perform surgery on bodies of babies and young children that they consider abnormal... At the same time, they hesitate to act in cases where trans individuals request surgery. (Davis et al., 2016: 491)

Intersex pathology today

- Psychosocial motivations remain the same.
- Limited teaching in medical colleges, midwifery, sexual health, relationship & education .
- Surgical techniques have started to change over the past 20 years. For eg, moving away from the 'make a hole, rather than a pole'.
- Data and diagnostic issues occur across different DHB's have meant limited to no robust collection of records. Hundards of surgical interventions to happen to infants, young people and adults every year in NZ.
- Genetic analysis has firmly taken root in the clinical management of VSC and use of the External Masculinizations Score, External Genital Scale and Phalometer – which are all serve to make clinical observation "objective" and rationalise subjective difference.
- There has been no formal investigation lead by government departments into how many surgical interventions are happening in NZ hospitals
- Some hospitals encourage 'multi-disciplinary teams' including advocates with lived experience and psychological support.

Be the change!

United Nations Committee on the Rights of the Child asked the NZ government in 2016 to:

- Develop and implement a child rights-based health-care protocol for intersex children.
- Investigate incidents of non-consensual medical treatment on intersex children, and provide redress to victims.
- Educate and train medical/psychological professionals on intersex and the consequences of unnecessary medical interventions.
- Extend free access to surgical interventions and intersex medical treatment to intersex children between the age of 16 and 18.

- Decolonisation should always be brought into any dialogue about demedicalisation.
- Support the call for more resources for healthcare training and development including community-led education and advocacy.
- International policies and legislation are prohibiting non-lifesaving medical interventions. This is happening in Australian states VIC and ACT. What will this mean for Aotearoa?
- Intersex led organisations call for the demedicalisation of intersex variations, while calling for greater healthcare competency to manage any health and wellbeing outcomes.

Resources

Supporting your intersex child:

<https://www.iglyo.com/wp-content/uploads/2018/10/Supporting-Your-Intersex-Child.pdf>

Starship Guidelines:

<https://starship.org.nz/guidelines/differences-of-sex-development-atawhai-taihemahema/>

Denise Steers – University of Otago

Navigating Healthcare Decision making with Parents, young people and doctors

(To be released November 2022)

International Classification of Pediatric Endocrine Diagnosis

<http://www.icped.org/revisions/0/2015/diagnoses/#!/4A.3>

