Intersex children in New Zealand are routinely undergoing unnecessary surgery, and that needs to change

October 26 2021, by Claire Breen, Katrina Roen

Until very recently, people with intersex variations have often been unseen, stigmatized and routinely discriminated against. Intersex Awareness Day today (October 26) is therefore an opportunity to examine how much progress has been made and how far we still have to go.
It's estimated 1.7 to 4% of people globally are intersex—meaning they don't fit within typical female or male norms.

In particular, the rights of children with intersex variations are coming under scrutiny.

With surgery in infancy or early childhood still considered an option, questions are now being asked about how to ensure no child is subjected to unnecessary procedures or treatment, and that the child's consent is obtained for necessary interventions.

> Intersex people undergo surgery when too young to give consent, inquiry told [https://t.co/TpCMtsCrKD](https://t.co/TpCMtsCrKD)

> — Guardian Australia (@GuardianAus) **October 18, 2021**

### Surgery can be delayed

Intersex people have variations in sex characteristics that can occur naturally at the level of chromosomes, hormones and/or anatomy.

There is a wide range of variations. Hypospadias, where the urethral opening appears on the underside of the penis, is most common. Although not a health problem, surgery to alter the hypospadic appearance is "routine" in many places, including Aotearoa New Zealand.

The latest [Ministry of Health data](https://www.health.govt.nz) shows that in 2017–18, 265 people aged under 15 were diagnosed with hypospadias, with 206 surgical operations performed—85% of those operations performed on children aged under five.

These surgeries could be delayed until the children are older and able to
give or refuse consent. There is no clear biomedical basis for such surgery, it is not lifesaving and it puts the child at risk (as surgery inevitably does).

While there are some gonadal variations (affecting the development of ovaries or testes) that can be life-threatening and require surgical treatment, few variations in sex characteristics are life-threatening in infancy.

Surgery on children with genital variations might appear to promote wellbeing but research highlights the harmful effects of any surgery intended to produce a more "male" or more "female" genital appearance.

Like their overseas counterparts, Aotearoa New Zealand intersex people who have spoken publicly have opposed the interventions they underwent as children.

**Who gives consent?**

The issue of genital surgery has implications for the legal rights of New Zealanders with variations in sex characteristics, including their right to refuse medical treatment, and the rules around informed consent.

The young age at which most surgeries are carried out means consent is provided by parents, who have the right and responsibility to decide on important matters affecting the child, including non-routine medical treatment.

With such decisions, the best interests and welfare of the child in their particular circumstances must be the paramount consideration. The right to be fully informed is contained in the Code of Health and Disability Services Rights.
In essence, every New Zealander has a right to an explanation of their condition and an explanation of the options available, including risks, side effects, costs and benefits of each option, and honest and accurate answers to questions, including the results of research.

But intersex advocates in Aotearoa New Zealand argue that they and their families have been isolated from sources of information and from others in similar situations.

And there is the added complexity of current responses to intersex variations being insensitive to cultural contexts, reflecting as they do binary Western constructions of gender that categorize individuals as either male or female.

**International progress**

The issue of genital surgery is gaining traction in international law. For example, the right to be protected from degrading treatment was extended to health-care settings in 2013, with the call from a UN special rapporteur for states to repeal any law allowing genital-normalizing surgery when "enforced or administered without the free and informed consent of the person concerned."

Overall, the right to health is violated when states fail to take steps to prevent young children from undergoing medically unnecessary, irreversible and involuntary surgery and treatment.

In 2016, the UN Committee on the Rights of the Child recommended Aotearoa New Zealand develop and implement a healthcare protocol for intersex children, based on children's rights, setting the procedures and steps to be followed by health teams.

This followed a submission to the committee from Aotearoa New
Zealand's Human Rights Commission. The UN committee called on the country to ensure no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, and to guarantee the child's right to bodily integrity, autonomy and self-determination.

In response to the recommendations of the UN committee, as well as domestic advocacy, the Ministry of Health directed the Paediatric Society to set up an intersex working group to develop guidelines for infants born intersex.

But this has so far failed to make significant changes to the practice of surgical intervention on children's genitalia.

**Aotearoa New Zealand can do better**

Meanwhile, advocates continue to call for legislation to defer interventions until children themselves are capable of consenting or expressing their own views.

Central to any policy, legislative or medical development must be the child's right to be free from discrimination.

Children have the right to have their voices heard. This means, with the exception of life-saving treatment, any interventions should be postponed until a child is competent to decide.

Where necessary, a skilled, independent advocate should be appointed to represent the child's interests. Current medical practice in Aotearoa New Zealand falls well short of those goals.

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