THE MISSING VOICE

A THEMATIC ANALYSIS AND STORIES OF ONGOING MEDICAL INTERVENTIONS ON INTERSEX CHILDREN IN AUSTRALIA

The Missing Voice provides an insight into the current surgical interventions on intersex children in Australia and the rationales driving these decisions.

This groundbreaking report reveals that children today remain at risk of non-urgent, deferrable procedures that may have lifelong physical and psychological consequences.

It calls for urgent reform to legislate and properly resource oversight frameworks across the country to safeguard the autonomy and rights of intersex children, like those implemented in the ACT and committed to in Victoria.

HOW WE DID IT

Equality Australia issued Freedom of Information (FOI) requests to every major children's hospital in the country about medical procedures performed on intersex children.

Heavy redactions and inconsistent record-keeping meant that only 83 cases from NSW and Queensland were suitable for thematic analysis, covering medical interventions between 2018 and 2023.

BACKGROUND

Innate variations in sex characteristics are a natural part of human diversity and are present in about 1.7% of the population.

People with intersex traits differ from medical and social norms for male and female bodies, including anatomy, reproductive organs or hormonal and chromosomal patterns.

Intersex children can undergo medical procedures which may have long-term consequences.

Consequences of surgery can include:

- Loss of sexual function and sensation
- Loss of fertility
- Urinary tract issues, including incontinence
- A need for ongoing medical treatment/repeat surgeries
- Incorrect gender assignment
- Loss of autonomy and loss of choice.

FINDINGS

1. Intersex children remain at risk of harm from medical procedures that could be deferred until they are old enough to consent for themselves.

2. Non-medical reasons and unbalanced considerations were repeatedly observed* in treatment discussions without appropriate attention to the risk of harm the decision may cause, including:

- Cosmetic justifications (46.99%)
- Gender reinforcement (16.87%)
- Unbalanced medical risks (25.30%)
- Parental distress/confusion (62.65%)

* 109 instances observed in the analysis.

3. The system lacks a robust, independent framework for resolving complex cases, including:

- processes for handling escalation of clinical disagreements and standardised assessment criteria;
- weighting of risk and/or harm versus benefits to support decision-making; and
- access of diverse lived and professional experience and clinical expertise to inform decisions.

4. Hospitals lack consistent, centralised processes and documentation practices to record treatment discussions and decisions, which is further exacerbated when needing to access available historic data to inform treatment recommendations.

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REAL STORIES OF HARM

The report includes 11 stories from intersex people, providing a rare and invaluable insight into the deeply personal consequences of early medical interventions.

> *"I had been sterilised due to a decision made by clinical specialists, and I will have to live with the consequences of that for my entire life."*
>
> *- Stephanie Saal*
>
> *"I feel robbed of an opportunity to be in my own body, instead of one some doctor picked out for me, just so I fit some imaginary binary."*
>
> *- Jade**
>
> *"The biggest thing for me is that my body has never felt like it belonged to me because I don't know what was done to it."*
>
> *- Eli*
>
> * Not their real name

WHAT NEEDS TO CHANGE

Medical decisions with lifelong consequences for children who cannot yet decide for themselves must be grounded in evidence and guided by human rights principles.

An independent oversight body would not delay urgent care where it is genuinely needed – but rather safeguard each child's right to grow up with as many choices open to them as possible.

Clinicians need a consistent and robust national framework to support them, and parents need access to information, services and support to ensure the best decision-making for their children.

RECOMMENDATIONS

RECOMMENDATION 1: LEGISLATIVE RESPONSE

State and territory governments should introduce legislation to establish:

- An independent oversight panel consisting of individuals with expertise in relevant clinical practice, law and human rights, ethics and lived experience, to review and approve proposed treatment plans, guided by clear assessment and approval criteria.
- A prohibition on medical treatment that modifies the sex characteristics of a protected person without their consent, except in an emergency or where an approved treatment plan is in place.

RECOMMENDATION 2: IMPROVED DOCUMENTATION AND REPORTING

Hospitals and health services should take immediate action to:

- Strengthen the quality of documentation and record keeping.
- Implement reporting standards to improve access to data to inform decision-making.

RECOMMENDATION 3: LISTENING TO AND WORKING WITH INTERSEX PEOPLE

State and territory and federal governments should:

- Co-design information and support systems with peer-led organisations representing people with variations in sex characteristics, to ensure that intersex voices are centred.

VIEWING THE REPORT

Access a full copy of *The Missing Voice*, visit: https://equalityaustralia.org.au/take-action/campaigns/intersex-human-rights/

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