# THE MISSING VOICE

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

# ABOUT EQUALITY AUSTRALIA

Equality Australia is a national LGBTIQ+ organisation dedicated to achieving equality for LGBTIQ+ people.

Equality Australia brings together legal, policy and communications expertise, along with thousands of supporters, to address discrimination, disadvantage and distress experienced by LGBTIQ+ people.

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We acknowledge that our offices are on the lands of Bunurong, Gadigal, Jagera and Turrbal peoples, and we pay our respects to traditional custodians.

# ACKNOWLEDGEMENT OF CONTRIBUTORS

We begin by expressing our sincere thanks to the 11 people who generously shared their personal stories with us. We are deeply grateful for your time and courage.

This report represents the collective effort of many contributors and authors, including former and current staff and contractors of Equality Australia. We thank everyone who played a role in shaping its development, including consultants Ed Miller and Lee Carnie.

We thank our technical reviewers, Dr Arlene Baratz, Dr Morgan Carpenter, Dr Jacky Hewitt and Dr James Moloney for their expertise and insight.

Thank you to our pro bono legal advisers and designers Leading Hand Design for their in-kind support.

InterAction for Health and Human Rights

This publication has been developed in collaboration with InterAction for Health and Human Rights, the leading national body by and for people with innate variations of sex characteristics.

Content should be attributed to Equality Australia.

# LANGUAGE DISCLAIMER

Equality Australia recognises the diverse perspectives on language used to describe variations of sex characteristics, and the strong views about which terms best reflect lived experience, physical characteristics and medical practices. Reporting on medical documents adds further complexity, as it requires maintaining fidelity to the primary material.

We use the terms 'innate variations in (or of) sex characteristics', 'people with intersex variations', and 'intersex people (or children)' interchangeably. We acknowledge that not all people born with variations in sex characteristics may use the term intersex to describe themselves, and that many people use the term intersex with pride.

We recognise that some clinical terminology is strongly objected to by intersex advocates on the basis that it can be disordering and stigmatising. For example, the medical abbreviation DSD can refer both to 'differences of sex development' or 'disorders of sex development' which can be viewed by some as taking a deficit lens to people with variations in sex characteristics. To accurately reflect clinical records, we use clinical terminology, including DSD when referring to, or quoting from, medical documents. Elsewhere, an effort has been made to use descriptive or illustrative language that makes the report accessible for non-clinicians, and inclusive for intersex people.

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# CONTENTS


ACKNOWLEDGEMENT OF CONTRIBUTORS ..... 2

LANGUAGE DISCLAIMER ..... 2

FOREWORD ..... 4

GLOSSARY OF KEY TERMS ..... 5

EXECUTIVE SUMMARY ..... 6

PART 1: THE CASE FOR REFORM ..... 8

Interpreting the findings: limitations of available data ..... 9

KEY FINDINGS ..... 10

Finding 1: Intersex children remain at risk of harm ..... 12

Finding 2: Non-medical reasons and unbalanced considerations in treatment discussions ..... 13

Finding 3: The system lacks a robust, independent framework for resolving complex cases ..... 22

Finding 4: Hospitals lack consistent, centralised processes and documentation of treatment discussions and decisions ..... 24

PART 2: REAL STORIES OF HARM ..... 26

PART 3: MOMENTUM FOR REFORM ..... 37

Domestic context ..... 38

International context ..... 41

PART 4: OUR REFORM PROPOSAL ..... 43

Recommendation 1: Legislative response ..... 47

Recommendation 2: Improved documentation and reporting ..... 47

Recommendation 3: Listening to and working with intersex people ..... 47

PART 5: OUR METHODOLOGY ..... 48

FOI requests ..... 49

Personal Stories ..... 51

Ethical Considerations ..... 51

PART 6: TECHNICAL REVIEWS ..... 52

Hudson Institute Review - Medical accuracy review of cases of concern ..... 53

Dr Arlene Baratz Review - Clinical and research-focussed technical review ..... 54

Dr Morgan Carpenter Review - Bioethical and lived expertise review ..... 56

APPENDIX: REFERENCE CASES ..... 58

# FOREWORD

## CEO, Anna Brown OAM
## Patron, Tony Briffa

***The Missing Voice*** brings together years of work analysing Freedom of Information (**FOI**) materials from hospitals across Australia. Because of heavy redactions and inconsistent record-keeping, we see only fragments of what happens behind closed doors. In some places, the door remains closed altogether.

Even from these partial insights, one message is unmistakable: what intersex advocates have said for decades is true. **Intersex children born today remain at risk of medical procedures that could be delayed, or avoided entirely, if stronger systems of oversight and support were in place.**

Families and clinicians often face complex and emotional decisions. An independent oversight mechanism would help ensure that choices made on behalf of children who are too young to decide for themselves are transparent, well-supported, and grounded in human rights principles. Such a process would not delay urgent care where it is genuinely needed, but it would help safeguard each child's right to grow up with as many choices open to them as possible.

**In the 83 cases we were able to examine in the thematic analysis,** we found repeated instances of non-medical considerations in treatment discussions, such as cosmetic or normative treatment rationales, without appropriate attention to the risks of harm. We also identified examples of unbalanced assessment of clinical risks, insufficient documentation of long-term risks, and clinical disagreement of treatment pathways. While many examples of thoughtful, compassionate care do exist, the potential for harm remains too great.

**Even one case of harm is one too many**, as the 11 personal accounts included in this report demonstrate. They remind us that behind every data point is a person whose body and autonomy deserve respect. We can do better for parents, who need clear, balanced information and meaningful support. We can also do better for clinicians, who require better resourcing and a framework that supports ethical decision-making under pressure.

Most importantly, we can do better for the children who are too young to advocate for themselves, ensuring that no one ever again has to say: "*I never felt like my body belonged to me.*"

**It is time to listen to these missing voices.**

# GLOSSARY OF KEY TERMS

| TERM | DEFINITION |
|---|---|
| 5-ALPHA REDUCTASE 2 DEFICIENCY (5-AR2D) | A variation that affects the conversion of testosterone to dihydrotestosterone (DHT). Children may be born with atypical genital development, and virilisation may occur at puberty. |
| ANDROGEN INSENSITIVITY SYNDROME (AIS) | A variation in which a person with XY chromosomes has a typical testosterone level, but their body does not respond to androgens in the usual way. This can result in typical female external genitalia, with internal testes. |
| CAH (CONGENITAL ADRENAL HYPERPLASIA) | A group of inherited conditions affecting hormone production, which can cause variations in genital development in infants and hormonal imbalances throughout life. |
| CLITOROPLASTY / VAGINOPLASTY | Surgical procedures that alter the appearance, size, or structure of the clitoris or vagina. These carry many severe risks including reduced sensation and scarring. |
| DSD (DIFFERENCES / DISORDERS OF SEX DEVELOPMENT) | A contested clinical umbrella term describing congenital variations in chromosomal, gonadal, or anatomical sex development. Many intersex advocates reject the "disorders" and "difference" framing as pathologising and taking a deficit lens to their bodies. |
| FREEDOM OF INFORMATION (FOI) MATERIALS | FOI materials refer to documents obtained through state and territory legislation which allow individuals or organisations to request access to government-held documents, in this case the hospital records of intersex-related medical procedures on children. The term 'Freedom of Information' is not universal – some jurisdictions use 'Right to Information' or 'Information' requests. |
| GONADECTOMY | Surgical removal of gonadal tissue (testes, ovaries, or ovotestes). Sometimes justified on perceived malignancy risk but results in irreversible sterilisation and lifelong hormone dependence. |
| HORMONE REPLACEMENT THERAPY (HRT) | Medication used to replace hormones that the body does not produce naturally, often required after gonadectomy. |
| HYPOSPADIAS | A variation in which the urethral opening appears on the underside of the penis rather than the tip. Mild cases often require no intervention; severe cases have high surgical complication rates. |
| KAROTYPE | A description of a person's chromosomal pattern E.g. 46,XX, 46,XY. |
| MULTIDISCIPLINARY TEAM (MDT) | Refers to the hospital-based committees that review and make recommendations about the care of children with innate variations of sex characteristics. MDTs are intended to support collaborative decision-making in complex cases. Typically made up of paediatric endocrinologists, urologists or surgeons, geneticists, and psychologists. For more on the role and composition of MDTs in Australia refer to the table on page 25. |
| ORCHIOPEXY | A surgical procedure to reposition an undescended testis into the scrotum. |
| SWYER SYNDROME / 46,XY COMPLETE GONADAL DYSGENISIS | A variation in which an individual with an XY karyotype develops female external genitalia, a uterus, and streak gonads that do not produce typical sex hormones. |
| VIRILISATION / UNDERVIRILISATION | Terms used to describe the extent to which androgen exposure has influenced genital development. |

# EXECUTIVE SUMMARY

**People with intersex variations have a wide range of innate physical traits that differ from medical and social norms for male and female bodies. While there is no universal agreement on the variations considered intersex, there are at least 40 known variations that occur across an estimated 1.7 per cent of the population.[1] This includes differences in anatomy, reproductive organs, hormonal patterns, or chromosomal patterns.**

Whether innate variations of sex characteristics present at birth or are discovered later during puberty, intersex children will often undergo medical procedures before they reach the age of consent. These procedures can impact sexual and reproductive function, hormonal balance, and gender assignment. They can have lasting impacts: negative self-image, the need for further surgery, loss of sexual pleasure, loss of reproductive function and dysphoria for people placed in bodies that don't accord with their identity.

We acknowledge that clinicians aim to provide thoughtful and compassionate care within challenging systems that have changed and developed over time. In many states, the establishment of multidisciplinary teams (**MDTs**) represents an important step toward more considered decision-making and oversight.

However, intersex advocates have long raised concerns that non-urgent, deferrable, or medically unnecessary procedures are still taking place – justified in part by references to stereotypes of sex, gender and sexuality, cosmetic factors or the parents' desire for their children's bodies to fit 'normal' expectations for girls and boys. Their call is for greater oversight of decision making, stronger consideration of the risks of early intervention, better support and information for parents, and stronger safeguards for the autonomy and rights of children. **We share and amplify that call.**

One of the most significant barriers to reform is the lack of publicly available data on the procedures that are still taking place on children below the age of consent, and the rationale for them. Put simply – we don't know which procedures are still taking place, and why.

**This report is an effort to change that.**

Between 2022 and 2024 Equality Australia issued Freedom of Information (FOI) requests to every major children's hospital in the country (or children's department where there was no dedicated children's hospital in that state). We sought relevant documents[2] about the medical procedures performed on the sex characteristics of intersex children. In response we received 248 documents, totalling 736 pages from hospitals in Sydney, Brisbane, Melbourne, Adelaide, and Hobart.[3] Only records from Sydney and Brisbane could be meaningfully analysed.

**These are not historical accounts but recent cases, spanning 2018 to 2023. What emerged from this material is concerning:**

- **Some hospitals appear to keep no records at all**[4] about the rationale for treatment decisions relating to the sex characteristics of the children in their care. This inhibits independent oversight and denies intersex people the opportunity to fully understand their medical history.

[1] Dr Morgan Carpenter, 'Intersex Variations, Human Rights and the International Classification of Diseases' (2018) 20(2) *Health and Human Rights Journal* 205, 207. Accurate estimations of intersex populations are difficult to obtain. InterAction cite a systematic review calculating an estimate of around 1.7% of all live births. For more information, see 'Demographics', *InterAction for Health and Human Rights* (Website, last reviewed 11 June 2024) https://interaction.org.au/demographics/.

[2] We sought reports, reviews, summaries, policies or guidelines relating to treatments and procedures performed on people born with intersex variations with intersex variations. We did not seek or receive individual treatment files, and rather only received case summaries of certain cases considered by MDTs.

[3] Only the Queensland Children's Hospital provided case summaries. The Sydney Children's Hospital's records were able to be analysed as while heavily redacted, they included specific discussion of decision making and likely outcomes. Records from South Australia were lists of procedures with no context. Victorian documents were too heavily redacted, and no case summaries were provided to sustain meaningful analysis. Tasmania provided no case documents but responded via email with case numbers of procedures on intersex children.

[4] No records were kept on file in Western Australia at all.

- **Where records exist, they are often patchy and inconsistent** and fall short of what would be required to conclusively evaluate the adequacy of the treatment rationale.[5]
- Of the 83 unique cases that were capable of being analysed[6] across 97 documents from NSW and Queensland, we observed 109 instances of **documented non-medical reasons or otherwise unbalanced considerations,[7] namely:**
  - cosmetic preferences for how a child's body should look, prior to the age they can have a say in these decisions.[8]
  - a desire to 'confirm' or reinforce gender assignments made at birth.[9]
  - unbalanced assessment clinical risks, including where monitoring rather than surgery may have been possible.[10]
  - responding to parental distress and confusion.[11]

These factors frequently intersect or compound. For example, parental distress about ensuring their child's body conforms to the gender assigned at birth may lead clinicians and parents into discussions about early cosmetic interventions intended to achieve that 'alignment.' There is also no clear framework available to resolve clinical disagreement or appropriately assess risks of harm in these complex cases, which means that parental distress can become the determining factor in treatment decisions.

**Bodily integrity, autonomy, and self-determination are fundamental human rights.** While we observed encouraging examples of good practice, even a single unjustified violation of these rights is unacceptable.

Our review found that the presence of non-medical rationales and unbalanced considerations in available documentation - combined with a weak evidence base, limited long-term outcome data, insufficient oversight and inconsistent or incomplete records - indicates that intersex children in Australia remain at risk of undergoing unnecessary surgeries before they are able to give informed consent.

Urgent reform is required to legislate and properly resource oversight schemes in states and territories across the country, like those implemented in the ACT and committed to in Victoria.

[5] In undertaking its technical review we commissioned of the FOI materials, the Hudson Institute commented that variability in documentation practices underscores the need for improved standardisation in reporting clinical rationales and supporting evidence. See Dr James Moloney and Dr Jacky Hewitt, 'Evaluation of Records of Medical Interventions in Children with Developmental Variations of Sex Characteristics in Australia' (Technical Review for Equality Australia, *Hudson Institute of Medical Research*, 28 October 2025) 13 **(Hudson Institute technical review (October 2025))** – note that we have published an abridged version of the full report provided to Equality Australia at: https://equalityaustralia.org.au/take-action/campaigns/intersex-human-rights/.

[6] The 248 documents contained 1444 records. 1130 records contained insufficient detail for analysis, 225 cases were too heavily redacted to sustain analysis, 9 were identifiably duplicates. For transparency, the full set of records that were capable of analysis are available for download at: https://equalityaustralia.org.au/take-action/campaigns/intersex-human-rights/. Note: there is duplication of individual patient records in the documentation, but our best estimate is that there are 83 individual patients represented in these records.

[7] We conducted this analysis by reading each case and evaluating it against the four categories of inappropriate considerations – we note that these factors were overlapping and compounding – some cases had one issue present, others had 3 or 4. For more information see Part 5: Our methodology on page 48.

[8] Observed in 39 of the 83 cases (46.99%).

[9] Observed in 14 of the 83 cases (16.87%).

[10] Overstated clinical risk observed in at least 4 of the 83 cases (4.82%) and a further 17 cases (20.48%) observed other issues with clinical rationale and evidence.

[11] Observed in 52 of the 83 individual cases (62.65%).

# PART 1

# THE CASE FOR REFORM

**Innate variations in sex characteristics are a natural part of human diversity and do not, in and of themselves, justify medical intervention. Accordingly, medical treatment that alters a person's sex characteristics should be undertaken only where there are strong, objective and compelling health-based reasons.**

Psychosocial factors, while important, can only be meaningfully understood and assessed by the individual themselves. Wherever possible, decisions should therefore be guided by the person's own expressed wishes and experiences, rather than assumptions made on their behalf or a reliance on generalised or outdated evidence.

An independent oversight body could offer crucial support to clinicians and families navigating this complex and sensitive area of medicine, particularly in cases where the patient is too young to express their own views. The establishment of an oversight body should not prevent or delay the timely provision of urgent medical treatment when it is clinically necessary.

Decisions regarding treatment should prioritise the preservation of the individual's future autonomy, ensuring that their personal wishes can be respected once they are able to make informed decisions for themselves. At all times, consideration should be given to how current choices can safeguard the widest possible range of options for the individual to determine their own path in the future.

## INTERPRETING THE FINDINGS: LIMITATIONS OF AVAILABLE DATA

This report is based on close review of clinical records received under FOI. There are several limitations to this approach:

- **Certain documents were not released.** This means the documents able to analysed may not capture every discussion with patients and families or the breadth of advice provided (verbally or in written form).
- **Documents are redacted.** The redaction of personal or identifying information might include information or context that may have changed the evaluation.
- **Many hospitals did not provide records at all or provide any records that were sufficiently detailed and capable of analysis.** This means the hospitals that were most transparent are the ones most open to scrutiny, not necessarily the most deserving of it.
- **There was no insight into private care.** FOI requests cover only public hospitals – leaving unanswered questions about what occurs outside of this system.
- **Not all intersex children will have their case reviewed by an MDT.** This means only a subset of cases were observed and cannot be viewed as representative of all clinical decision-making.
- **There are a broad range of intersex variations.** Records obtained are not representative of all variations of sex characteristics (of which at least 40 are known to exist).[12]

Where we refer to a 'concern' or 'issue' we are not making a conclusion about the quality of the underlying clinical decision making. We are instead describing an absence or inconsistency in the documentation of risks and benefits of a particular treatment decision, consideration of alternatives including delayed intervention, the presence of inappropriate treatment rationales, or a lack of engagement with the patient's human rights or consent.

Many of these concerns may reflect selective, abridged or incomplete documentation rather than an incomplete clinical discussion. Regardless, given the high stakes and lifelong consequences of the decisions in question, this warrants further attention.

[12] Most of the cases that were capable of analysis are from Sydney Children's Hospital which should, according to its terms of reference, consider all children with intersex variations for whom operative or medical intervention is being contemplated, but not those with isolated undescended testes or hypospadias (other than complex hypospadias) - The Sydney Children's Hospital Network, *Terms of Reference: SCHN Differences of Sex development (DSD) Multidisciplinary Review Meeting* (30 May 2023).

# KEY 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:**
   a. Cosmetic justifications;
   b. Gender reinforcement;
   c. Unbalanced assessment of medical risks; and
   d. Parental distress and confusion.
3. **THE SYSTEM LACKS A ROBUST, INDEPENDENT FRAMEWORK FOR RESOLVING COMPLEX CASES, INCLUDING:**
   - formal 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 decision-making.
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.**

## FINDING 1: INTERSEX CHILDREN REMAIN AT RISK OF HARM

This report's overarching finding is that intersex children born today remain at risk of harm from procedures that could have been deferred until they are able to provide informed consent. This is the result of a combination of factors: non-medical reasons[13] or unbalanced considerations within documented treatment discussions, a poor evidence base with limited long-term outcomes data, a lack of oversight in complex cases where clinical disagreement cannot be escalated or a diversity of experience and expertise obtained, and inconsistent and inadequate documentation that prevents effective independent oversight.

These issues are compounded by the lack of long-term outcome data on interventions involving intersex children. Gaps in the evidentiary foundation for clinical decision-making for intersex children, despite nearly a century of clinical practice, was identified as an issue by the Hudson Institute of Medical Research (**Hudson Institute**) in its independent review of 17 cases flagged as potential cases of concern.[14] In this context, stronger documentation and greater oversight are critical to protect patients.[15]

[13] By 'non-medical' we mean factors, considerations or rationales influencing clinical decision-making that are not directly related to the patient's immediate or long-term health needs. Sometimes the term 'non-therapeutic' is used to mean the same.

[14] Hudson Institute technical review unpublished analysis (October 2025) 3, 25.

[15] Ibid.

Set against the serious concerns already described, it is important to note that the picture was not uniformly negative; observed examples of good practice include:

- referring children and families to appropriate psychosocial support.[16]
- carefully probing and questioning parents' assumptions about pursuing medical procedures to reinforce an assigned gender.[17]
- deferring decisions in order to obtain further testing,[18] to monitor the situation,[19] or to allow the child time to express their own wishes about what happens to their body.[20]

# FINDING 2: NON-MEDICAL REASONS AND UNBALANCED CONSIDERATIONS IN TREATMENT DISCUSSIONS

Of the 83 cases capable of analysis from the FOI materials, we observed 109 instances of non-medical reasons and unbalanced considerations in discussions about the treatment of a child with an intersex variation. These issues are categorised across four themes:

**A. COSMETIC JUSTIFICATIONS**
**B. GENDER REINFORCEMENT**
**C. UNBALANCED CLINICAL RISKS**
**D. PARENTAL DISTRESS AND CONFUSION**

Because each of the 83 cases could contain up to four categories of issues, there were 332 potential opportunities for these issues to arise. We observed 109 instances (or approximately 33% of all possible instances), demonstrating that these issues were not isolated but appeared with notable frequency, pointing to a system-level problem rather than a series of random or unrelated events.

At least one issue category was observed in 55 cases. Of these observations in the analysis:

- 24 cases contained issues from one category
- 16 cases contained issues from two categories
- 14 cases contained issues from three categories
- one case contained issues from four categories

The presence of these issues in MDT minutes does not, in itself, establish the weight they were given during the decision-making process. However, when such issues are documented without adequate consideration of long-term benefits and risks, articulation of reasonable alternatives (including deferral) and explicit reflection on the patient's bodily autonomy and future capacity to provide informed consent, they give rise to the risk of harm.

Multiple technical reviews affirmed that the documentation of treatment rationales often used low-grade evidence, outdated literature, or incomplete consideration of long-term patient outcomes.[21]

This overall context heightens the risk that procedures may be recommended and conducted – in circumstances where deferral may have been a safe option for the patient. In turn this reduces overall patient, family and community confidence in the current system of decision-making.

[16] See for example: FOI Document, *Doc ID 23* (NSW, 2018) – 12-year-old referred specifically for exploration of gender identity after the group agreed further input was required before proceeding with any recommendation; FOI Document 25 (NSW, 2018) – referral for parents of 1 year old, with an offer for psychosocial support now and also noted for future for the child, and parents also offered support/advocacy group referral details.

[17] See for example: FOI Document, *Doc ID 64* (NSW, 2021) – discussion about exposure to testosterone and potential to defer decision until the patient is older as gender orientation may change, along with discussion on preserving gonads if low malignancy risk to support decision when patient is older/in adolescence; FOI Document, *Doc ID 85* (NSW, 2022) – parents see child as male, but group discussed that it is important to keep options open whilst more medical information comes available and particularly as the child's own identity is formed as there is no way of predicting gender identity from the karyotype, and that surgeries would not commit child to that gender.

[18] See for example, FOI Document, *Doc ID 45* (NSW, 2019) – treatment for a 1-year-old deferred as malignancy risk and other testing had not been completed / been confirmed, and as a result of the panel discussions and no immediate risk, the decision was deferred until testing complete or until a later stage when the child can be involved (e.g. adolescence) or unless anything changes in the meantime.

[19] See for example, FOI Document, *Doc ID 104* (NSW, 2022) for 7-year-old girl, where the group found no urgency to perform surgery now, recommended to monitor pubertal hormones and monitor puberty clinically to defer until an age where the child can be involved in the decision.

[20] See for example, FOI Document, *Doc ID 29* (NSW, 2019) and related *Doc ID 43* (NSW, 2019) – determined in relation to 11-year-old girl, balance of risks pointed to strong preference to delay any surgery until the child can be involved in decision-making, reinforced on follow up appointment; FOI Document, *Doc ID 45* (NSW, 2019) – in relation to 1-year-old boy, in a second appointment after initial deferral, the team outlines non-urgency and the ability to hold off on surgery until mid-teen years to involve child in process of consent.

[21] Hudson Institute technical review unpublished analysis (October 2025) 3, 25; Dr Morgan Carpenter, 'Decision-making by Australian hospital multidisciplinary teams regarding treatment of children with innate variations of sex characteristics: An analysis of redacted information produced by Freedom of Information requests, prepared by Morgan Carpenter, PhD, on contract to Equality Australia for InterAction for Health and Human Rights' (Technical Review for Equality Australia, InterAction for Health and Human Rights, November 2025) [8.2] **(Dr Carpenter technical review (November 2025))**; Dr Arlene Baratz, 'Clinical and Research-Focused Technical Review' (Technical Review for Equality Australia, 1 October 2025) **(Dr Baratz technical review (October 2025)).**

## A. COSMETIC JUSTIFICATIONS

**In 40 of 83 (48%) of the cases that were capable of analysis we found that cosmetic preferences were considered during clinical deliberations involving children who were too young to express their own wishes about the proposed interventions.**

Surgeries on the most sensitive parts of a child's body should not be undertaken without their consent merely to make genitals look more 'typical' or to ease adult discomfort with bodily differences. **Yet our analysis shows that cosmetic factors can still be a contributing or primary factor in surgeries and other interventions.**

Multidisciplinary teams discuss 'avoiding stigmatisation of genital variation'[22] and superficially functional rationales for treatment, such as ensuring boys can urinate standing up.[23] This can overlay with parents' desires for normal appearing genitalia despite evidence that many appearance-based interventions can require multiple follow-up surgeries, cause loss of sexual sensation, and may not align with the child's future identity.[24]

All three technical reviews of the data confirmed initial observations that cosmetic justifications were prevalent in the cases. In an independent review of a subsection of 17 cases initially flagged by Equality Australia as cases of concern the Hudson Institute observed that 15 of these involved cosmetic rationales for treatment, with some having a cosmetic reason as a primary justification.

This could be ascertained by either the absence of functional rationale, or by notes referencing psychosocial factors such as maintaining a child's privacy about their condition that their variation may be a 'barrier' for the child or to 'avoid stigmatisation' for the child (in addition to alleviating parental anxiety).[25] It is notable that in the cases analysed by the Hudson Institute involving cosmetic justifications, the evidence-base[26] to justify the treatment was either not recorded at all, or the clinicians:

- cited literature that did not address the treatment rationale at all;[27]
- referred to an "ungraded good practice statement",[28] which is a recommendation sought to inform clinical decisions based on expert opinion or indirect evidence, rather than a formal evidence grading system; and
- relied on low-grade evidence that involves 'largely low powered studies…very infrequently directly addressing whether surgery should be done early or late'.[29]

Two cases had mixed functional and cosmetic rationales. One example had a functional rationale, but the Hudson Institute highlighted that there had been concerns discussed by the multidisciplinary team that the parents may have been reporting an issue with urinating in order to expedite the surgery for another reason.[30]

### CASE STUDY: COSMETIC JUSTIFICATIONS FOR FEMINISING SURGERY IN PEOPLE WITH CAH

Congenital Adrenal Hyperplasia (**CAH**) is a genetic condition that affects how the body makes certain hormones. It can change the way female genitalia look and develop. For example, the clitoris may be larger than usual, or the openings for the urinary tract and vagina might join and share a common channel.

Doctors will still sometimes recommend surgery for people with CAH to reduce the risk of urinary tract infections (**UTIs**), to make it easier to use tampons later in life without discomfort and prevent possible distress the child may feel about the appearance of their genitalia as they grow up.[31] Some clinicians justify early surgery for CAH on the basis that it is easier to operate while a patient is young.[32]

These surgeries – often referred to as 'feminising procedures' – are highly invasive procedures performed

[22] FOI Document, *Doc ID 022* (NSW, 2018).

[23] FOI Document, *Doc ID 148* (Vic, 2022). The minutes of a meeting of the Differences of Sex Development Multidisciplinary Team Meeting, Royal Children's Hospital & Monash Children's Hospital Minutes, on 8.6.2022 include a note as follows: 'Can peeing to stand be considered functional or cosmetic, it has cultural significance, and whether this is/is not a reasonable consideration for genital surgery... consensus was that this form of intervention should fall with in parental discretion... Overall DSD forum consensus that the decision regarding genital surgery and associated interventions (i.e. androgen prior to surgery) should be determined by the parents.'

[24] For example, a study by Kalfa et al identified that 30% of adults with CAH who had received surgical interventions as children had a 'poor' sex life, and up to 50% required follow up surgery to allow for intercourse. See Dr Carpenter technical review (November 2025) citing Nicolas Kalfa et al, 'Adult Outcomes of Urinary, Sexual Functions and Fertility after Pediatric Management of Differences in Sex Development: Who Should Be Followed and How?' (2024) 20(3) *Journal of Pediatric Urology 367*.

[25] See FOI Document, *Doc ID 115* (NSW, 2023); FOI Document, *Doc ID 130* (QLD, 2022), FOI Document, *Doc ID 022* (NSW, 2018).

[26] Hudson Institute used the GRADE system of analysis to evaluate how strong the evidence is for a particular intervention. More information on the technical review is available on page 53 of this report.

[27] FOI Document, *Doc ID 105* (NSW, 2018).

[28] FOI Document, *Doc ID 22* (NSW, 2018).

[29] FOI Document, *Doc ID 53* (NSW, 2020).

[30] Further detailed comparison of cases can be found in Table 8 in the Appendix on page 60.

[31] Dr Baratz technical review (October 2025) 5; see Peter Clayton et al, 'Consensus Statement on 21-Hydroxylase Deficiency from the European Society for Paediatric Endocrinology and The Lawson Wilkins Pediatric Endocrine Society' (2002) 58 *Hormone Research* 188, 190.

[32] Hudson Institute technical review unpublished analysis (October 2025) 10 (Table 3).

on the most sensitive parts of a child's body to reshape or reduce the size of a clitoris (**clitoroplasty**) or create or widen a vaginal opening (**vaginoplasty**). Potential harms can range from the need for ongoing dilation procedures, urinary incontinence, loss of sexual pleasure and sensitivity and pain during penetrative sex in adulthood.[33]

Consistent with our reform proposal,[34] medical procedures should only be undertaken without informed consent to avoid the risk of serious physical and psychological harm. Feminising surgeries should face the highest bar of scrutiny when it comes to the justification of early intervention before a child can consent. **But in three of the cases obtained under FOI we found several instances in which inappropriate or inaccurate considerations were raised in support of early feminising surgeries.**

In cases citing cosmetic rationales, clinicians sometimes also recorded non-medical justifications or psychosocial reasons such as avoiding stigma or made claims about medical risks or benefits. However, a technical review by Dr Arlene Baratz found little evidence to support these interventions (see Table 1 below).

### INAPPROPRIATE CONSIDERATIONS IN CAH SURGERY DISCUSSIONS

| CASE CONTEXT | SUPPORTING LITERATURE |
|---|---|
| One of the benefits of female genitoplasty listed as a rationale for early intervention is for 'avoiding stigmatisation of genital variation' and 'preventing parental anxiety.'[35] | Studies show stigma experienced by adults with CAH occurs in various settings even though most had previous surgery.[36] Two-thirds experienced stigma related to visible physical differences like hirsutism or deep voice, not genital difference.[37] Notably, 25% reported that doctors' actions caused stigma, mostly through frequent genital exams in teaching settings.[38] Rather than being a consequence of genital difference, shame can result from the mere fact of having genitals that 'required surgery.'[39] |
| Prevention of UTIs listed as a rationale for surgery in several cases, raised by both clinicians and parents.[40] | Literature shows girls with CAH who have a common urogenital sinus are not predisposed to UTI before surgery and an intact urogenital sinus does not increase UTI risk later.[41] Surgery also does not prevent significant non-infectious urinary issues. In long-term follow up of adults, whether they had surgery or not, adults with CAH were more likely to have urinary symptoms, particularly incontinence, than age-matched controls.[42]<br><br>Urinary outcomes in adults are poorly studied[43] and yet, anecdotally, many families continue to say they were told that feminising genitoplasty will prevent urinary issues.[44] |
| 'Better healing,' because of early surgery listed as a factor in support of early surgery.[45] | There are no comparative studies showing healing is better in infancy than adolescence.[46] Without research directly comparing outcomes of early versus late feminising genitoplasty, we cannot know which is better – yet early surgery appears to continue based on this assumption. |

[33] Hudson Institute technical review unpublished analysis (October 2025) 10-11 (Table 3). The Hudson Institute graded early feminising genitoplasty in children with CAH as having a *very* low grade of evidence, citing literature from 2001 – 2018.

[34] Our reform proposal is set out in full in Part 4 on page 43.

[35] Dr Baratz technical review (october 2025), 5. Referring to FOI Document, Doc ID 022 (NSW, 2018).

[36] Heino Meyer-Bahlburg et al, 'Stigma Associated with Classical Congenital Adrenal Hyperplasia in Women's Sexual Lives' (2018) 47(4) *Archives of Sexual Behaviour 943*; Pierre Mouriquand et al, 'Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how? (2016) 12(3) *Journal of Pediatric Urology* 139.

[37] Heino Meyer-Bahlburg et al, 'Syndrome-Related Stigma in the General Social Environment as Reported by Women with Classical Congenital Adrenal Hyperplasia' (2017) 46(2) *Archives of Sexual Behaviour* 341.

[38] Heino Meyer-Bahlburg et al, 'Stigma in Medical Settings as Reported Retrospectively by Women with Congenital Adrenal Hyperplasia (CAH) for their Childhood and Adolescence' (2017) 42(5) *Journal of Pediatric Urology* 496.

[39] Heino Meyer-Bahlburg et al, 'Stigma Associated with Classical Congenital Adrenal Hyperplasia in Women's Sexual Lives' (2018) 47(4) *Archives of Sexual Behaviour* 943.

[40] Dr Baratz technical review (october 2025), 5-6. Referring to FOI Document, *Doc ID 022* (NSW, 2018) and FOI Document, *Doc ID 053* (NSW, 2020).

[41] Zeina Nabhan, Richard Rink and Erica Eugster, 'Urinary tract infections in children with congenital adrenal hyperplasia' (2006) 19(6) *Journal of Pediatric Endocrinology and Metabolism* 815.

[42] Melissa Davies et al, 'Congenital adrenal hyperplasia and lower urinary tract symptoms' (2005) 95(9) *BJU International* 1263.

[43] Martine Cools et al, 'Caring for individuals with a difference of sex development (DSD): a Consensus Statement' (2018) 14(7) *Nature Reviews Endocrinology* 415.

[44] Dr Baratz technical review (October 2025) 5.

[45] FOI Document, *Doc ID 022* (NSW, 2018)

[46] Sarah Creighton et al, 'Timing and nature of reconstructive surgery for disorders of sex development - Introduction' (2012) 8(6) *Journal of Pediatric Urology* 610; Carla Murphy, L Allen and Mary Anne Jamieson, 'Ambiguous genitalia in the newborn: an overview and teaching tool' (2011) 24(5) *Journal of Pediatric and Adolescent Gynecology* 236.

**INAPPROPRIATE CONSIDERATIONS IN CAH SURGERY DISCUSSIONS**

| CASE CONTEXT | SUPPORTING LITERATURE |
|---|---|
| In one case, the MDT references predictions about an intersex child's eventual gender identity, 'The majority of XX people with CAH will have female gender identity'.[47] | Much of the literature in this area comes from older, methodologically flawed studies that conflate gender identity with gender role behaviours and used inconsistent measurements.[48] In one of the best available studies, 12% of female-assigned children with CAH meet all DSM-5 criteria for gender dysphoria.[49] That equates to 1 in 8 patients, nearly 7 times higher than non-intersex children in the general population (1.8% of children under 16 in Australia).[50] |
| This both relies on assumptions about a child's future gender identity to justify surgery and overlooks evidence that people with CAH have a substantially higher likelihood of gender diversity. | Another study found that while two-thirds of people with CAH identify clearly as women, one-quarter describe mixed or two-gender identity, and 6% ultimately identified as male.[51] 41% have markedly low scores in their certainty of belonging to one gender.[52] |

Table 1: Application of existing literature to treatment considerations referenced in CAH cases, drawn from technical reviewer Dr Arlene Baratz's analysis.

## B. PREMATURE GENDER REINFORCEMENT

**In 15 of 83 (18%) of the cases that were capable of analysis we found that reinforcement of gender assigned at birth was considered during clinical deliberations about treatment of patients who were too young to express their own wishes about the proposed interventions.**

Many people with intersex variations face procedures and hormone treatments used to 'confirm' or 'reinforce' gender assignments made at birth.[53] The goal of these interventions is to help align the development of a child's body along the pathway of their predicted future gender identity – a judgment that is based on chromosomes, current hormone levels, and/or genital appearance.

But these decisions can lock people's bodies onto a path where their physical characteristics may become discordant with their gender identity. Longitudinal data that shows that gender assignments will be wrong in over 12% of CAH cases[54] and research shows that people with intersex variations experience gender more diversely and fluidly than the general population.[55]

[47] Dr Baratz technical review (october 2025), 7. Referring to FOI Document, *Doc ID 130* (QLD, 2022).

[48] Pierre Mouriquand et al, 'Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how? (2016) 12(3) *Journal of Pediatric Urology* 139; Vickie Pasterski et al, 'Increased Cross-Gender Identification Independent of Gender Role Behavior in Girls with Congenital Adrenal Hyperplasia: Results from a Standardized Assessment of 4- to 11-Year-Old Children' (2015) 44(5) *Archives of Sexual Behaviour* 1363.

[49] Vickie Pasterski et al, 'Increased Cross-Gender Identification Independent of Gender Role Behavior in Girls with Congenital Adrenal Hyperplasia: Results from a Standardized Assessment of 4- to 11-Year-Old Children' (2015) 44(5) *Archives of Sexual Behaviour* 1363.

[50] 'Estimates and Characteristics of LGBTI+ populations in Australia: Trans and gender diverse', *Australian Bureau of Statistics* (Latest release, 19 December 2024) https://www.abs.gov.au/statistics/people/people-and-communities/estimates-and-characteristics-lgbti-populations-australia/latest-release.

[51] Katinka Schweizer et al, 'Gender Experience and Satisfaction with Gender Allocation in Adults with Diverse Intersex Conditions (Divergences of Sex Development, DSD)' (2013) 5(1) *Psychology & Sexuality* 56.

[52] Ibid.

[53] Intersex children are assigned male or female at birth, and having an intersex variation does not mean people are of a third sex or gender. Community-controlled organisations in Australia and overseas have supported sex assignment as necessary, but not followed by non-urgent interventions without consent. See Dr Carpenter technical review (November 2025) 28.

[54] Vickie Pasterski et al, 'Increased Cross-Gender Identification Independent of Gender Role Behavior in Girls with Congenital Adrenal Hyperplasia: Results from a Standardized Assessment of 4- to 11-Year-Old Children' (2015) 44(5) *Archives of Sexual Behaviour* 1363.

[55] Martine Cools et al, 'Caring for individuals with a difference of sex development (DSD): a Consensus Statement' (2018) 14(7) *Nature Reviews Endocrinology* 415.

## PERSONAL STORIES: THE HARM OF MEDICAL ENFORCEMENT OF GENDER

David's experience demonstrates the profound harm of using medical intervention to enforce gender assignments. Assigned female at birth in 1993, David began experiencing masculinising changes around age 11. Rather than allowing these changes to continue, doctors placed David on intensive hormone treatments – testosterone blockers and additional estrogen – to ensure he would 'fit in with his peers'. *'Doing nothing wasn't even presented as an option. They wanted me on the right track so I could grow breasts and get a period and be like a normal girl... how I would want a husband and kids one day and needed to be attractive to a partner. I was actually happy as I was and with the changes happening to my body. I was spoken over and not included.'*

David developed breasts and a female body shape before stopping estrogen at 18. He later began testosterone to reverse the feminising changes and had top surgery to masculinise his chest. *'I was medicated to high heaven to be a woman, and I really tried to lean into it and make the most of it, but it always felt wrong and uncomfortable... Homophobia and transphobia aren't directly considered a part of the intersex stuff, but it's what actually underpins a lot of the reasoning behind medical intervention.'*

Agli's story reveals similar harm from assumptions about what bodies 'should' do. Born with Swyer syndrome (46,XY chromosomes but female appearance), Agli's parents were told they were 'a boy but not a boy' and needed surgery to remove gonads. The surgery was performed days before Agli's 18th birthday and without their meaningful consent. *'My body was functioning well, and I was living happily. My body didn't need to be interfered with but there was a cultural expectation that the female body needs to behave in a particular way... My mum said after they left me at the hospital, they wished they could have come back and taken me home. They've had to live with the trauma of that decision for the rest of their lives.'*

Eli's s experience demonstrates the most severe outcome: gender dysphoria compounded by infant surgeries they cannot remember or understand. Raised as a girl despite later discovering XY chromosomes, Eli attempted suicide for the first time at age six. *'I've never felt like a girl - my whole life there's not been one single moment.'* Eli has unexplained genital scarring, persistent incontinence, and was unable to access medical records from the now-closed hospital where they were born. *'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.'*

Full stories are in Part 2 of this report.

### FOI CASE STUDY: GENDER ENFORCEMENT FOR A PATIENT WITH 5-AR2D

In February 2018, a child with 'female infant appearance, apart from... testis in the labia' was diagnosed as likely having 5-alpha reductase 2 deficiency (**5-AR2D**).[56]

The MDT initially noted that literature supports raising such children as male because females 'often' show preference for changing to male when virilisation starts. However, outcomes for children who are 'severely undervirilised' are difficult to predict.

The MDT recommended awaiting genetic testing results before any gender reassignment. Six months later, after genetic confirmation of 5-AR2D, the family changed gender assignment to male and the Team discussed orchiopexy and complex hypospadias repair, 'recommending supporting surgery if the family wants it.'

Early surgery to reinforce a male assignment has a risk of reinforcing a misassigned gender, in circumstances where it would be preferable to wait for a child to make their own decisions about change to their bodies.

[56] FOI Document, *Doc ID 015* (NSW, 2018).

## C. UNBALANCED ASSESSMENT OF CLINICAL RISKS

While it is understandable that a caring parent might want to act quickly to prevent an avoidable cancer risk, the analysis shows that risks presented to parents can be overstated or lack vital context and appropriate attention to weighing risks against potential long-term harm to a child or young person, leading to invasive surgeries proceeding in more cases than may be necessary.

Appearing in multiple cases across our analysis, gonadectomy – the removal of ovaries, testes, streak gonads, or ovotestes – was often justified primarily or solely on grounds of malignancy risk. Yet evidence shows that for several variations these risks have been significantly overstated and are comparable to cancer risks that clinicians routinely manage through monitoring in the general population rather than pre-emptive organ removal.[57]

The consequences of gonadectomy extend well beyond cancer prevention. Children lose natural hormone production, requiring lifelong hormone replacement therapy. They face increased risks of osteoporosis, cardiovascular disease, and other long-term health complications. **Most significantly, intersex people can be permanently sterilised before they can understand what fertility means or express any preference about their reproductive future.**

The records show that parents' fear of malignancy was, understandably, a driving factor in seeking gonad removal in several cases. However, it should be noted that parental pressure did not always result in a recommendation for surgery. In one Queensland case, a father expressed frustration about repeated delays in proceeding with gonad removal, despite clinical advice that monitoring alone was appropriate. Notes indicate the medical team explained that surgery should be deferred until the child could consent, especially since she had only recently learnt of her diagnosis and needed "some time to comprehend this information and formulate her own questions [and] perspective on future interventions."[58]

In the 83 cases that we identified as being capable of analysis, 36 discussed malignancy risk to varying degrees of detail and, of these, 11 cited malignancy risk as a rationale for treatment. Because many of the available records provide limited detail as a result of redactions or otherwise insufficient notetaking, it is not possible to determine the precise cancer risk in each case of this subgroup. However, technical reviews of this data set identified that at least two cases contained overstated risks, involving inaccurate reliance on obsolete data, or misapplied use of data.[59] Details of these cases appear in the table below.

[57] Dr Carpenter technical review (November 2025) [8.6] citing Erica M Weidler et al, 'A Management Protocol for Gonad Preservation in Patients with Androgen Insensitivity Syndrome' (2019) 32(6) *Journal of Pediatric and Adolescent Gynecology* 605; Michele A O'Connell et al, 'Establishing a Molecular Genetic Diagnosis in Children with Differences of Sex Development: A Clinical Approach' (2023) 96(2) *Hormone Research in Paediatrics 1* ('Establishing a Molecular Genetic Diagnosis in Children with Differences of Sex Development'); Cindy Ho et al, 'Malignancy Risk in Turner Syndrome+Y, Early Gonadectomy, and the Ethics of Parental Choices' (2025) Pediatrics e2024067171.; Ieuan Hughes et al, 'Consensus Statement on Management of Intersex Disorders' (2006) 91 *Archives of Disease in Childhood* 554.

[58] FOI Document, *Doc ID 131* (QLD, 2022).

[59] Dr Carpenter technical review (November 2025) [8.6], 39; Dr Baratz technical review (October 2025) 6-11.

### FOI CASE STUDY: OVERSTATED CANCER RISKS LEADING TO GONADECTOMIES

| CASE CONTEXT | SUPPORTING LITERATURE |
|---|---|
| A phenotypically female child with mosaic Turner syndrome and Y chromosome material was recommended for bilateral gonadectomy before starting growth hormone treatment. The stated rationale was a high cancer risk and alignment with 'international guidelines.'[60]<br><br>While notes acknowledge 'no proof that growth hormone treatment would accelerate a malignancy,' early surgical intervention was recommended as 'clinical practice has been for gonadectomy prior to growth hormone treatment in view of the high risk of atypical features in dysgenetic intra-abdominal gonads with Y material.' | Recent studies show the malignancy risk in such cases is around 3-3.5%, far lower than often cited. A 2020 study examining children with mosaic Turner syndrome and Y chromosome material found that 42% experienced spontaneous breast development and 11% had spontaneous menstruation, with a 3% rate of gonadal malignancy.[61] These findings suggest that some individuals with TS+Y have functional ovarian tissue and potential fertility. A 2025 study confirmed a similar 3.5% malignancy rate and that prior exposure to growth hormone was not predictive of development of gonadal tumours.[62] The child in this case was likely sterilised at a young age based on cancer risk estimates comparable to risks managed through monitoring in many other contexts and it appears that monitoring would have been possible here.[63] |
| In a 2022 case in Queensland, the clinical team justified gonadectomy by referring to literature describing 'intermediate' risk of germ cell malignancy.[64] | The team justified a gonadectomy by referring to outdated literature describing an 'intermediate' risk of germ cell malignancy. That same literature, however, recommended ongoing monitoring rather than surgical removal of the gonads.[65] |

Table 2: Application of existing literature to cases involving overstated cancer risks leading to gonadectomies, drawn from technical reviewer Dr Arlene Baratz's analysis.

### PERSONAL STORIES: THE LIFELONG CONSEQUENCES OF CANCER FEAR

Surgeons at a prominent Melbourne paediatric hospital removed Tony's internal testes when she was seven and started her on hormone treatment at age 11 in 1981.

Tony discovered only in her late 20's that she had been born with Androgen Insensitivity Syndrome. Her parents were told their daughter's otherwise healthy gonads had to be removed because of high cancer risk. *'The surgical removal of someone's healthy gonads without their consent is a huge violation. It wouldn't be legally done to anyone else but done to people like me just because we're different and not to help us in any way. I wish doctors left me alone.'*

For most of her adult life, Tony felt *'desexed before adolescence, like a domestic cat.'* The treatment left her unable to relate to people as an intimate partner and there were times when she considered whether life was worth living. Years of non-compliance with hormone replacement due to body image issues resulted in osteoporosis – a direct consequence of gonadectomy performed based on inflated cancer risk.

[60] FOI Document, *Doc ID 085* (NSW, 2022).

[61] Elizabeth Dabrowski et al, 'Turner Syndrome with Y Chromosome: Spontaneous Thelarche, Menarche, and Risk of Malignancy' (2020) 33(1) *Journal of Pediatric and Adolescent Gynecology* 10.

[62] Tazim Dowlut McElroy et al, 'Gonadal Tumors in Individuals with Turner Syndrome and Y Chromosome Mosaicism: A Retrospective Multisite Study' (2025) 38(2) *Journal of Pediatric and Adolescent Gynecology* 154.

[63] Dr Baratz technical review (October 2025), commenting on Case 5: Turner Syndrome with Y-Chromosome Material (TS+Y).

[64] FOI Document, *Doc ID 130* (QLD, 2022).

[65] See Dr Carpenter technical review (November 2025) 40, citing Ieuan Hughes et al, 'Consensus Statement on Management of Intersex Disorders' (2006) 91 *Archives of Disease in Childhood* 554, and referring to Jacqueline Morin, Leslie Peard and Amanda F Saltzman, 'Gonadal Malignancy in Patients with Differences of Sex Development' (2020) 9(5) *Translational Andrology and Urology* 2408, 2413.

Mimi's mother took her daughter to see a doctor at eight months old for what she thought was a hernia. She was told her daughter had undescended testes and the potential risk of malignancy meant they should operate. Mimi's parents were not told about alternative interventions, including non-surgical options, information about deferral, or any psychosocial support.

Mimi had a gonadectomy at a London hospital in 1997, requiring lifelong hormone replacement therapy. She went on to struggle with body image issues and low self-esteem. *'It made me feel like my body was wrong, alien and bad. But intersex people are natural and normal and a very beautiful part of our human experience. The psychological harm far outweighed the potential benefits of trying to 'fix' my body.'*

Full stories are in Part 2 of this report.

Aside from concerns related to malignancy, other examples where it appeared the risks and benefits may not have been fully addressed in the documentation involved hypospadias interventions[66] and early vaginoplasty in the case of CAH.[67]

Through the analysis, at least 21 cases observed a noticeable absence of appropriate or balanced MDT discussion of risks of harm, particularly where discussions were skewed toward possible clinical risks that were not supported by sufficient evidence to substantiate the concern. In some cases, there was notable discussion of potential to delay surgery, however benefits were not discussed in the same level of detail as the clinical risks or otherwise weighted against them. We are not suggesting relevant risks shouldn't be raised, rather that records indicated appropriate details of alternate options were not presented, or were documented in an unbalanced manner.

In all 21 cases, it was observed that presentation of clinical risks to parents and young people for decision-making lacked adequate discussion on other potential harms – particularly life-long harms – to the child or young person if surgery was performed early, as opposed to being delayed or deferred until the risks were better known or evidenced or the young person could have a say in their treatment.

## D. PARENTAL DISTRESS AND CONFUSION

**In 52 of 83 (62%) of the cases that were capable of analysis we found that parental distress or confusion[68] was a feature of clinical deliberations involving intersex children.**

Parental involvement in medical decision-making is usually viewed as a proxy for treatment decisions aligned with the child's best interests, where a child is incapable of making a decision for themselves. It's clear from the FOI materials that parents are very influential in shaping treatment, especially in the context of procedures that lack a strong evidence base or clinical consensus. But even in cases where evidence may point towards or recommend deferring surgery, the documents paint a picture of clinical decision-making in which parents often have the final say, even against advice of doctors.

This is evidenced not only by the case files that were capable of being analysed but by documented discussions around clinical guidelines and decision-making from the MDT forum minutes held in Victoria. For example, the minutes of a joint Disorders of Sex Development MDT Meeting of the Royal Children's Hospital & Monash Children's Hospital in June 2022 find that the 'overall DSD forum consensus [is] that the decision regarding genital surgery and associated interventions (i.e. androgen prior to surgery) should be determined by the parents.'[69]

This underscores the critical importance of ensuring the healthcare system can respond to parental distress and confusion in sometimes challenging circumstances, with comprehensive information, peer support connections, and psychological counselling. Parental distress may understandably arise when a child experiences pain, discomfort or other adverse health impacts related to their specific circumstances. Such distress should not be minimised and serious risk of harm should continue to justify necessary medical intervention.

[66] FOI Documents, *Doc ID 5, 10 and 11* (NSW, 2018).

[67] FOI Document, *Doc ID 22* (NSW, 2018).

[68] We note that sometimes notes would explicitly refer to parents presenting as distressed or concerned but other times this could be inferred from the notes because of the way in which it was recorded that parents were expressing strong perspectives or preferences in the absence of all relevant information and considerations, or despite to medical risks outlined by clinicians.

[69] FOI Document, *Doc ID 148* (VIC, 2022).

The challenge is that there are inevitably cases where parental distress is founded in stereotypes and compliance with social norms of gender and what a body should look like. In such cases, the appropriate response is to ensure families receive the necessary information, time and support they need to explore and understand all possible options for the child, including deferral until the child can decide for themselves. Clinicians must be consistently well-supported to provide this level of care to families. Any improvements to standards, processes and support are only possible with reform to health systems, including adequate resourcing.

While there were often clinical referrals for parents or older children for psychosocial support, this was not consistent across the cases, We observed at least 14 cases of the 83 cases analysed where there was no documented discussion or emphasis on the importance of psychological support or otherwise no discussion or referral observed at all, including where parental distress or concern was noted. Further, distinct or clear referrals to specialist community-controlled support services such as Intersex Peer Support Australia or InterLink were infrequent, observed in only six cases.[70] We note that inadequate record keeping of referral information provided could be a potential explanation.

**FOI CASE STUDY: RESPONDING TO PARENTAL DISTRESS AND CONFUSION**

| CASE CONTEXT | QUOTES FROM MDT MINUTES |
|---|---|
| A 2020 NSW case, where the MDT is considering clitoroplasty surgery on a 2-year-old child. The position of the MDT is that surgery should be delayed, however, they leave the door open to it based on parental insistence. | 'Parents very keen for feminising surgery to be performed in childhood rather than delaying until patient can participate in decision-making. They understand the rationale for delayed surgery, however, are concerned about possible negative psychological consequences.... If the family wish to pursue genital surgery the case should be re-discussed at a future DSD meeting.'[71] |
| A 2022 Queensland case. Based on antenatal scans, parents had given their child a girl's name and were emotionally committed to their child being a girl. The child was born with CAH, an enlarged clitoris that appeared more like a small penis, with the urethral opening occurring at the underside of the tip.<br><br>The child had no vaginal opening, and her labia were fused – appearing more like a scrotum. While the child had no testis – consistent with the child being genetically female, her external genitalia were more male-appearing. | 'Parents presented as distressed at the possibility of deferring surgery beyond infancy...Family are firm in their opinion that [REDACTED] has always been a girl and should be raised as a girl...Had given her a female name antenatally. Started calling her by her name and using female pronouns (prior to biochemical confirmation of Dx). Family would like for [REDACTED] to have surgery including vaginoplasty as soon as possible...' |
| A 2022 NSW case, that underscores the importance of clinician patience and emphasis on education and support seems likely to have successfully deferred surgery despite parental distress and desire for early surgery. | Parents were 'counselled against proceeding with hypospadias repair by both their [REDACTED] and their [REDACTED] but remain keen to go ahead.'[72]<br><br>'From her experience with other patients [REDACTED] suggested that it would be wise to delay any surgery for at least a year to allow the [REDACTED] and to allow the parents to re-assess the need for surgery in the light of that...The forum agreed with this advice and suggested: 1) The family be counselled that reassessing the need for surgery...3) consideration of a second opinion if the parents need to explore the options further.' |

[70] FOI Document, *Doc ID 19* (NSW, 2018); FOI Document, *Doc ID 25* (NSW, 2018); FOI Document, *Doc ID 29* (NSW, 2019); FOI Document, *Doc ID 50* (NSW, 2020); FOI Document, *Doc ID 87* (NSW, 2022); FOI Document, *Doc ID 104* (NSW, 2022), FOI Document, *Doc ID 132* (QLD, 2023).

[71] FOI Document, *Doc ID 53* (NSW, 2020).

[72] FOI Document, *Doc ID 105* (NSW, 2022).

| CASE CONTEXT | QUOTES FROM MDT MINUTES |
|---|---|
| A 2023 NSW case of complex hypospadias in which the clinical team has clear concerns about conducting a repair on a child in infancy where there is an uncertain outcome and yet remain deferential to parental perspectives. | 'The group had clear concerns about operating on a child with an uncertain developmental and medical outcome and whether the risk of surgery and its complications, including multiple surgeries could have a negative impact on the developmental progress in the crucial toddler years. Conversely, operating on an older child with developmental delay could be more traumatic for the young person. Parents have expressed that they want the best outcome for and the importance of the parent-child bond for long term developmental outcome and psychological wellbeing was also discussed.<br><br>Recommendation: to discuss the concerns raised at the MDT with the parents and if the parents still wish to proceed with the knowledge of the risks of surgery and is happy to operate, this will be supported.'[73] |
| A 2022 NSW case shows the challenges clinicians face in the absence of long-term clinical data, and the weight given to parents in this context. The case concerns a presentation of perineal hypospadias and includes significant discussion of the pros and cons of surgery, the benefits of waiting until the child can consent, acknowledgement that patients cope better with surgeries that come at their own request, and the importance of psychological support for parents. | 'The urologists reported that they had yet to have the experience of parents deciding against hypospadias repair and felt that in this particular case, it was an expectation by the parents for repair because of the [male] sex of rearing... The group discussed that there has been debate amongst surgeons in recent years about the pros and cons of repair of in childhood because of the high complication rate...'<br><br>'The Forum agreed to support the parents' decision; however the Forum also recommended that the parents be made aware that there was significant dissent regarding whether the surgery should go ahead and that some members felt it should be deferred for some years to allow [REDACTED] to participate in this decision.'[74] |

Table 3: Cases illustrating the influence of parental distress and confusion on MDT decision-making.

[73] FOI Document, *Doc ID 115* (NSW, 2023).

[74] FOI Document, *Doc ID 085* (NSW, 2022).

### FOI CASE STUDY: PARENTAL DISTRESS CREATES A SENSE OF URGENCY FOR HYPOSPADIAS REPAIR

Hypospadias is a relatively common variation that involves the urethral opening being located on the underside of the penis rather than at the tip. A hypospadias repair is one of the most common procedures highlighted in this report and presents a genuine dilemma for clinical oversight due to both the spectrum of presentations and of possible outcomes.

In mild cases of hypospadias where the urethral opening is located near the tip but angled downwards, surgery can be minor and carries a high success rate which is often cited as a justification for treating early. It is important to note that while many people are satisfied with the surgical outcome of mild hypospadias repairs - these success rates remain the same into adulthood, and urologists note that older patients typically cope better with interventions because they are more likely to come at the patient's own request.[75]

More severe, complex or 'proximal' cases of hypospadias can occur when the urethral opening is located closer to the base of the penis, or where hypospadias occurs in the presence of other genetic variations. Unlike mild cases, proximal hypospadias report complication rates of 56%, even in leading children's hospitals.[76] These complications can cause lifelong consequences, ongoing pain, urinary or sexual dysfunction, and the need for further surgeries.

Hypospadias cases accounted for 13 of the cases involving parental distress. While it's not possible to determine based on the MDT minutes whether each of these cases involved a complicated or 'proximal' case of hypospadias, it is possible – as it is more visible, and therefore more likely to give rise to parental distress or a desire for normalising genitoplasty.

In her technical review for this report, Dr Arlene Baratz highlights the latest research, including recent conclusions that proximal hypospadias is associated with a greater chance of long-term dissatisfaction with outcome.[77] According to a 2023 study, those with a known DSD diagnosis had a complication rate of 62%, and nearly half the complications arose 2 years after initial hypospadias repair.[78] This rate is higher than that of 56% previously reported in boys with proximal hypospadias.[79]

The most common complications include fistulas (an unintended hole causing urine to leak), meatal stenosis (a narrowed urine opening), wound or glans dehiscence (the incision reopening), persistent curvature of the penis and urethral diverticulae (a pouch forming in the urine tube), all of which can cause life-long problems with urination, pain or infection and may need more surgery.[80]

### PERSONAL STORIES: EARLY SURGERY LEADING TO A CASCADE OF FURTHER INTERVENTIONS

Jade had surgery to create a neo-urethra at twelve months of age. Their parents did not feel like they were given the relevant statistics for the higher rates of complications with two stage repairs, and only found this information out later.

Following that surgery, Jade experienced three years of constant urinary infections, a urethral breakdown, and further surgery at 18 months when doctors removed the vagina and uterus, believing (incorrectly) that vaginal remnants were causing the infections. At age 10, Jade required dilation for urethral stricture due to scarring that failed to grow with them.

Jade talks about their struggles with understanding why the surgeries took place and how it made them feel *'robbed of an opportunity to be in my own body, instead of one some doctor picked out for me, just to fit some imaginary binary.'*

Jade's full story is in Part 2 of this report.

[75] See for example, FOI Document, *Doc ID 085* (NSW, 2022).

[76] Christopher J Long et al, 'Intermediate Term Follow-up of Proximal Hypospadias Repair Reveals High Complication Rate' (2017) 197 *Journal of Urology* 852.

[77] Dr Baratz technical review (October 2025), referring to Duncan Wilcox and Warren Snodgrass, 'Long-term Outcome Following Hypospadias Repair' (2006) 24 *World Journal of Urology* 240; Melise Keays and Sumit Dave, 'Current Hypospadias Management: Diagnosis, Surgical Management, and Long-term Patient-centred Outcomes' (2017) 11 *Canadian Urological Association Journal* S48.

[78] Kathryn Scougall et al, 'Predictors of Surgical Complications in Boys with Hypospadias: Data from an International Registry' (2023) 6(4) *World Journal of Pediatric Surgery* 1.

[79] Christopher J Long et al, 'Intermediate Term Follow-up of Proximal Hypospadias Repair Reveals High Complication Rate' (2017) 197 *Journal of Urology* 852.

[80] FOI Document, *Doc ID 085* (NSW, 2022).

# FINDING 3: THE SYSTEM LACKS A ROBUST, INDEPENDENT FRAMEWORK FOR RESOLVING COMPLEX CASES.

Disagreement is not uncommon in clinical settings and should be expected in complex treatment decision-making, especially where there is limited evidence of high-quality, long-term outcomes data on the comparative impact of interventions versus the impact of not-intervening or deferring intervention. As all technical reviewers for this report note and, as reflected in multiple MDT discussions,[81] the evidence base and clinical standards relating to treatment options for intersex people are evolving rapidly.[82] What was once best practice can fall out of date before the long-term outcomes are available to be evaluated.[83]

When medical professionals cannot reach consensus on the appropriateness of surgery that carries irreversible consequences for a child, this signals a clear need for stronger support mechanisms and more robust oversight and input in clinical decision-making.

The FOI documents contain several cases (at least 12[84] or around 14.46% of cases) in which notable to significant disagreement or dissent is observed, yet no clear mechanism for escalation, resolution or additional expert input is evident.[85] In many of these cases, parental preference ultimately becomes the determining factor.[86] This can be problematic because, as highlighted in the previous section, parents may be making decisions while experiencing emotional distress and without access to complete or comprehensible information regarding the implications of their decision.

In one case, clinicians expressed concerns about the parents preferred course of treatment, namely to avoid a gonadectomy. The MDT minutes record deliberation about potential consequences of overriding parental preference, particularly given they might be considered a reasonable alternative by a court.[87] This dynamic is further exacerbated by *Re: Carla*, discussed below, which narrowed the scope of the court's role and broadened the ambit of parents' authority to consent.[88] Irrespective of the merits of the individual case, the broader implication is that, in the absence of a strong evidence base, a heightened threshold of clinical consensus and conviction is effectively required before an MDT will contemplate overriding parental views.

The cumulative result is a system in which clinicians operate without recourse to an independent, adequately resourced oversight body capable of providing authoritative, case-specific guidance to ensure treatment decisions are appropriately weighted against potential adverse outcomes and made in accordance with the child's best interests.

[81] FOI Document, *Doc ID 085* (NSW, 2022).

[82] Hudson Institute technical review unpublished analysis (October 2025); Dr Carpenter technical review (November 2025); Dr Baratz technical review (October 2025).

[83] For example, long term outcomes following hypospadias cannot be ascertained until adulthood, due to physical growth and changes in anatomy – Dr Carpenter technical review (November 2025) 31.

[84] Refer to Table 9 in the Appendix for more details.

[85] The clearest illustration of this is in FOI Document, *Doc ID 085* (NSW, 2022) and FOI Document, *Doc ID 115* (NSW, 2023).

[86] FOI Document, *Doc ID 116* (NSW, 2023) - '[REDACTED] asked if surgery could be performed based on parental request... The group agreed that there was no medical indication or urgency for surgery at this time. The group disagreed about the timing of genital surgery. Many of the group felt that if the surgeon, child, and parents agreed that surgery could proceed. However, not all of the group agreed with surgery at this time.'

[87] FOI Document, *Doc ID 092* (NSW, 2022).

[88] See the next section for discussion of *Re: Carla (Medical Procedure)* [2016] FamCA 7.

## THE CASE OF RE: CARLA

*Re: Carla (Medical Procedure)* [2016] FamCA 7, involved a five-year-old child with 17β-hydroxysteroid dehydrogenase 3 deficiency (XY chromosomes, raised female) who had, prior to coming before the court, previously undergone genital 'normalising' surgery (clitoral recession and labiaplasty) without independent external review.

In this matter, the court held that a proposed bilateral gonadectomy — rendering the child infertile — was in the best interests of Carla and was 'therapeutic'. This meant that it fell within the scope of parental consent, meaning court authorisation was not required.

The decision raises several concerns, including that:

- It exemplifies a medico-legal approach focused on aligning intersex bodies with social expectations for male and female bodies; Carla's treating team sought to align her body with a normative female appearance and function, and the court framed the treatment as medically necessary so that the treating team could proceed unimpeded.
- Medical opinion accepted by the court emphasised the child's 'female gender identity', relying primarily on stereotypical indicators of femininity (e.g. pink curtains, Barbie bedspread, glittery sandals) without interrogation about whether these might reflect other influences (whether parental, clinical or otherwise).
- The court did not robustly examine whether urgent action was required. The asserted cancer risk justification drew on outdated data about the extent of risk, which nonetheless recommended monitoring, not removal.[89] Yet, the court did not explore whether delay until the child could consent might have been appropriate.

The case of *Re: Carla* not only provided Family Court endorsement for the legitimacy of non-urgent, 'normalising' surgeries for intersex children but also effectively appears to have ended external scrutiny of similar cases going forward, given the lack of cases involving intersex children before the Family Court since that time.

The case departed clearly from earlier cases such as *Re: Lesley* (2008), in which the Court had determined that similar surgery required Court sanction. This seriously narrows the circumstances under which the Court must intervene to only those where disagreement arises.

The decision highlights the absence of human rights-based oversight in medical decision-making for intersex children and the risk that it may result in decision-making that relies on gendered and outdated treatment rationales. After *Re: Carla*, medical teams and parents may feel less legally obliged to bring such cases before court, especially if the procedure is framed as 'therapeutic', and so the Family Court has a very limited oversight role in this context.

[89] 'Re Carla – Family Court', *InterAction for Health and Human Rights* (Web Page, 20 January 2016) https://interaction.org.au/resource/re-carla-family-court/.

# FINDING 4: HOSPITALS LACK CONSISTENT, CENTRALISED PROCESSES AND DOCUMENTATION OF TREATMENT DISCUSSIONS AND DECISIONS.

**Through the process of seeking records, we found that some hospitals maintain no centralised documentation of surgeries or treatment decisions, and others inconsistently or inadequately document discussions and treatment rationales.**

Intersex people frequently report significant barriers to accessing their own medical records, often leaving them without a clear understanding of what was done to them and why. In this context, thorough and accessible documentation is critical for individual patients and supports accountability and transparency of the system as a whole.

As discussed above, each hospital provided varying levels of access to medical records through the FOI request process:

- Western Australia's Perth Children's Hospital provided no information about cases or records of discussions, on the basis that they do not keep records on file.
- South Australia's Women's and Children's Hospital provided procedure codes, though treatment discussions and decision-making records were not available.
- New South Wales' Sydney Children's Hospitals Network released information across redacted (some heavily redacted) MDT records, and in some cases using templates that provided limited detail and were unsupported with associated documents referred to in the form. Some records clearly referred to follow-up consultations in treatment notes.
- Victoria's Royal Children's Hospital MDT discussion records were limited to skeleton agendas rather than detailed case notes.
- Queensland Children's Hospital was the only hospital that provided individual de-identified case summaries including follow-up consultations and treatment notes.

While differences in FOI regimes can explain the variation in hospital responses to some extent, the lack of records retained by some hospitals is alarming, and the inconsistency overall points to the need for improvement in documentation practices across the sector.

The inconsistency in documentation is also linked to the variation in the current decision-making structures. MDTs are groups of medical specialists who meet to discuss and make recommendations about treatment for children with variations in sex characteristics. Each hospital determines its own MDT structure, meeting procedures, documentation practices, and decision-making protocols. Some states maintain dedicated MDTs for variations in sex characteristics, while others use general paediatric review processes.[90]

This lack of standardisation means that the composition of teams, the cases they review, the information presented to parents, and the documentation of their deliberations can vary significantly between hospitals and jurisdictions. These differences affect both the quality of oversight and the consistency of documentation. **The table on the following page steps out how each state approaches clinical decision-making and the types of documents they were able to release as a result.**

Lack of centralised data collection makes obtaining long-term outcomes data almost impossible. When patients experience complications or require follow up care, they may present at different hospitals or jurisdictions years later, making it difficult to connect outcomes to earlier procedures. The transition from paediatric to adult care can also create discontinuities, meaning that clinicians making early intervention decisions may not routinely receive feedback on long-term outcomes - information that would be valuable for refining their approach.

[90] Refer to Table 5 for a state by state comparison of multidisciplinary teams involved with the health care of intersex children in Australia.

| STATE | HOSPITAL | DSD MDT? | TORS | MDT COMPOSITION | WHAT GETS REFERRED? | RECORDS PROVIDED? |
|---|---|---|---|---|---|---|
| NSW | Sydney Children's Hospital | Yes - usually 4-6 meetings annually. | Yes | Quorum requires: 1 coordinator, 1 endocrinologist, 1 gynaecologist, 1 paediatric surgeon, 1 geneticist, 1 psychologist OR ethics representative.<br><br>Parents do not attend - parental views are documented indirectly via clinicians | All children with intersex variations considered for operative or medical intervention are to be directed to the DSD MDT, with different levels of review by condition. Only 'complex hypospadias' is classed as an intersex variation for referral. | Agendas, whether quorum was met, redacted discussion notes and redacted outcomes. |
| VIC | Royal Children's Hospital | Yes - usually 8-10 meetings annually. | No | Large clinician attendance. Up to 42 clinicians attended a single meeting.<br><br>Parents do not attend the MDT - parental views are documented in other forms | Not all complex hypospadias are brought to MDT. Presentation occurs if clinicians seek broader discussion. | Heavily redacted minutes provided, no repository of outcomes. |
| QLD | Queensland Children's Hospital | No - but similar Multiprofessional Team Review / monthly audits | No | A case list shows participation by endocrinology, paediatric surgery, orthopaedics, paediatrics, rehabilitation and genetics. Parents do not attend. | Not stated in released documents. | Provided case summaries. |
| SA | Women's and Children's Hospital | Yes - usually three meetings annually and urgently as required. | Yes | Paediatric urologists, gynaecologists, clinical geneticists, paediatric endocrinologists, bioethicists, and Psychological Medicine. Parents do not attend. | Cases where there is uncertainty about sex of rearing, consideration of irreversible management that affects sex of rearing, fertility or genital appearance, and diagnostic uncertainty. Other cases as deemed necessary. | List of procedures was provided according to Medicare code. MDT minutes are stored in individual patient files and were not released in consolidated form. |
| WA | Perth Children's Hospital | Yes - meeting frequency not stated. | No | Composition not detailed in released records. | Not stated. | No records were provided - hospital advised such records aren't kept. |

Table 4: State by state comparison of multidisciplinary teams involved with the health care of intersex children in Australia.

# PART 2

# REAL STORIES OF HARM

**The following 11 personal accounts provide rare and invaluable insight into the lived experiences of intersex people who have undergone medical interventions without their informed consent. Sharing such intimate and often painful experiences requires extraordinary courage, and their voices compel us to confront the human face of medical practice and policy.**

Only through first-hand testimony can we fully understand the profound and enduring impact of these interventions — the physical, emotional, and lifelong consequences that data alone cannot convey. Reading these stories is an essential step toward recognising the reality of harm and the urgent need for systems that uphold their dignity and autonomy over their bodies.

An asterisk (*) indicates the person is not using their real name.

# JADE*

Jade was a '*beautiful healthy baby*' who was born at home in regional Australia in 2009.

Jade had indeterminant genitalia and testing revealed a mix of male and female chromosomes. Ultrasound imaging later found an undescended teste with a 'streak' ovary, a hemi-uterus and vagina.

Surgeons at a Melbourne hospital told Jade's parents their baby was 70% a boy and would need to fit in with peers, with one doctor saying Jade would need to be able to wee standing up.

Jade's parents sought opinions at hospitals in Brisbane, Melbourne and Adelaide before proceeding with the first surgery when Jade was six months of age, when the streak ovary was removed because doctors advised it posed a high risk of cancer.

The surgeon also recommended the routine removal of Jade's vagina and uterus, but Jade's parents declined because they only wanted to do surgery that was medically necessary. Jade had a second surgery to create a neo-urethra at twelve months of age, after which followed three years of almost constant urinary infections.

> ***"It was very stressful. Jade was sick all the time. We had a healthy child up until the second surgery. While the risks were explained to us, they did not give us the statistics for the higher rates of complications which are associated with the more complex two stage repairs, which we found out later."***

Jade suffered from urine infections almost every month until they were three years old. These infections resulted in many hospital visits, different antibiotics and a flying doctor transfer interstate when Jade's neo-urethra broke down and started leaking into their body.

This required a third surgery at around eighteen months of age and doctors removed Jade's vagina and uterus, thinking that the vaginal remnants may be the cause of the infections.

> ***"It was hard to challenge the surgeons, there was an attitude of 'this is just how we do this'. We had to fight for information and ultimately the surgery didn't stop the infections. I understand that all the recommendations were well meaning, however there was a lot of pressure to just comply and to not ask questions or have a different opinion."***

When Jade was ten, they had a dilation procedure for a urethral stricture as the scarring had failed to expand and grow with them. Jade has struggled to make sense of why doctors performed the third surgery.

> ***"I struggle to understand why they did the surgeries and why further testing was not done to confirm vaginal remnants were the cause of infection before such a massive decision was made for me.***
>
> ***"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."***

# STEPHANIE SAAL

It wasn't possible for doctors to determine Stephanie's sex when she was born at a Queensland hospital in 1995.

Before her mother could hold her, Stephanie was taken away for a raft of tests and when the doctors returned, her parents were told their baby had both male and female anatomy and chromosomes.

They were also told they couldn't take Stephanie home until she had feminising surgery to 'normalise' her sex characteristics. Doctors urged her parents to raise their baby as female, 'fix' her body, and then never speak about her intersex variation again.

> ***"My parents faced the worst moment any parent could have – being told their child needed to be fixed and corrected instead of celebrating their newborn."***

By the time she had turned three, Stephanie had undergone two invasive surgeries and various tests, including the removal of internal testes after doctors told her parents they could become cancerous later in life.

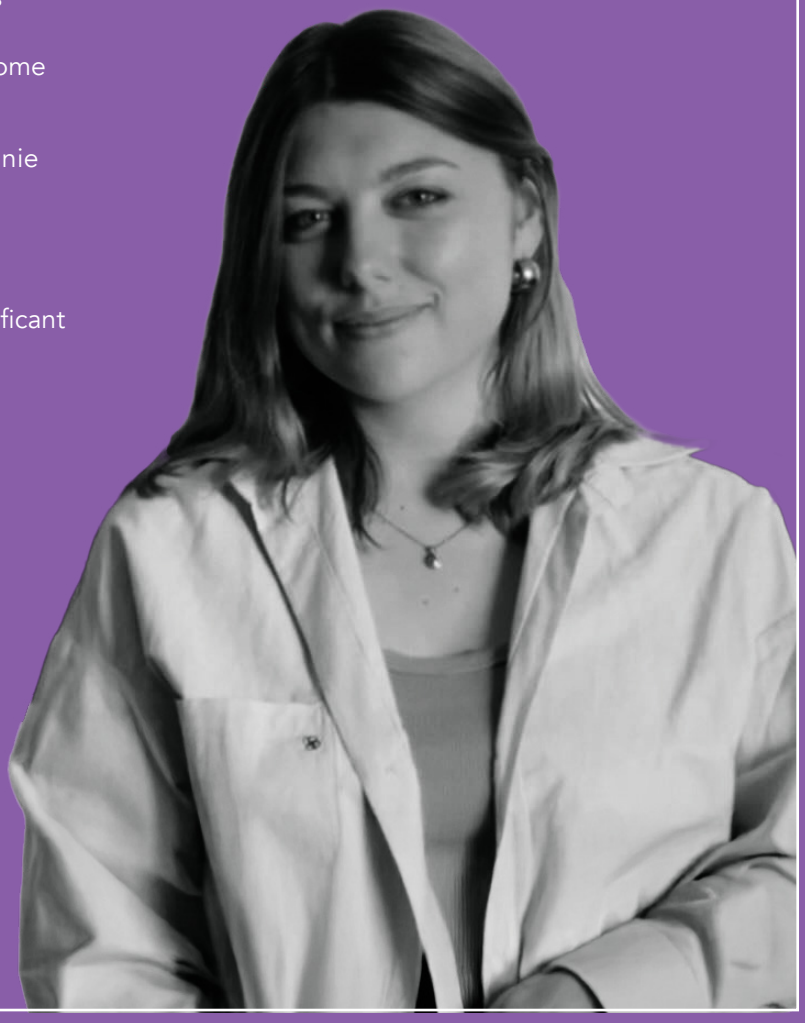
After an incorrect diagnosis at birth, Stephanie was finally found to have an incredibly rare intersex variation.

The surgeries recommended based on the incorrect diagnosis would go on to have significant consequences for her physical and mental wellbeing while the silence around her innate variation created *'a wall of disconnection and discomfort'*.

Stephanie's parents decided to tell her about her innate variation when she was nine years old.

Stephanie went to see endocrinologists for hormone treatments because her body does not produce oestrogen. During one of these visits, she was given the devastating news that she might have been able to conceive a child if she had not had surgery as a baby.

> ***"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. An intersex person should never be made to feel ashamed of their body, and parents should never be told that they should be embarrassed for having an intersex child. We are beautiful."***



## MIMI HALL

When she was 12 years old Mimi Hall met with doctors who told her she was born with a condition called 17 beta hydroxysteroid dehydrogenase deficiency.

They also told her she would not have periods or be able to conceive. But they tried to reassure her that she was a female.

> ***"I used to think I was a fraud of a female and that if anyone found out this secret that even I didn't understand it would be the most shameful thing."***

Mimi also discovered that under doctors' advice, her parents had agreed for her to have surgery at a London hospital in 1997.

Mimi's mother had taken her to see a doctor for what she thought was a hernia. Instead, she was told her daughter had undescended testes and the potential risk of malignancy meant they should operate. They did not inform her parents of alternate intervention options, or provide non-surgical options, information about deferral, or psychosocial support.

Mimi had a gonadectomy when she was eight-months of age, removing her reproductive organs, and requiring her to take hormone replacement therapy for life. She went on to struggle with body image issues and low self-esteem.

> ***"It made me feel like my body was wrong, alien and bad. But intersex people are natural and normal and a very beautiful part of our human experience."***

> ***"The psychological harm far outweighed the potential benefits of trying to 'fix' my body."***

Mimi's mother said she was given little support at the time and was not informed about the longer-term side effects and potential for psychological harm.

> ***"Knowing what I do now, I would definitely defer treatment until she could be part of the decision - to give that control back to her."***

## MAX*

Max was born with ambiguous genitalia at a Canberra hospital in the 1980s. Shortly after birth, they were separated from their parents and kept in the neonatal unit for testing.

A few days later, when Max was finally returned to their parents, doctors explained that their child 'had the potential to grow up into a healthy baby girl'.

> ***"They were told they had to take certain steps so I could have a normal life and because there could be a risk of cancer. It was never presented like they had a choice."***

Doctors chose to remove one of Max's gonads because it appeared more testicular, believing the remaining ovary would produce sufficient hormones to support feminizing development. There were other surgeries before Max turned two to normalise the appearance of their genitals.

> ***"All my baby photos are essentially in hospital."***

> ***"The whole assumption was that I wasn't male enough to be a male so they just would make me a female."***

Doctors advised Max's parents to keep their child's variation private, believing silence would offer Max the best chance at a 'normal' life. But unlike their peers, Max grew up with surgical scars, frequent medical appointments, and regular trips to an endocrinologist in Sydney.

> ***"I used to write stories in Grade One about aliens hiding in public - people who were different and weird, and concealing their identity. I had this sense there was something wrong with me and I knew there was something that made me different. I was just never given language to understand it."***

During yearly visits to the endocrinologist, Max was told that their hormone-replacement therapy was necessary because their ovary wasn't producing enough hormones.

> ***"It was never presented to me as, 'You had an ovary and a testicle, and we removed the testicle.'"***

Shortly before Max turned 18, their parents told them the full story of their medical history and shared the records they had kept over the years.

> ***"It took a long time for me to make sense of what happened to me. I had always been a gender non-conforming child. I was always a tomboy and then when I was told I was intersex, it felt like it came down to a coin flip as to whether I was male or female. I would not have chosen a female identity for myself."***

> ***"I hate what was done to me and why it was done to me, and I wish I was given the autonomy to make decisions for myself."***

## SARAH*

Sarah's parents were expecting a baby boy, so when she was born in the mid-1990s appearing to be a girl but with XY chromosomes, doctors at the South Australian hospital immediately took her away for testing.

Doctors gave her confused and distressed parents little information, and what later turned out to be a misdiagnosis. On the basis of this misdiagnosis, Sarah's parents were advised to have her internal testes removed when she was aged three.

> ***"I (Sarah's mother) was convinced by the medical specialists that there was only one way to proceed. As it turns out, I now realise we could have adopted a 'wait and see' approach."***

Post surgery, other complications emerged in early childhood, resulting in more tests and another diagnosis. In her early teens, Sarah was placed on hormone replacement therapy for life. She knows another person with a similar diagnosis who did not have a gonadectomy and their body is now able to produce some of its own hormones.

> ***"I would give anything for the same opportunity which was unnecessarily taken away from me as an infant."***

> ***"All along, the intention of doctors was to 'fix' me. There was an emphasis on making sure everything looked 'normal' from birth right up to my teen years. Nobody ever explained the potential physical or psychological harm I would experience or took into consideration what I might have wanted in the future."***

Doctors advised Sarah's parents not to mention her diagnosis to her and to keep it a secret from friends and family. Sarah only discovered her medical history when she was 14. This signalled to Sarah that her intersex variation was something to be ashamed of and caused anxiety as well as self-esteem and body image issues.

> ***"I was a fairly smart kid. I knew something was off and that I wasn't being told the full story. Later, I found out that doctors advised my parents not to tell me about my own body, which was and is, to this day, distressing to reflect on."***

The secrecy, combined with a complete lack of any psychological or peer support, led to Sarah feeling alone for the first 25 years of her life, especially in high school.

> ***"I hope no other intersex child ever has to experience the same non-consensual medical interventions as I did - or go without psychological or other supports."***

# TONY BRIFFA

Surgeons at a prominent paediatric hospital in Melbourne removed Tony's internal testes when she was seven and started her on hormone treatment in 1981, at age 11.

During her childhood Tony had frequent genital examinations by numerous doctors and medical students, although she was never told the truth about the way she was born and what medical interventions had been performed on her.

Tony only discovered that she had been born with Androgen Insensitivity in her late 20s.

Her treatment left her very confused about what and who she was. Tony struggled with understanding whether she was biologically female or male, whether she was a woman or a man, how to have intimate relationships with a partner, or whether she was worthy of a relationship.

For most of her adult life Tony felt that she was *'desexed before adolescence, like a domestic cat or dog'*.

This left her unable to relate to people as an intimate partner and there were times in her life when she considered whether it was worth going on.

> ***"The surgical removal of someone's healthy gonads without their consent is a huge violation. It wouldn't be legally done to anyone else but done to people like me just because we're different and not to help us in any way. I wish doctors left me alone."***

Tony's treatment meant she also needed hormone treatment to replace those her body naturally produced, and years of non-compliance due to body image issues resulted in osteoporosis.

Tony's parents were told their daughter's healthy gonads had to be removed because of a high risk of cancer. They were also told that she should have been born a boy but was looked like a girl because her body doesn't respond to androgens.

> ***"It's a nonsense saying I should have been born a boy. I am not a failed boy. I was born a girl with an innate variation of sex characteristics. Who are doctors to say what and who I should have been. I am proudly me."***

# DAVID*

David was around 11 years old when he started experiencing an atypical puberty, developing a muscular physique and growing thick hair on his face, legs and pubic region.

Having been assigned female at birth in 1993, David was taken by his parents to their local GP in Sydney who referred them to an endocrinologist and gynaecologist.

They were told that David would continue going through male puberty, with more masculinising changes, unless there was medical intervention.

It was agreed that David should start on an intensive regime of hormone treatments, including a testosterone blocker and additional estrogen, to ensure he fit in with his peers.

> ***"Doing nothing wasn't even presented as an option. They wanted me on the right track so I could grow breasts and get a period and be like a normal girl."***

David wasn't asked how he felt or what he wanted, and he remains troubled by the doctors' logic which centred on looking more feminine and attractive to boys.

> ***"I was spoken over and not included. I was actually happy as I was and with the changes happening to my body. They were talking about how I would want a husband and kids one day and needed to be attractive to a partner."***

David wasn't aware of the word intersex until his 20s and he now believes he could have been born with non-classic congenital adrenal hyperplasia (**NCAH**), although he has never received a formal diagnosis. He stopped taking estrogen when he turned 18 but had already developed a large chest and female body shape.

> ***"I was medicated to high heaven to be a woman, and I really tried to lean into it and make the most of it, but it always felt wrong and uncomfortable."***

David initially identified as non-binary before starting on a full course of testosterone to reverse the feminising changes to his body at 21. He has since had top surgery to masculinise his chest.

> ***"I'm still angry about it but I'm also resigned to what happened. Homophobia and transphobia aren't directly considered a part of the intersex stuff, but it's what actually underpins a lot of the reasoning behind medical intervention. I think clinicians genuinely think they're doing the best thing but what they think is best might not be best for everyone."***

## MARGIE MCCUMSTIE

When Margie turned 17, she went with her mother to a doctor to find out why she hadn't started menstruating.

She was told that her body had not formed properly in utero and that she needed a full hysterectomy or risk getting cancer. The surgery was performed in 1990, just weeks after she turned 18.

When Margie asked her doctor about counselling and support groups, she was told they were for older women who already had children, and she would be better off 'getting on with her life'.

Margie's doctor asked to photograph her naked for medical purposes but she refused. Her doctor continued to use this as leverage for access to her medical records in the years that followed.

Margie has had to take hormones and experiences depression and anxiety. She has a range of medical conditions including osteoporosis. Just before her 50th birthday, she consulted yet another doctor who suggested further medical testing.

Margie then discovered she had been born with Complete Androgen Insensitivity syndrome, had XY chromosomes and the surgery performed on her was likely to have been to remove undescended testes.

***"I was lied to both about the hysterectomy and the risk of cancer, which was actually very small and could have been managed by monitoring. I felt so violated then and I still do today."***

Margie has not been able to access her own medical records and now her operating doctor has died she fears she will never know the truth.

***"Why was my body considered so shameful? Why were decisions made about my body without considering what I might want? I've been prodded and probed, examined excessively and had my bodily autonomy disregarded and violated."***

## MICHELLE

Michelle was diagnosed with Congenital Adrenal Hyperplasia (**CAH**) a few days after her birth in WA.

Genital surgery was performed on Michelle in 1971 when she was four years old at a hospital in WA.

Doctors sought to reduce the size of her clitoris and make her vaginal opening larger. Painful dilation procedures were later required to keep Michelle's vagina open.

The clitoral amputation (**clitoridectomy**) and vaginoplasty left her with irreversible damage to her genitals and scar tissue that continues to shape how she lives as an adult today. Michelle suffers from a loss of sensation and sexual function.

Although the surgeries were medically unnecessary, the doctors told Michelle's parents they would give their daughter the opportunity to live a 'normal' life, get married and have children.

Michelle has XX chromosomes, high levels of androgens that are suppressed with steroids and female reproductive tissue. She has never had children and is same sex attracted.

***"Surgery changed my life forever. It has caused lifelong mental and physical harm to my body and made intimate relationships difficult."***

Photographs were taken of Michelle's' body while she was a child which were subsequently published in pediatric magazines. Michelle never consented to these photos and neither did her parents.

Girls with classic CAH can be born with genitals that are different from other girls due to their high levels of androgens in utero.

## AGLI

Agli went to see a doctor at 17 years of age because they had not started menstruating. This led to exploratory surgery and tissue testing.

Within a few weeks, Agli was diagnosed with Swyer syndrome, also known as 46,XY complete gonadal dysgenesis. The doctor in Tasmania explained the situation to Agli's migrant parents, who had limited English, by saying their child was 'a boy but not a boy'.

Swyer syndrome refers to a condition where an individual with a 46,XY karyotype develops female external genitalia, a uterus, and streaked gonads. Symptoms often become apparent during adolescence.

The doctor strongly advised surgery for Agli to remove the gonads to reduce the risk of cancer.

> ***"Intellectually I understand the cancer risk but to this day I do not know, emotionally or psychologically, if that was all necessary. My body was functioning well, and I was living happily."***

Overwhelmed and trusting the belief that 'doctors know best', Agli's parents agreed to the surgery. Agli was operated on without their consent in 1985, just days before their 18th birthday.

> ***"It was all so rushed. My mum said that after they left me at the hospital, they wished they could have come back and taken me home. They've had to live with the trauma of that decision."***

After the surgery, Agli was placed on hormone therapy, which resulted in the development of secondary sex characteristics - like any other non-intersex female.

> ***"I did not feel there was a need for my body to be interfered with, but my cultural expectations also influenced how I felt. At the time, with limited knowledge, I just wanted to belong. A maturing female body had to look a particular way so as not to draw negative attention."***

Agli was told they would not be able to have children except through IVF with a donor. There was no support counselling, the doctors had limited knowledge, and they reinforced the need for ongoing hormonal therapy.

> ***"So little medical knowledge is shared with people to support informed decision-making. There are very few cases where it is truly urgent. In most cases, you can give time - and that time is very important."***

> ***"As an adult, I actively challenge gender stereotypes and reject binary categorisation, choosing to identify as non-binary. With growing confidence and understanding about IVSC (innate variations of sex characteristics), I now live a full and purposeful life - as a partner, parent, academic, researcher, and activist."***

# ELI

Eli was born in 1988 at a hospital on the Gold Coast and raised as a girl.

As they grew into adulthood, Eli struggled with a lack of sexual function and persistent gender dysphoria. They had unexplained scarring on their genitals, and continue to suffer from incontinence.

> ***"I've never felt like a girl - my whole life there's not been one single moment."***

Eli tried to take their own life for the first time when they were six. They have continued to struggle with reoccurring anxiety and a fear of hospitals. Since medically transitioning at 30, Eli's depressive symptoms have alleviated, and they no longer use anti-depressants or psychiatric drugs.

> ***"It was the beginning of finding me. Once my body started changing and my hormones balanced out was when my life really began. I didn't need that medication anymore because I finally felt at home in my body."***

Around this same time, Eli noticed the scars on their body from the surgeries they had as a baby, which had become more visible in response to the testosterone.

> ***"When I really started looking my mind was just blown. I couldn't believe it."***

Eli's suspicion they might be intersex was validated in 2023 when they did an ancestry search for the family of their deceased biological father. The results of their DNA analysis showed Eli had XY chromosomes, indicating a male genotype.

> ***"Every family member I went to about this told me to talk to my mum, but she refused to speak to me."***

Since then, two GPs have confirmed that it's likely Eli was born with a variation in sex characteristics, possibly CAH. Eli was unable to obtain their early medical records after the Gold Coast hospital they were born in permanently closed several years ago.

Eli continues to suffer from several health issues in addition to the trauma of not knowing what medical interventions were performed on them as an infant.

> ***"I always thought there was something really defective in my body. When I started having sex, I never really had any proper sexual function. I've had complex health needs my whole life and I've always had hormonal issues and lacked bladder control.***
>
> ***'But 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. I just want answers – I just want the truth."***

# PART 3

# MOMENTUM FOR REFORM

**Intersex people continue to face stigma, discrimination, and human rights violations within medical settings. Advocacy by intersex community organisations, human rights bodies, and independent advocates has long sought to address these harms, particularly in relation to medical interventions undertaken without the fully informed consent of the individual.**

# INTERSEX ADVOCACY AND REFORM: AUSTRALIA AND INTERNATIONAL CONTEXTS

In recent years, this advocacy has produced tangible progress. Australia's peak human rights institutions have recognised the need for systemic reform, and a number of jurisdictions - most notably the Australian Capital Territory - have introduced or are developing legislative frameworks to safeguard bodily integrity and autonomy. Parallel developments internationally reflect a growing consensus that medically unnecessary or non-consensual interventions on intersex people constitute human rights violations.

The following timeline provides an overview of key milestones in intersex advocacy and reform in Australia, highlighting the evolution from early community activism to the establishment of human rights–based policy, professional guidance, and legislative initiatives. It traces both domestic and international developments, illustrating efforts to ensure that lmedical decision-making respects the autonomy, dignity, and rights of people with variations in sex characteristics.

## DOMESTIC CONTEXT

**1985**

- The first meeting of what would become Intersex Peer Support Australia (**IPSA**) takes place at the Royal Children's Hospital, Melbourne.[91]

**2009**

- Intersex Human Rights Australia (formerly Organisation Intersex International Australia Limited, currently InterAction for Health and Human Rights) is established.[92]

**2011**

- Australian Human Rights Commission (**AHRC**) includes intersex issues within its broader human rights and anti-discrimination work.[93]

[91] 'Governance: Reports and developments by year', *InterAction for Health and Human Rights* (web page) https://interaction.org.au/governance/.

[92] 'Timeline of legal community and other key events: Summary', *InterAction for Health and Human Rights* (web page) https://interaction.org.au/resource/timeline/.

[93] See Australian Human Rights Commission, *Addressing sexual orientation and sex and/or gender identity discrimination* (Consultation report, 2011) https://humanrights.gov.au/sites/default/files/document/publication/SGI_2011.pdf; 'Australian Human Rights Commission releases 2011 consultation report', *InterAction for Health and Human Rights* (Media Release, 5 May 2011) https://interaction.org.au/13291/australian-human-rights-commission-releases-intersex-inclusive-consultation-report/.

## 2013

- The Australian Senate Community Affairs References Committee conducts the first comprehensive national inquiry into surgical and medical interventions modifying the sex characteristics of people born with intersex variations.[94]

  It found that many practices lacked robust scientific evidence and were often aimed at conforming bodies to binary male or female norms rather than addressing genuine health needs.

  The inquiry raised concerns about inadequate data collection, poor transparency and consent practices, and insufficient long-term follow-up.

  The report's recommendations included:[95]

  - Developing national guidelines for intersex medical care grounded in human rights principles, favouring deferral of non-essential or 'normalising' procedures until the individual can provide fully informed consent
  - Establishing and funding multidisciplinary teams with appropriate coordination, record-keeping, and research support to ensure consistent, evidence-based care across Australia.

  Creating independent oversight mechanisms for decisions about medical interventions made without personal consent, through civil and administrative tribunals, the Family Court, or a dedicated medical procedures advisory committee.

  Later that year, in a world first, the *Sex Discrimination Act* was amended by the *Sexual Orientation, Gender Identity and Intersex Status Act 2013* to include 'intersex status' as a protected attribute under federal law.

## 2014

- The Australian Medical Association (**AMA**) addresses intersex medical practices in its 2014 Position Statement on Sexual and Reproductive Health, marking an early acknowledgement by a major professional body of the ethical concerns surrounding non-consensual medical interventions on intersex children.[96]

  The statement advised '[n]ormalising cosmetic genital surgery on intersex infants should be avoided until a child can fully participate in decision-making'.[97]

## 2017

- A significant group of Australian and New Zealand intersex advocates, peer support volunteers and organisations publish the Darlington Statement for the Australian and Aotearoa/New Zealand region.

  The statement includes calls for:[98]

  - Immediate prohibition as a criminal act of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent, and a call for consent to be freely-given and fully informed by individuals, with individuals and families having mandatory independent access to funded counselling and peer support.
  - The provision of alternative, independent, effective human rights-based oversight mechanism(s) to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations.

[94] 'Second Report: Involuntary or coerced sterilisation of intersex people in Australia', *Parliament of Australia: Senate Standing Committees on Community Affairs* (web page) https://www.aph.gov.au/parliamentary_business/committees/senate/community_affairs/involuntary_sterilisation/sec_report/index.

[95] Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or coerced sterilisation of intersex people in Australia* (October 2013) xiii-xv.

[96] Australian Medical Association, 'Sexual and Reproductive Health - 2014' (Position Statement, 17 July 2014) https://www.ama.com.au/articles/sexual-and-reproductive-health-2014.

[97] Ibid.

[98] 'Darlington Statement', *Darlington Statement* (web page) https://darlington.org.au/statement/.

**2018**

- The Royal Australian and New Zealand College of Psychiatrists expresses its support for the deferral of sex assignment treatment decisions which have irreversible consequences until the person can provide informed consent, except in cases of medical necessity.[99]

**2021**

- The Victorian Government commits to the development of an intersex protection system, including a prohibition on deferrable medical interventions that modify sex characteristics without consent, independent oversight of care, and improved data collection.[100]
- The Victorian Department of Health commissions Equality Australia to provide legal policy advice on a proposal implementing this commitment, working in consultation with Intersex Human Rights Australia (IHRA), people with variations of sex characteristics and their families, and other key stakeholders including health professionals. Following consultation, Equality Australia produces two reports:
  - *A Right to Be, Belong & Become*, a listening report detailing what we heard in our consultations on a proposal for a Victorian intersex oversight panel (August 2021).[101]
  - *Victorian Intersex Oversight Panel Proposal*, our final report and recommendations to the Victorian Government (September 2021).[102]
- The Australian Human Rights Commission (**AHRC**) publishes its final report 'Ensuring Health and Bodily Integrity: Towards a Human Rights Approach for People Born with Variations in Sex Characteristics', recommending a human rights-based approach with requirements for independent oversight for medical interventions, while only allowing medically necessary interventions to continue.[103]
- The Australian Medical Association (**AMA**) releases a position statement which affirmed the *Yogyakarta Principles* and outlined the need for better care to be provided for 'people with inherent variation of sex characteristics'.[104]

**2022**

- NSW's LGBTIQ+ Health Strategy (2022-2027) acknowledges a need to 'respond to practices of unnecessary and deferrable medical interventions, undertaken in infancy and childhood, to normalise the appearance of intersex bodies'.[105]

**2023**

- The Australian Capital Territory becomes the first jurisdiction to enact legislation specifically designed to protect the rights of people with variations in sex characteristics and establishing an independent oversight model for medical decision-making.[106]

**2024**

- The Queensland Government commits to 'undertake a review and analysis of health service responses to treat and support people with innate variations in sex characteristics, including medical interventions on children with innate variations in sex characteristics, in consultation with intersex organisations'.[107]

[99] Australian Human Rights Commission, 'Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics' (Final Report, October 2021) 82 citing Royal Australian and New Zealand College of Psychiatrists, Submission No 26 to Australian Human Rights Commission, *Intersex Inquiry* (2021) 2.

[100] Department of Health and Human Services (Vic), *(i) Am Equal: Future Directions for Victoria's Intersex community* (May 2021) https://www.health.vic.gov.au/publications/i-am-equal#vision.

[101] Equality Australia, *'A Right to Be, Belong & Become': Listening report from our consultations on a proposal for a Victorian Intersex Oversight Panel* (Report, August 2021) https://equalityaustralia.org.au/wp-content/uploads/2023/01/Listening-Report-A-right-to-be-belong-and-become.pdf.

[102] Equality Australia, *Victorian Intersex Oversight Panel Proposal: Final report and recommendations to the Victorian Government* (Final report, September 2021) https://equalityaustralia.org.au/wp-content/uploads/2023/01/Final-report-to-Victorian-Government-re-proposed-intersex-scheme.pdf.

[103] Australian Human Rights Commission, *Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics* (Report, October 2021).

[104] Australian Medical Association, *LGBTQIA+ Health - 2021* (AMA Position Statement, 18 November 2021) 2, 9 https://www.ama.com.au/articles/lgbtqia-health-2021.

[105] Department of Health (NSW), *NSW LGBTIQ+ Health Strategy 2022-2027: For people of diverse sexualities and gender, and intersex people, to achieve health outcomes that matter to them* (2 March 2022) 28 https://www.health.nsw.gov.au/lgbtiq-health/Pages/lgbtiq-health-strategy.aspx.

[106] *Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023* (ACT).

[107] Department of Treaty, Aboriginal and Torres Strait Islander Partnerships, Communities and the Arts (Qld), *Pride in our Communities Action Plan 2024-2026: Queensland's plan for supporting LGBTIQ+ communities to shine* (2024) 18 https://www.families.qld.gov.au/_media/documents/families/pride-action-plan.pdf.

**2025**

- Delegates at the AMA National Conference unanimously pass a motion recognising innate variations in sex characteristics as natural human diversity, opposing pathologisation of intersex people, and calling for the deferral of all non-urgent medical and surgical interventions in individuals unable to give personal, informed consent.[108]

  The motion specifies that such interventions are often carried out on infants or young children, without robust evidence of long-term benefit and without meaningful participation of the individual affected.

- The Western Australian Government commissions intersex advocates to share a briefing on intersex rights.[109]

## INTERNATIONAL CONTEXT

The international legal and policy landscape over the past decade has increasingly recognised and taken action to protect the human rights of intersex people. Several countries have enacted laws prohibiting medically unnecessary interventions on intersex children, and international human rights bodies have affirmed these protections.

Key developments include:

**2014**

- **World Health Organisation and other UN agencies** opposed early sterilising surgeries on intersex children.[110]

**2015**

- **Malta** enacts the Gender Identity, Gender Expression and Sex Characteristics Act, becoming the first country to prohibit non-consensual 'normalisation' surgeries and other unnecessary medical interventions on intersex children.[111]

**2015**

- A panel of experts in international human rights law, sexual orientation, gender identity, gender expression and sex characteristics update the **Yogyakarta Principles** from 10 years earlier. The Yogyakarta Principles articulate the views of international human rights legal experts on the application of international human rights law on matters concerning sexual orientation, gender identity and expression, and sex characteristics. Principle 32 of the Yogyakarta Principles plus 10 states (emphasis added):

> Everyone has the right to bodily and mental integrity, autonomy and self-determination irrespective of sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to be free from torture and cruel, inhuman and degrading treatment or punishment on the basis of sexual orientation, gender identity, gender expression and sex characteristics. ***No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.***[112]

[108] Euan Kielly, 'AMA backs landmark call to end unnecessary intersex surgeries', *The Medical Republic* (online, 13 August 2025) https://www.medicalrepublic.com.au/ama-backs-landmark-call-to-end-unnecessary-intersex-surgeries/119184.

[109] Toby Whittington, Michelle McGrath, David Goncalves and Morgan Carpenter, *In/Visible: Intersex Rights, Recognition & Reform in Western Australia Beyond 2025* (WA Government LGBTIQA+ Inclusion Strategy Reference Group, July 2025) https://interaction.org.au/resource/in-visible-wa-2025/; see also 'Lesbian, gay, bisexual, transgender, intersex, queer and asexual plus (LGBTIQA+) Reference Group', *Government of Western Australia* (Web Page) https://www.wa.gov.au/government/lesbian-gay-bisexual-transgender-intersex-queer-and-asexual-plus-lgbtiqa-reference-group.

[110] OHCHR, UN Women, UNAIDS, UNFPA, UNICEF and WHO, *Eliminating forced, coercive and otherwise involuntary sterilization: An interagency statement* (2014) 14.

[111] *Gender Identity, Gender Expression and Sex Characteristics Act 2015* (Malta) s 14.

[112] *The Yogyakarta Principles Plus 10* (adopted 10 November 2017, Geneva) 10.

## 2018

- **Portugal** passes Law No. 38/2018 on the Right to Self-Determination of Gender Identity and Expression and the Protection of Each Person's Sex Characteristics, restricting medically unnecessary treatments on intersex minors unless required to prevent serious health risks.[113]

## 2019

- **Iceland** adopts the Act on Gender Autonomy (No. 80/2019), introducing legal protections against non-consensual medical interventions on intersex children and affirming the right to bodily integrity and self-determination.[114]
- **The United Nations Office of the High Commissioner for Human Rights** releases a background note on human rights violations against intersex people.[115]

## 2021

- **Germany** passes the Act to Protect Children with Variations of Sex Development which prohibits certain surgeries on intersex infants and minors unless they are medically essential and the child can meaningfully consent or a family court grants approval.[116]

## 2022

- **Greece** enacts Law No. 4958/2022, prohibiting medical interventions on the sex characteristics of intersex minors under 15 unless authorised by a court following multidisciplinary review.[117]

## 2023

- **Spain** implements Article 19 of Law 4/2023, prohibiting non-consensual genital modification practices for intersex children under 12 and imposing strict conditions for those aged 12 to 16.
- The **United Nations Office of the High Commissioner** for Human Rights releases a technical note on human rights of intersex people.[118]

## 2024

- **The United Nations Human Rights Council** adopts its first resolution specifically affirming the rights of intersex people, calling on States to prohibit medically unnecessary and non-consensual interventions and to ensure access to justice, redress, and effective oversight.[119] The resolution was sponsored by the governments of Finland, South Africa, Chile and Australia.

## 2025

- The first formal report specifically addressing the rights of intersex people is published. **Office of the United Nations High Commissioner for Human Rights** published its report: 'Discriminatory laws and policies, acts of violence and harmful practices against intersex persons'[120].

[113] *Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada peso 2018* [Law No 38 of 2018] [Right to Self-Determination of Gender Identity and Expression and the Protection of Each Person's Sex Characteristics] (Portugal).

[114] *Act on Gender Autonomy 2019* [No 80 of 2019] (Iceland) ch III.

[115] Office of the United Nations High Commissioner for Human Rights, *Background Note on Human Rights Violations Against Intersex People* (24 October 2019).

[116] *Act to Protect Children with Variations of Sex Development 2021* (Germany).

[117] *Μεταρρυθμίσεις στην ιατρικώς υποβοηθούμενη αναπαραγωγή και άλλες επείγουσες ρυθμίσεις* 2022 [Law No 4958 of 2022] [Reforms in medically assisted reproduction and other urgent regulations] (Greece).

[118] Office of the United Nations High Commissioner for Human Rights, *Technical note for States and other stakeholders on the human rights of intersex people* (3 November 2023).

[119] *Human Rights Council, Combating discrimination, violence and harmful practices against intersex persons,* UN Doc A/HRC/55/L.9 (21 March 2024).

[120] *Human Rights Council, Discriminatory laws and policies, acts of violence and harmful practices against intersex persons: Report of the Office of the United Nations High Commissioner for Human Rights,* UN Doc A/HRC/60/50 (8 August 2025).

# PART 4

# OUR REFORM PROPOSAL

## Our proposal would create an oversight body to strengthen and support decision making. This panel would include health professionals, people with lived experience, lawyers and experts in human rights and assess proposed medical treatments as well as provide other educational and regulatory functions.

The proposal would prohibit medical treatment modifying the sex characteristics of an intersex person where they are not able to consent to the treatment and it is not medically urgent or otherwise approved by the oversight panel.

### 1. WHO IS A PROTECTED PERSON?

People who are unable to give *informed* consent and who have an innate variation in sex characteristics, including a prescribed variation such as hypospadias, bladder exstrophy, or congenital adrenal hyperplasia.

### 2. WHICH TREATMENTS ARE COVERED?

Only medical treatments making permanent or irreversible changes to a person's sex characteristics or changes that are reversible only with invasive treatment, are covered. Surgical or hormonal treatments and medical dilation procedures should be included, but not circumcision of a penis through removal of a foreskin covering the glans (**circumcision**) performed on a child without a variation of sex.

### 3. IN WHAT CIRCUMSTANCES ARE TREATMENTS PERMITTED TO PROCEED?

a. **When informed consent is obtained:** Informed consent requires a person to be capable of providing consent and to have been given adequate information and time to make an informed decision about their treatment without pressure or coercion. To provide informed consent a person must be given:
   - affirming, clearly understandable, information about their variation.
   - a prescribed list of peer and psychological support contacts.
   - information about the option and consequences of having no medical treatment.
   - information about the option of deferring medical treatment and its consequences.
   - a reasonable opportunity to discuss the treatment with someone else, including with or without the presence of someone else, as they wish.

b. **When it is a matter of urgency:** A treatment can proceed without the consent of the protected person if a medical practitioner reasonably considers that it is a matter of urgency to save the person's life, prevent serious damage to their health, or prevent them from suffering significant pain or distress, and the person has not otherwise refused treatment.

c. **When treatment is approved by an oversight body:** The scheme establishes an oversight body with the power to approve individual care plans or create exemptions for a class of medical treatments. The oversight body is comprised of:
   - doctors, psychologists, bioethicists and specialists in the care of intersex people,
   - intersex people and their family members,
   - legal experts in human rights, children's rights or the rights of people with disabilities.

### 4. HOW SHOULD THE OVERSIGHT BODY ASSESS AND APPROVE TREATMENT?

a. **Class exemption orders:** A class exemption order would allow an ordinary medical decision-maker, such as a parent or guardian, to consent to certain low-risk or time sensitive treatments. Draft orders must be published for consultation, with input from relevant Ministers, experts, and affected communities before finalisation. Each order should automatically expire after five years unless reviewed and renewed by the oversight panel.

b. **Individual care plans:** These would be required for protected persons who do not have capacity to provide informed consent to treatments that would modify their sex characteristics. The oversight body would approve treatment for individuals without consent, only if satisfied the treatment cannot be deferred without harm, and that decisions reflect their best interests, or wherever possible, their wishes.

### 5. REPORTING

Health service providers should be required to report all medical treatments performed without personal consent that modify a protected person's sex characteristics. Reports should include basic demographic information, the nature and reason for treatment, alternatives considered, and whether the treatment occurred under an emergency exception, registered care plan, or class exemption order. Reporting should also include details of deferred treatments or instances where treatment was not recommended. These reporting obligations will enable independent monitoring, promote transparency, and strengthen accountability across the health system.

Table 6: Details of reform proposal for medical treatments that modify the sex characteristics of intersex people.

The table below compares key features of the current system governing medical decisions involving children with intersex variation, and compares the status quo with our proposed model. It highlights the difference that this increased oversight would make: ensuring decisions are informed by lived expertise and evidence, better protecting the rights and wellbeing of families, and providing support to clinicians through clearer guidance and a more consistent, robust framework.

| | CURRENT SYSTEM | OUR PROPOSAL | WHAT DIFFERENCE WOULD IT MAKE? |
|---|---|---|---|
| DECISION-MAKING AUTHORITY | Parents/guardians are decision makers procedures performed on their children, taking advice from clinicians. | Establishes an independent oversight body including health professionals, intersex people, lawyers, ethicists, and human rights experts to approve individual care plans.<br><br>Parents / guardians remain the decision makers but can only authorise treatment approved by the oversight body. | While still including parents in the process and retaining their role as ultimate decision maker for children too young to consent, the new process provides expert review and guidance, which is particularly useful when clinical teams disagree. Ensures lived experience and up-to-date evidence informs decisions consistently across cases. |
| | Where disagreement between clinicians and parents exists the Family Court or other superior courts in their parens patriae jurisdiction[121] have jurisdiction to decide on the best interests of the child. | Provides a forum to resolve disagreements about treatment. | Ensures expert, specialist input into decision-making, and ensures expedited decisions for patients when disputes arise, in a more accessible forum than a court. |

[121] *Parens patriae* jurisdiction is the court's protective power to act in the best interests of a person who cannot decide for themselves, most often exercised in cases involving children or vulnerable individuals.

CONTINUED.

| | CURRENT SYSTEM | OUR PROPOSAL | WHAT DIFFERENCE WOULD IT MAKE? |
|---|---|---|---|
| **DECISION-MAKING AUTHORITY** | Child could in theory apply to the family court, but in practice is not empowered or able to do so. | Requires robust consideration of whether a person can provide informed consent, consideration of their will and preferences and best interests. | Ensures that the voices of intersex people are heard as part of the decision making process. |
| **EVIDENCE REQUIRED FOR TREATMENT** | Lack of clear legislative requirements means procedures are able to proceed based on cosmetic preference or to comply with 'normative' expectations, family preference, or inaccurate assumptions about comfort and convenience. | Requires deferral of treatment except in the case of:<br>1. Urgent medical necessity<br>2. Informed patient consent<br>3. Oversight body approval (class exemption, or individual treatment plan) in cases where treatment is required to avoid serious psychological or physical harm. | Prevents inadequate or inappropriate rationales for surgery or treatment of children below the age of consent, or in relation to adults with limited decision-making capacity, where deferral is possible. |
| **CLINICAL DISAGREEMENT** | No mechanism for resolution; tendency to default to parental preference when MDT members disagree. | Independent oversight body serves as arbiter, must consider whether deferral better serves child's interests. | Resolves cases where medical teams disagree, without defaulting to parental anxiety or the expense and stress of a Family Court process. |
| **INFORMATION PROVIDED** | Inconsistent information and documentation. Complication rates can be minimised. Referral to and engagement with counselling and peer support not standard. | Mandatory provision of factual information about particular variation, peer support contacts, and education about the option and consequences of no treatment or deferred treatment. | Addresses cases where parents weren't told of major complication rates, potential for infertility, or where deferral is possible to allow the person to make their own decision when ready. |
| **LONG-TERM FOLLOW-UP** | No requirement, which means that future complications may never be connected to original surgery, particularly following transition from child to adult care. | Oversight body tracks outcomes; mandatory reporting creates longitudinal data. | Addresses current inability to know true complication rates or long-term impacts. |

Table 7: Comparison of current with proposed system for decision-making on medical interventions without informed consent.

## RECOMMENDATION 1: LEGISLATIVE RESPONSE

State and territory governments should introduce legislation to establish independent oversight frameworks for medical interventions performed on children and adults with innate variations of sex characteristics without the capacity to provide informed consent. Key features should include:

- 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.
- Consistently applied and documented informed consent processes, that ensure intersex people and their families receive accurate, balanced and affirming information, including on access to peer and psychological support.
- Mandatory, standardised reporting obligations for hospitals and health services on all relevant medical interventions or other treatment plan decisions (e.g. deferred procedures).

## RECOMMENDATION 2: IMPROVED DOCUMENTATION AND REPORTING

Hospitals and health services should take immediate action to strengthen documentation and reporting standards. Key features should include:

- Documentation, data collection and reporting is standardised, ensuring consistent, high-quality information is recorded and available on medical interventions and other treatment decisions involving people with innate variations in sex characteristics.
- De-identified data should be published regularly, disaggregated by procedure type and age group, to strengthen accountability and inform continuous improvement of care.

## 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. Key features should include:

- Consultation and participation in the development and implementation of legislation and policy changes.
- Inclusion of lived-experience perspectives on independent oversight panels.
- Adequate funding by state and federal funding to provide peer support services for parents, carers and children.

# PART 5

# OUR METHODOLOGY

**This report brings together three years of work, combining collection of records, assessment and sorting of received documents, analysis of medical records and collecting personal case studies.**

# FOI REQUESTS

Between December 2022 and June 2024, Equality Australia used FOI legislation to obtain documents about medical procedures performed on intersex children in public hospitals across Australia (New South Wales, Queensland, Victoria, South Australia, Western Australia) that relate to their sex characteristics. FOI legislation requires organisations to release information unless there is an overriding public interest against their disclosure.

FOI requests are not a perfect tool for oversight of clinical decision-making. There are inconsistencies in the kinds of data held in each jurisdiction, and depending on how that data is stored and formatted, privacy restrictions may be applied more or less stringently. Documents are also often heavily redacted to remove identifying information.

Despite these limitations, we were able to obtain records in New South Wales and Queensland that gave us meaningful insight into the procedures that are taking place, as well as the kinds of discussions had in the lead up to those procedures.

## SCOPE OF OUR FOI REQUESTS

We requested documents created after 1 January 2018 regarding medical procedures performed on intersex children under the age of 16 years that involve the modification of their sex characteristics.

- For the four hospitals with MDTs tasked with discussing medical procedures on intersex children, we specifically requested documents related to the meetings, procedures and composition of these teams, including MDT meeting agendas and minutes.
- For the two hospitals without MDTs, we requested documents such as reports, summaries, recommendations, advice, policies, guidelines, meeting minutes and agendas or other documents created by or for the hospitals after 1 January 2018 relating to medical procedures for intersex children that involved the modification of their sex characteristics.
- We also obtained publicly accessible information on Medicare Benefits Schedule (**MBS**) item numbers that have been claimed through Medicare, and that may relate to procedures performed on intersex children.

## RECORDS RECEIVED

As a result of these requests, we received 248 documents from children's hospitals in Sydney, Brisbane, Melbourne, Perth, Adelaide and Hobart - totalling 736 pages.

- Only the Queensland Children's Hospital provided case summaries, which are the most helpful documents for understanding the unique details of individual cases.
- Sydney Children's Hospital – provided heavily redacted minutes from MDT meetings, including specific discussion of decision making and likely outcomes.
- The Royal Children's Hospital in Melbourne provided heavily redacted minutes from MDT meetings discussing particular cases, but otherwise no case summaries.
- The South Australian Women's and Children's Hospital provided a list of procedures that had been performed on intersex people, but no context as to rationales since MDT meeting minutes are kept in individual patient files which could not be released.
- Perth Children's Hospital provided no information about particular cases or records of discussions about them on the basis that those records are not kept on file.

## PRIVACY CHALLENGES

In a healthcare context, the privacy of individuals is an understandable consideration weighing against disclosure of information under FOI requests. We carefully excluded identifying information about patients, clinicians or family members from our requests.

Hospitals were inconsistent in their decision-making with respect to privacy concerns. Some documents were wholly withheld without what we consider to be appropriate justification. Other documents would be

heavily redacted, including sections that did not appear to contain any identifying information. Many of these decisions were successfully challenged at significant additional cost and time.

### PROCESS CHALLENGES

In the process of obtaining information, we experienced the following challenges:

- **Response times:** Despite a standard 30-day time period, the shortest processing time across hospitals was 68 days (Royal Hobart Hospital), with the longest being 327 days (Sydney Children's Hospital). In the case of Queensland Children's Hospital and South Australian Women and Children's Hospital we had to follow up many times over a number of months to receive any response.
- **Costs:** We incurred significant costs in the initial application fees and the hourly processing charges applied to the review of documents for release. Challenging decisions and reviewing the scope of requests required expert legal input.
- **Scope of requests:** Hospitals pushed back on the scope of our requests, which we negotiated with each hospital that requested it. In several cases, documents were not provided, despite us having reason to believe existed. In one case (Sydney Children's Hospital), when we challenged the initial release, we received four times the number of documents initially released under the same scope.

## INITIAL ANALYSIS

We initially compiled a database from the received case documents and, to the best of our ability, identified individual treatment cases where MDT notes are available for analysis. We then grouped possible duplicate records and, to the extent possible, tagged each record with information on:

- the intersex variation of the patient;
- the age or age range of the patient;
- the proposed procedure, treatment or surgery;
- where available, the rationale for surgery;
- perspective of parents and clinicians;
- recommendations of the MDT; and
- likely outcome of those recommendations.

The database was then independently reviewed for accuracy, categorisation and completeness of available data. In the process, we avoided making determinations on the deferability of procedures, instead highlighting cases where the rationale for surgery, perspective of parents involved in decision-making or adequacy of note taking raised concerns. A subset of 17 cases was identified for specific close consideration.

## TECHNICAL REVIEWS

Between December 2024 and October 2025, we commissioned and received three separate technical reviews of the data. More information on this process follows in Part 6.

Our initial review of the documents had identified at least 17 'cases of concern', which reviewers were directed to focus on – these were flagged as potentially including inappropriate considerations in treatment discussions.

All technical reviews confirmed that these 17 cases were appropriately captured.

We then determined that additional analysis was needed of all identifiable cases to ensure this final report presents an accurate and comprehensive picture of the trends and issues identified by Equality Australia and the reviewers.

## FINAL THEMATIC ANALYSIS

The final stage was a process of qualitative coding for prevalence of issues or themes throughout the dataset, which was completed in November 2025. To analyse the material in a systematic and comparable way, we developed a coding framework and applied it consistently across all cases.

Our approach involved reviewing each of the 83 cases for the presence or absence of specific features or issues of interest. The categories were based on our prior research and consideration of the dataset and informed by the technical reviews. Our assumption is that certain issue categories, when evident in treatment considerations, introduce heightened risks of unnecessary or deferrable treatments occurring – especially when multiple issues were identified in a case, thereby exacerbating this risk.

These categories are:

- Cosmetic justifications – focussed on appearance or meeting normative expectations of male and female bodies, apart from where indications were the situation involved an older child (11 years or

above) being involved in decision-making about their own body.

- Gender reinforcement – references to aligning a child's body with an assumed or desired gender identity, aside from cases involving older children where indications were the situation involved a young person-led process of gender affirmation.
- Parental distress or confusion – where strong parental preferences were documented, indicated by overt or more subtle references to parental anxiety, distress, or expectations, sometimes where parents were expressing strong views despite clinical advice about high risks and a lack of medical necessity or urgency.
- Unbalanced assessment of clinical risk – indications that claims about medical risks that may be inflated, unsupported, or where there was insufficient documentation of risks of performing surgery early versus benefits of deferral.

Within the 83 individual cases more than one category could, and often did, arise more than once in a single case.

Of the 332 potential instances (4 possibilities x 83 cases), 109 instances were identified in the case materials.

We also separately counted instances of clinical disagreement – where clinicians expressed conflicting views about treatment or necessity of intervention. The purpose of coding these instances was to investigate the extent to which the MDT approach lacks a robust mechanism to resolve disputes when they arise – we identified 12 examples of this.

We intentionally avoided a binary 'positive/negative' classification, as many cases exhibited both what we saw as good practice and concerning aspects. Particularly in the absence of detailed case files for each individual, this approach would have produced a misleading representation of the data, with high chance for either overstating or understating the extent of the issues.

## PERSONAL STORIES

In Part 2, and throughout this report, we share the experiences of intersex people reflecting on the medical interventions they underwent as children.

Equality Australia sought to include their stories to inform and ground this report in real-world experiences, particularly given the appropriate limitations of the FOI material for privacy and ethical reasons.

We issued a call for case studies through our social media channels, email supporter list, and existing networks of intersex stakeholders. Through this process, we identified a number of individuals whose stories needed to be heard.

From November 2024 to November 2025, Equality Australia conducted interviews with participants about their personal experiences. This often involved multiple follow-ups to ensure their accounts were represented accurately and respectfully.

We recognise that sharing such experiences can be confronting. Equality Australia sought to ensure that each person was supported throughout the process and at every stage individuals were given the option to withdraw their story if they no longer wished to share it.

During the final stages of report development, all contributors were re-engaged to confirm their ongoing consent and to review the final version of their story prior to publication. Each person was given the choice to use their real name or adopt a pseudonym to protect their privacy.

We are deeply grateful to those who chose to share their stories, and we look forward to a future where such accounts no longer need to be told.

## ETHICAL CONSIDERATIONS

We understand that in children's health care, protecting the privacy of individual patients must take precedence. We have carefully considered the potential risk of re-identification in both the preparation and publication of this report and the related data.

All identifying details of patients, their families, and clinicians were redacted by government FOI decision-makers, effectively eliminating any realistic risk of re-identification.

We have not sought, and will not seek, to re-identify any individuals. Our analysis relies solely on information that is lawfully and publicly available.

# PART 6

# TECHNICAL REVIEWS

**To enhance the integrity of this report's findings, three technical reviews were conducted between August and October 2025, and their analyses informed the content of this report. The technical reviews are all available for download in full, from our website at equalityaustralia.org.au/take-action/campaigns/intersex-human-rights/.**

# HUDSON INSTITUTE REVIEW - MEDICAL ACCURACY REVIEW OF CASES OF CONCERN

The Hudson Institute is a leading Australian medical research institute recognised internationally for discovery science and translational research. The Hudson Institute was independently commissioned by Equality Australia as a non-affiliated, scientific body to provide an objective analysis[122] of the cases that Equality Australia have independently identified as potentially having insufficiently evidenced medical rationales for the MDT outcomes listed in each case.

## DR JAMES MOLONEY

Dr Moloney is a medical doctor, general paediatrics advanced trainee at the Sydney Children's Hospital, and a research assistant at the Hudson Institute within the Centre for Endocrinology and Metabolism.

## DR JACQUELINE HEWITT

Dr Hewitt is a medical doctor, consultant paediatric endocrinologist and clinician-scientist with clinical and research expertise in the development of sex and gender. She is a Monash University Affiliate with the Hudson Institute within the Centre for Endocrinology and Metabolism. She is a senior lecturer at Monash University, and examines for the Royal Australasian College of Physicians. Dr Hewitt also sits on the editorial review board for a number of key endocrine journals, and sits on multiple national and international health advisory committees. She consults for national and international governmental bodies on issues regarding sex and gender.

**Disclosure:** The Institute is represented on the Victorian Disorders of Sex Development Multidisciplinary Team at the Royal Children's Hospital in Victoria.[123] However, as no records from Victoria were suitable for analysis due to the extent of redactions, the reviewers did not have access to or involvement with any Victorian cases in the course of conducting their technical review. We note that Dr Moloney is a general paediatrics advanced trainee at the Sydney Children's Hospital, which was within scope of this analysis and report. However, he started at the hospital in February 2025, which does not relate to period of records analysed. Dr Moloney was supervised for the duration of the review by Dr Hewitt.

## ABOUT THE ANALYSIS

The Hudson Institute provided a report containing their analysis following a process where they academically graded the evidence provided in each of the 17 cases identified by us at Equality Australia as 'cases of concern'. The analysis focuses on structured academic grading of the quality of evidence[124] provided in the medical records, assessing the extent to which risks and benefits were considered for each of the proposed procedures. In their report, the Institute also summaries what consensus guidelines were available pertaining to the medical and surgical decisions made for the identified cases.

In their summary of the results of the analysis, the Institute found that:

- all 17 records considered included a recommendation for surgical intervention, within 5 also discussing and recommending a non-surgical intervention.
- functional rationales were documented across the cohort in 5 cases (such as wound healing and prevention of UTIs), but most of the cases did not provide any specific functional rationale to explain the need for surgery.

[122] Hudson Institute technical review (October 2025).

[123] 'Endocrinology and Diabetes: Differences of Sex Development', *The Royal Children's Hospital Melbourne* (Web Page) https://www.rch.org.au/endo/differences-of-sex-development/.

[124] The researchers employed the GRADE system (Grading of Recommendations, Assessment, Development and Evaluations), which uses a structured approach to assign a rating of high, moderate, low, or very low certainty to the evidence. For more information refer to Manya Prasad, 'Introduction to the GRADE Tool for Rating Certainty in Evidence and Recommendations' (2024) 25 *Clinical Epidemiology and Global Health* 101484.

- rationales for hypospadias were focussed on potential urological complications and the perceived risk of psychological distress where genital appearance did not align with parental expectations on the designated sex of rearing, and of the interventions only one was in response to acute medical indicia, namely dysuria (although this may have been raised by guardians to expedite surgery).
- some cases had cosmetic factors as a primary justification, and in 5 cases parental expectations for genital appearance to align with normative standards were noted.
- only 4 of the 17 cases had references to published literature to substantiate all or part of the interventions proposed.
- in 5 records, no explicit rationale for surgical or medical management was recorded – although this appears to reflect incomplete records of deliberations and considerations within the MDT meetings.

The Institute states that these findings 'highlight variability in documentation practices and underscore the need for improved standardisation on in reporting clinical rationales and supporting evidence for clinical interventions in a population on for which the grade of medical evidence for intervention is typically low'.

Significantly, the Institute comments that there remains a paucity of robust empirical evidence in delineating the' optimal management strategies for children with development variations of sex characteristics', and further notes that there are currently no high-quality comparative studies evaluating outcomes between early and delayed surgical intervention for hypospadias repair or feminising genioplasty, pointing to a recent 2025 review that emphasises the lack of available data to guide decision-making.[125]

The Institute highlights that meeting records likely omit citations of literature which informed their deliberations and recommendations, and while this may be consistent with standard medical documentation practices this might be 'less appropriate in ethically complex and professionally evolving areas' such as this.

The Institute concludes their review by stating that the 'substantial deficit in both the availability of robust empirical data to guide clinical decision-making in this domain and limitations of documentation practices within MDT records.' They clarify that where there is limited evidence to support clinical decision-making, it does not necessarily mean whether interventions should or should not occur, but rather that 'there exists areas of medical practice in the field of variations of sex characteristics with limited evidence-based guidance to support clinical decisions either way.'

Overall, the findings of the Institute's technical review underscores 'the need for improved clinical research, clinical guidance, and the development of documentation standards for several clinical interventions in children with variations of sex characteristics.' They further recommend 'comprehensive and standardised data collection and research analysis' to ensure that 'future care is informed by the best available science and aligned with contemporary professional standards.'

An abridged version of the full analysis is available on our website.[126]

## DR ARLENE BARATZ REVIEW - CLINICAL AND RESEARCH-FOCUSSED TECHNICAL REVIEW

Dr Arlene Baratz is a U.S.-based physician with more than two decades of leadership in medical research, education, and peer support.

Her advocacy began in the early 1990s after two of her children were identified as having intersex traits. Seeking community and accurate information, she became deeply involved in intersex peer-support networks, helping to connect families and improve medical practices.

She has since held leadership roles with the Intersex Society of North America (**ISNA**), InterConnect (formerly the Androgen Insensitivity Syndrome Support Group), and interACT: Advocates for Intersex Youth. Through these roles, she has worked to expand support for adolescents and parents, develop trauma-informed clinical guidelines, and build dialogue between intersex communities and medical professionals.

As Coordinator of Medical and Research Affairs at InterConnect and Chair of the Medical Advisory Group

[125] Helena Engberg, Lisa Örtqvist and Gunnar Holmdahl, 'The Options for Delayed Surgery – Is There Evidence Available for Delayed Genitoplasty in Differences/Disorders of Sex Development?' (2025) 39(4) *Best Practice & Research Clinical Endocrinology & Metabolism*.

[126] 'Intersex Human Rights', Equality Australia (web page) https://equalityaustralia.org.au/take-action/campaigns/intersex-human-rights/.

at interACT, Dr Baratz has collaborated widely with clinicians and researchers to ensure that clinical practice and research are patient-centred, evidence-based, and grounded in lived experience. She has published extensively, presented at medical and academic conferences, and contributed to the development of some of the earliest family-led guidelines for the management of differences of sex development.

Dr Baratz was engaged to conduct an independent technical review[127] of the case file materials obtained for this report to determine whether we had accurately identified 17 cases as being 'cases of concern'. Further, she was tasked with identifying and analysing five specific examples that illustrate key themes in current medical practice about the care of intersex children and young people, with reference to relevant peer-reviewed literature and international standards of care.

## ABOUT THE ANALYSIS

Firstly, Dr Baratz independent review of the documents confirmed that the cases of concern were appropriately identified in Equality Australia's initial analysis. Dr Baratz then selected 5 illustrative case studies from the broader case set of 83 cases obtained through FOI that were capable of analysis. Her analysis of these 5 cases draws on peer-reviewed medical literature and international standards of care to assess the clinical reasoning recorded in MDT case reports. Overall, Dr Baratz concludes in her analysis that current MDT rationales and decision-making processes are frequently inconsistent with available evidence and international best practice. Her findings strengthen the case for transparent communication with families and for deferring irreversible medical interventions until patients can engage directly in decisions about their treatment.

In the 5 cases she selected for deeper analysis, Dr Baratz notes that the most up-to-date literature available was either not cited, or inaccurate conclusions were drawn from it. As a result, she identifies repeated reliance on outdated or unsubstantiated claims - such as presumed psychosocial benefit, prevention of UTIs, or 'better healing' after early surgery - to justify interventions lacking evidentiary support. In turn, she points out that families may not be presented with the full picture from clinicians when making decisions about whether to proceed with surgical interventions.

In her analysis, Dr Baratz finds significant discrepancies between the rationales recorded in MDT minutes and contemporary medical evidence. The selected 5 cases involved situations where:

- parents do not appear to have been given an in-depth exploration of complications for proposed surgery on infant with complex hypospadias and chordee; also hypopituitarism and biliary atresia.
- consideration was being given to orchiopexy, hypospadias repair, where surgery was recommended 'if the family wants it' despite the risk of genital surgery reinforcing a misassigned gender.
- parents were supported in their request for early vaginoplasty for their infant with 46,XX CAH and Prader 3 genital difference, despite a high risk of adverse outcomes.
- clinical notes did not indicate a realistic presentation to parents of the risks of early genital surgery to sexual function and sensation on a child with 46,XX (presumed CAH), nor the chance for errors in surgical reinforcement of early childhood gender assignment.
- gonadectomy was recommended in a female child with mosaic Turner Syndrome with Y material (TS+Y), while acknowledging the lack of evidence, because it was generally 'clinical practice' prior to initiating growth hormone therapy.[128]

There are several key themes highlighted by Dr Baratz with respect to documentation and the use of clinical evidence:

- Where the evidence base is sparse it is even more important to engage with the evidence that *does* exist, because individual clinicians do not often track the long-term outcomes or complications of the patients they treat.
- Documentation and comprehensive record keeping is vital in paediatric care, because knowledge can be lost in the transition from paediatric to adult care.

In clinical fields where our understanding changes rapidly, it is important that doctors have the time and resources to engage with the latest studies, and understand the strengths and weaknesses of the literature they cite. In cases where MDTs did provide evidence of clinical outcomes, there were several instances in which the underlying studies had been contested, discredited or complicated by more recent studies.

[127] Dr Baratz technical review (October 2025).

[128] This was not specifically noted as a case of concern by Equality Australia.

# DR MORGAN CARPENTER REVIEW - BIOETHICAL AND LIVED EXPERTISE REVIEW

Dr Morgan Carpenter is the Executive Director of InterAction for Health and Human Rights, a national charity by and for people with innate variations of sex characteristics. A human rights advocate with lived experience of an innate variation of sex characteristics, he has 20 years of experience in intersex organising, including as a co-founder of Intersex Human Rights Australia, one of InterAction's two founding organisations, and the head of its Policy Program since 2013. In 2013 he designed the intersex flag around the concepts of bodily autonomy and bodily integrity and made it freely available.

Dr Carpenter is also an Associate Professor and bioethicist at Sydney Health Ethics in the University of Sydney School of Public Health where he leads Interconnect Health Research, a Medical Research Future Fund project on the health and wellbeing of people with innate variations of sex characteristics. He is also a board member of the Australian Capital Territory's Variations in Sex Characteristics Restricted Medical Treatment Assessment Board.

In the intersex movement, his particular interest is to build community, and coherent, ethical and effective infrastructure — including norms, data models, regulation, services, and community-owned organisations. Bringing his expertise and lived experience to bear, he has been named as a significant contributor to 2023 legislative protections from harmful practices in medical settings in the Australian Capital Territory, and to a 2021 Australian Human Rights Commission report on the health and human rights of people born with variations of sex characteristics. He has written extensively on the issues directly addressed in this report and engages tirelessly on a domestic and international stage for the health and human rights of people with innate variations of sex characteristics.

## ABOUT THE ANALYSIS

Dr Morgan Carpenter's analysis[129] was provided to Equality Australia after separately considering the FOI materials forming the basis of this report.

Dr Carpenter observes that early surgical and hormonal interventions continue to be the norm, despite evidence of significant harms from non-urgent, elective treatments. These harms include trauma, pain, loss of sensation and sexual function, infertility, incontinence, limited or absent disclosure of health information, lack of informed decision-making and access to peer support, and distress arising from infertility or reduced fertility. Psychosocial support is treated as secondary to surgical management, reflecting a bio-medical model that prioritises 'normalising' bodies of intersex people over psychosocial, holistic and lifelong approaches to health and wellbeing.

The analysis provides valuable context on the health needs of people with innate variations of sex characteristics, the history of the intersex movement and the fight for human rights. It outlines key developments that coincided with the period of the FOI requests (2018–2023), including the Australian Human Rights Commission's report, legislative and policy reforms, and expanded funding for peer support services.

In explaining the composition and role of MDTs, Dr Carpenter highlights:

- inherent limitations as dealing with only a subset of cases considered to be 'clinical dilemmas',[130] leading to significant underrepresentation of more common traits[131] within the FOI materials analysed for this report.
- their operation in bio-medical and surgical paradigms, with a lack of inclusion of psychosocial and bioethical experts, peer support and community-controlled organisation representatives and people with lived experience generally.

The analysis critiques the current MDT approach because it excludes human rights and ethical perspectives and can create an 'echo chamber for surgical and biomedical eminence', with parents being strongly influenced by the 'objectivity and prestige associated with recommendations by senior clinicians, particularly surgeons, which then 'limits parents' abilities to engage with alternative perspectives'.[132]

[129] Dr Carpenter technical review (November 2025).

[130] Morgan Carpenter, 'Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands' (2023) 19(1) *Clinical Ethics* 3, 8-11 citing Mike O'Connor, 'The Treatment of Intersex and the Problem of Delay: The Australian Senate Inquiry into Intersex Surgery and Conflicting Human Rights for Children' (2016) 23(3) *Journal of Law and Medicine* 531, and Komal Vora and Shubha Srinivasan, 'A Guide to Differences/Disorders of Sex Development/Intersex in Children and Adolescents' (2020) 49(7) *Australian Journal of General Practice* 417.

[131] Dr Carpenter points out that traits likely to be under-represented include most cases of hypospadias, surgery for CAH, MRKH, congenital forms of hypogonadism, and hormonal treatment associated with 47,XXY and related sex chromosome variations.

[132] Morgan Carpenter, 'Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands' (2023) 19(1) *Clinical Ethics* 3, 8.

After closely considering the FOI materials, Dr Carpenter identifies that:

- feminising surgeries continue to be justified on psychosocial grounds despite the lack of evidence that early intervention improves health and wellbeing, and where there are examples of reported poor outcomes from similar procedures in similar jurisdictions overseas.[133]
- decisions about gonadectomies continue to rely on exaggerated malignancy risks and outdated data, resulting in the removal of healthy gonads where monitoring would suffice, where monitoring has been recommended in many instances since a 2006 clinical statement.
- hormone treatments may occur without intersex people having been given sufficient information or support to understand their own values and preferences for treatment during puberty and adolescence.
- psychosocial support and peer support as alternative models of care are mostly absent from discussions between clinicians.

Dr Carpenter's analysis sets out his separate analysis of the FOI materials, finding that of 83 cases, 49 had adverse findings, 42 had positive findings, with 6 instances where there was insufficient data. Only 3 cases met community expectations regarding medical treatment and referral to peer and psychosocial support. He explains the categorisation of adverse or positive findings as follows:

> Adverse findings include inappropriate rationales for surgery; predetermined outcomes based on sex registration; surgery occurring despite pro forma clinical acknowledgement of a need for 'realistic outcomes', high complication rates and dissatisfaction; and loss of detail arising from a transition to checklist discussions of hypospadias cases.
>
> Positive findings include the ability of an adolescent to participate in decision, referral for psychosocial support in situations of distress or clinical identification of need, lack of urgency in relation to non-essential interventions, deferral of surgery, and conduct of additional testing prior to decision-making. These do not necessarily indicate that children have been treated in line with community expectations and human rights norms.

In relation to masculinising surgeries, Dr Carpenter highlights a 'robust debate' about the outcomes, complications, risks and timing of hypospadias surgeries in February 2022, however that by June 2022 the debate had given way to the use of a pro-forma checklist for these cases, which appears to now permit early selective surgeries to proceed with reduced scrutiny.

He observes that discussions about surgeries generally frame debate as debate about timing of surgery, while concern expressed by community and human rights institutions focuses on medical necessity and personal consent.

Dr Carpenter establishes that all feminising and masculinising surgeries are contested within multidisciplinary teams, despite continuing unabated. This contestation recognises that it is possible for clinical practices to change in line with community expectations and human rights norms.

Further, Dr Carpenter notes the reference to medical photography of infants and children, which seems to remain routine, despite human rights concerns and the well-documented potential to cause harm and distress to patients.

Dr Carpenter concludes that the FOI materials provide 'serious cause for concern regarding clinical practices in Australian hospitals.' His analysis highlights the need for structural reform and genuine accountability in decision-making.

[133] Nicolas Kalfa et al, 'Adult Outcomes of Urinary, Sexual Functions and Fertility after Pediatric Management of Differences in Sex Development: Who Should Be Followed and How?' (2024) 20(3) *Journal of Pediatric Urology.*

# APPENDIX

# REFERENCE CASES

| DOC ID | MEDICAL (Y/N) | MEDICAL INTERVENTION | SURGICAL (Y/N) | TYPE OF SURGERY | DETAILS | COSMETIC RATIONALE (Y/N) | FUNCTIONAL RATIONALE (Y/N) | EVIDENCE PROVIDED FOR THE RATIONALE | GRADE OF EVIDENCE PROVIDED |
|---|---|---|---|---|---|---|---|---|---|
| 9 | Y | DHT Gel | Y | Hypospadias repair | 46 XY; None identified | Y – presumed in the absence of any functional rationale | None provided | None provided | N/A |
| 15 | Y | DHT Gel | Y | Hypospadias repair Orchidopexy | 46 XY; 5ARD | Y – presumed in the absence of any functional rationale | None provided | Shabir, et al., 2015 Maimoun, et al., 2011 Byers, et al., 2017 | The provided evidence addresses the recommended sex—rearing of children with 5ARD. The evidence does not comment on the rationale for medical intervention. |
| 22 | N | N/A | Y | Vaginoplasty | Not provided - presumptive 46 XX; CAH | Y – avoiding stigma of genital variation by restoring female anatomy, preventing parental anxiety | Y – better healing, UTI prevention | CAH Endocrine Society Clinical Practice Guideline, Speiser et al., 2018 | Ungraded – decision derived from an ungraded good practice statement |
| 53 | N | N/A | Y | Clitoroplasty | 46 XX; CAH | Y – presumed in the absence of any functional rationale | N – noted risk of anorgasmia with surgery as a con, but no functional benefits highlighted | Creighton et al., 2001 Creighton et al., 2004 Crouch et al 2008 Hughes et al., 2006 Warne G et al., 2005 Almasri et al., 2018 CAH Endocrine Society, Clinical Practice Guideline, Speiser et al., 2018 | Very low – the evidence provided addresses several relevant outcomes, but largely low powered studies and very infrequently directly addressing whether surgery should be done early or late |
| 58 | Y | DHT Gel | Y | Hypospadias repair 'Cosmetic surgery' | 46 XY; 5ARD | Y – presumed in the absence of any functional rationale | N – none provided | None provided | N/A |
| 60 | N | N/A | Y | Hypospadias repair | 46 XY; None identified | Y – presumed in the absence of any functional rationale | N – none provided | None provided | N/A |
| 80 | Y | DHT Gel | Y | Hypospadias Repair / Orchidopexy | 46 XY; Presumed 5ARD | Y – presumed in the absence of any functional rationale. Mentions 'realistic expectations re cosmetic outcome' | Partial – Mentions 'realistic expectations re functional outcomes in adulthood' without any reference to any particular rationale | None provided | N/A |
| 85 | N | N/A | Y | Hypospadias repair | Mosaic 45 XO; Genetic mosaicism | Y – expectation of the parents for repair [of hypospadias] because of the sex of rearing | Y – the potential for psychological harm of not repairing in childhood is unknown and may be significant | None provided | N/A |
| 92 | N | N/A | Y | Hypospadias repair | 46 XY; Not documented | Y – presumed in the absence of any functional rationale. Note that the parents were counselled that child may consider that surgery has impaired cosmesis | N – noted that parents were counselled that child may consider that surgery has impaired function | None provided | N/A |
| 105 | N | N/A | Y | Hypospadias repair | Redacted; Redacted | Y – presumed in the absence of any functional rationale | N – surgery advised against by forum | None provided | N/A |
| 107 | N | N/A | Y | Hypospadias repair | 46 XY; Not documented | N- None documented | Y – reporting discomfort on urination, but no report of whether the team felt surgery would impact this | None provided | N/A |

| DOC ID | MEDICAL (Y/N) | MEDICAL INTERVENTION | SURGICAL (Y/N) | TYPE OF SURGERY | DETAILS | COSMETIC RATIONALE (Y/N) | FUNCTIONAL RATIONALE (Y/N) | EVIDENCE PROVIDED FOR THE RATIONALE | GRADE OF EVIDENCE PROVIDED |
|---|---|---|---|---|---|---|---|---|---|
| 111 | Y | DHT Gel | Y | Hypospadias repair | 46 XY; Redacted | Y – Presumed in the absence of any functional rationale | N – none documented | None provided | N/A |
| 110 | N | N/A | Y | Hypospadias repair / Chordee correction / Orchidopexy | 46 XY; Redacted | Y – parents would like to normalize appearance of genitalia | N – none documented | None provided | N/A |
| 115 | N | N/A | Y | Hypospadias repair | 46 XY; Redacted | Y – Parents see hypospadias as another barrier for him if left uncorrected | N – none documented | None provided | N/A |
| 116 | N | N/A | Y | Hypospadias repair | 46 XY; None identified | N – none documented. | Y – parents reporting discomfort on urination, however, note concerns from MDT that this is reported by parents potentially to expedite surgery | None provided | N/A |
| 130(3) | N | N/A | Y | Hypospadias repair | 46 XY; NR5A1 mutation | Y – immediate improvement in stream dynamics, long term urinary and sexual function, preferable for tissue healing, greater success for toilet training | N – none recorded | Cools et al, 2012 Morin et al, 2020 Pyle et al, 2017 | The evidence provided gives rationale to the decision made around gonadal biopsy. No evidence was provided with regards to the rationale for the decision to proceed with a hypospadias repair. |
| 130(4) | N | N/A | Y | Vaginoplasty | 46 XX; CAH | Y – parents want to maintain child's privacy regarding her condition (e.g. when changing nappy, where cosmetic appearance of genitalia may raise questions) | Y – needing a separate vaginal opening for menses, reducing risk of recurrent UTI, concerns that child will remember pain | None provided | N/A |

Table 8: A table outlining each of the cases flagged as a case of concern by Equality Australia, with a summary outlining medical context, recommendation of the team, rationale, supporting evidence and outcome from Hudson Institute's analysis of the grade of evidence.

| FOI DOC REF # | FOI DOCUMENT REFERENCE NAME | CASE # IN FOI DOC | YEAR OF BIRTH | PATIENT AGE | SEX OF REARING | COSMETIC | UNBALANCED CLINICAL RISK | REFERRAL TO PSYCHOLOGICAL SUPPORT | GENDER REINFORCEMENT | PARENTAL DISTRESS OR CONFUSION | CLINICAL DISAGREEMENT | MALIGNANCY RISK DISCUSSED | MALIGNANCY RISK CITED IN RATIONALE |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2 | NSW - 2018.02 - DSD Meeting Outcomes (1) | 1 | 2017 | <1 year old | M | - | - | - | - | X | X | - | - |
| 3 | NSW - 2018.02 - DSD Meeting Outcomes (2) | 1 | 2017 | <1 year old | F | - | - | - | X | X | - | - | - |
| 4 | NSW - 2018.02 - DSD Meeting Outcomes (3) | 1 | 2004 | ~14 years old | U | - | - | - | - | - | - | X | - |
| 5 | NSW - 2018.02 - DSD Meeting Outcomes (4) | 1 | 2017 | <1 year old | M | X | X | X | X | X | - | - | - |
| 7 | NSW - 2018.05 - DSD Meeting Outcomes (1) | 1 | 2006 | ~12 years old | F | - | - | - | OC | X | - | X | X |
| 8 | NSW - 2018.05 - DSD Meeting Outcomes (2) | 1 | 2004 | ~14 years old | U | - | - | - | - | - | - | X | - |
| 9* | NSW - 2018.05 - DSD Meeting Outcomes (3) | 1 | 2017 | ~1 year old | M | X | - | - | X | X | X | - | - |
| 10 | NSW - 2018.05 - DSD Meeting Outcomes (4) | 1 | 2017 | <1 year old | M | X | X | X | X | X | - | - | - |
| 11 | NSW - 2018.05 - DSD Meeting Outcomes (5) | 1 | 2017 | ~1 year old | M | X | - | - | - | X | - | - | - |
| 12 | NSW - 2018.05 - DSD Meeting Outcomes (6) | 1 | 2006 | ~12 years old | M | - | - | - | - | - | X | X | - |
| 14 | NSW - 2018.08 - DSD Meeting Outcomes (1) | 1 | 2016 | ~2 years old | F | X | - | - | X | X | - | - | - |
| 15* | NSW - 2018.08 - DSD Meeting Outcomes (2) | 1 | 2017 | <1 year old | F (>M) | - | - | - | X | X | - | - | - |
| 16 | NSW - 2018.08 - DSD Meeting Outcomes (3) | 1 | 2017 | ~1 year old | M | - | - | - | - | - | - | X | X |
| 17 | NSW - 2018.08 - DSD Meeting Outcomes (4) | 1 | 2005 | ~13 years old | F | - | X | X | - | X | X | - | - |
| 18 | NSW - 2018.08 - DSD Meeting Outcomes (5) | 1 | 2018 | <1 year old | M | - | - | - | - | - | - | X | X |
| 19 | NSW - 2018.08 - DSD Meeting Outcomes (6) | 1 | 2017 | ~1 year old | M | - | X | X | - | - | - | X | X |
| 20 | NSW - 2018.08 - DSD Meeting Outcomes (7) | 1 | 2006 | ~12 years old | M | - | - | - | - | - | X | X | - |
| 22* | NSW - 2018.11 - DSD Meeting Outcomes (1) | 1 | 2018 | <1 year old | F | X | X | X | - | X | - | - | - |
| 23 | NSW - 2018.11 - DSD Meeting Outcomes (2) | 1 | 2006 | ~12 years old | F | - | - | - | OC | X | - | X | X |
| 24 | NSW - 2018.11 - DSD Meeting Outcomes (3) | 1 | 2005 | ~13 years old | F | - | X | X | - | X | X | - | - |
| 25 | NSW - 2018.11 - DSD Meeting Outcomes (4) | 1 | 2017 | ~1 year old | M | - | X | X | - | - | - | X | X |
| 28 | NSW - 2019.02 - DSD Meeting Outcomes (2) | 1 | 2005 | ~14 years old | F | - | X | X | - | X | X | - | - |
| 29 | NSW - 2019.02 - DSD Meeting Outcomes (3) | 1 | 2008 | ~11 years old | F | - | - | - | - | - | - | X | - |
| 31 | NSW - 2019.04 - DSD Meeting Outcomes (1) | 1 | 2017 | ~2 years old | M | X | X | - | - | - | - | - | - |
| 32 | NSW - 2019.04 - DSD Meeting Outcomes (2) | 1 | 2013 | ~6 years old | M | - | - | - | - | - | - | X | - |
| 33 | NSW - 2019.04 - DSD Meeting Outcomes (3) | 1 | 2018 | ~1 year old | M | - | - | - | - | - | - | - | - |
| 34 | NSW - 2019.04 - DSD Meeting Outcomes (4) | 1 | 2018 | ~1 year old | M | - | - | - | - | X | - | X | - |
| 36 | NSW - 2019.06 - DSD Meeting Outcomes (1) | 1 | 2018 | ~1 year old | M | X | X | - | X | X | - | X | X |
| 38 | NSW - 2019.08 - DSD Meeting Outcomes (1) | 1 | 2003 | ~16 years old | F | - | - | - | - | - | - | - | - |
| 40 | NSW - 2019.08 - DSD Meeting Outcomes (3) | 1 | 2006 | ~13 years old | F | - | X | - | - | X | - | - | - |
| 41 | NSW - 2019.08 - DSD Meeting Outcomes (4) | 1 | 2016 | ~3 years old | M | - | - | - | - | - | - | X | - |
| 43 | NSW - 2019.10 - DSD Meeting Outcomes (1) | 1 | 2008 | ~11 years old | F | - | - | - | - | - | - | X | - |
| 44 | NSW - 2019.10 - DSD Meeting Outcomes (2) | 1 | Unsure | Unsure | M | X | - | - | - | X | - | X | - |
| 45 | NSW - 2019.10 - DSD Meeting Outcomes (3) | 1 | 2018 | ~1 year old | M | - | - | - | - | X | - | X | - |
| 47 | NSW - 2019.11 - DSD Meeting Outcomes (1) | 1 | 2005 | ~14 years old | F | - | - | - | - | X | - | X | - |
| 48 | NSW - 2019.11 - DSD Meeting Outcomes (2) | 1 | 2016 | ~3 years old | F | - | - | - | - | - | - | - | - |
| 50 | NSW - 2020.02 - DSD Meeting Outcomes (1) | 1 | 2007 | ~13 years old | F | OC | - | - | - | X | - | - | - |
| 51 | NSW - 2020.02 - DSD Meeting Outcomes (2) | 1 | 2007 | ~13 years old | F (>M) | - | - | - | OC | X | - | X | - |
| 53* | NSW - 2020.06 - DSD Meeting Outcomes (1) | 1 | 2018 | ~2 years old | F | X | X | X | X | X | X | - | - |
| 54 | NSW - 2020.06 - DSD Meeting Outcomes (2) | 1 | 2007 | ~13 years old | F | - | - | - | - | X | - | X | X |
| 56 | NSW - 2020.08 - DSD Meeting Outcomes (1) | 1 | 2012 | ~8 years old | F | - | X | - | - | - | - | X | - |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 58* | NSW - 2020.10 - DSD Meeting Outcomes (1) | 1 | 2019 | ~1 year old | M | X | - | - | X | X | - | - | - |
| 59 | NSW - 2020.10 - DSD Meeting Outcomes (2) | 1 | 2018 | ~2 years old | F | - | X | X | - | X | - | X | X |
| 60* | NSW - 2020.10 - DSD Meeting Outcomes (3) | 1 | 2019 | ~18 months old | M | X | X | X | - | X | - | - | - |
| 61 | NSW - 2020.10 - DSD Meeting Outcomes (4) | 1 | 2006 | ~14 years old | M | - | - | - | - | - | X | X | - |
| 63 | NSW - 2021.02 - DSD Meeting Outcomes (1) | 1 | 2019 | ~2 years old | M | - | - | - | - | - | - | - | - |
| 64 | NSW - 2021.02 - DSD Meeting Outcomes (2) | 1 | 2016 | ~4 years old | F | X | - | - | X | X | - | X | - |
| 65 | NSW - 2021.02 - DSD Meeting Outcomes (3) | 1 | 2020 | <1 year old | M | X | X | X | X | X | X | X | - |
| 66 | NSW - 2021.02 - DSD Meeting Outcomes (4) | 1 | 2020 | <1 year old | F | X | - | - | X | X | - | X | - |
| 67 | NSW - 2021.02 - DSD Meeting Outcomes (5) | 1 | 2018 | ~1 year old | M | X | X | - | X | X | - | X | X |
| 68 | NSW - 2021.02 - DSD Meeting Outcomes (6) | 1 | 2017 | ~5 years old | M | X | X | - | - | - | - | - | - |
| 70 | NSW - 2021.04 - DSD Meeting Outcomes (1) | 1 | 2016 | ~5 years old | M | - | X | X | - | - | - | - | - |
| 71 | NSW - 2021.04 - DSD Meeting Outcomes (2) | 1 | 2007 | ~13-14 years old | F | - | - | - | - | - | - | - | - |
| 72 | NSW - 2021.04 - DSD Meeting Outcomes (3) | 1 | 2020 | <1 year old | F | X | - | - | X | X | - | X | - |
| 73 | NSW - 2021.04 - DSD Meeting Outcomes (4) | 1 | 2007 | ~14 years old | F | OC | - | - | - | X | - | - | - |
| 75 | NSW - 2021.06 - DSD Meeting Outcomes (1) | 1 | Unsure | ~14 years old | M | - | - | - | - | - | - | X | - |
| 77 | NSW - 2021.08 - DSD Meeting Outcomes (1) | 1 | 2012 | ~9 years old | F | X | - | - | - | X | - | - | - |
| 78 | NSW - 2021.08 - DSD Meeting Outcomes (2) | 1 | 2020 | <2 year old | M | X | X | X | X | X | X | X | - |
| 80* | NSW - 2021.10 - DSD Meeting Outcomes (1) | 1 | 2020 | <2 year old | M | X | X | - | X | X | - | - | - |
| 81 | NSW - 2021.10 - DSD Meeting Outcomes (2) | 1 | 2006 | ~15 years old | M | - | - | X | - | X | - | X | - |
| 82 | NSW - 2021.10 - DSD Meeting Outcomes (3) | 1 | 2010 | ~11 years old | M | - | - | - | OC | X | - | - | - |
| 84 | NSW - 2022.02 - DSD Meeting Outcomes (1) | 1 | 2021 | <1 year old | M | X | - | - | X | X | - | X | - |
| 85* | NSW - 2022.02 - DSD Meeting Outcomes (2) | 1 | 2020 | ~2 years old | M | X | X | X | X | X | X | X | - |
| 87 | NSW - 2022.04 - DSD Meeting Outcomes (1) | 1 | 2006 | ~15 years old | F | - | - | - | - | - | - | - | - |
| 88 | NSW - 2022.04 - DSD Meeting Outcomes (2) | 1 | 2006 | ~16 years old | M | - | - | X | - | X | - | X | - |
| 89 | NSW - 2022.04 - DSD Meeting Outcomes (3) | 1 | 2021 | ~1 year old | F | X | - | - | - | X | X | - | - |
| 90 | NSW - 2022.06 - Complex Hypospadias (1) | 1 | 2021 | <1 year old | M | X | - | - | - | - | - | - | - |
| 91 | NSW - 2022.06 - Complex Hypospadias (2) | 1 | 2021 | <1 year old | M | X | - | - | - | - | - | - | - |
| 92* | NSW - 2022.06 - Complex Hypospadias (3) | 1 | 2021 | <1 year old | M | X | - | - | - | X | - | - | - |
| 94 | NSW - 2022.06 - DSD Meeting Outcomes (1) | 1 | 2006 | ~16 years old | F | - | - | - | - | - | - | X | - |
| 95 | NSW - 2022.06 - DSD Meeting Outcomes (2) | 1 | 2021 | <1 year old | M | X | - | - | X | X | - | X | - |
| 96 | NSW - 2022.06 - DSD Meeting Outcomes (3) | 1 | 2010 | ~12 years old | M | - | - | - | - | - | - | X | - |
| 98 | NSW - 2022.07 - Complex Hypospadias (4) | 1 | 2021 | <1 year old | M | X | - | - | - | - | - | - | - |
| 99 | NSW - 2022.08 - Complex Hypospadias (5) | 1 | 2021 | <1 year old | M | X | - | - | - | X | - | - | - |
| 101 | NSW - 2022.08 - DSD Meeting Outcomes (1) | 1 | 2021 | ~1 year old | M | X | X | X | - | X | - | X | - |
| 102 | NSW - 2022.10 - Complex Hypospadias (6) | 1 | 2021 | ~1 year old | M | X | - | - | - | X | - | - | - |
| 104 | NSW - 2022.10 - DSD Meeting Outcomes (1) | 1 | 2015 | ~7 years old | F | - | - | - | - | X | - | X | - |
| 105* | NSW - 2022.10 - DSD Meeting Outcomes (2) | 1 | 2021 | <1 year old | M | X | - | - | - | X | - | - | - |
| 106 | NSW - 2022.10 - DSD Meeting Outcomes (3) | 1 | 2007 | ~15 years old | F | OC | - | - | - | X | - | - | - |
| 107* | NSW - 2022.10 - DSD Meeting Outcomes (4) | 1 | 2016 | ~6 years old | M | - | X | - | - | X | X | - | - |
| 108 | NSW - 2023.02 - Complex Hypospadias (7) | 1 | 2021 | ~2 years old | M | X | - | - | - | X | - | - | - |
| 110* | NSW - 2023.02 - DSD Meeting Outcomes (1) | 1 | 2020 | ~3 years old | M | X | X | - | - | X | - | - | - |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 111* | NSW - 2023.02 - DSD Meeting Outcomes (2) | 1 | 2022 | ~1 year old | M | X | - | - | - | X | - | - | - |
| 112 | NSW - 2023.02 - DSD Meeting Outcomes (3) | 1 | 2006 | ~16 years old | F | OC | - | - | - | - | - | - | - |
| 113 | NSW - 2023.04 - Complex Hypospadias (8) | 1 | 2022 | <1 year old | M | X | - | - | - | - | - | - | - |
| 115* | NSW - 2023.04 - DSD Meeting Outcomes (1) | 1 | 2020 | ~3 years old | M | - | - | - | - | X | X | - | - |
| 116* | NSW - 2023.04 - DSD Meeting Outcomes (2) | 1 | 2016 | ~7 years old | M | - | X | - | - | X | X | - | - |
| 117 | NSW - 2023.04 - DSD Meeting Outcomes (3) | 1 | 2022 | <1 year old | F | X | X | X | - | - | - | - | - |
| 118 | NSW - 2023.04 - DSD Meeting Outcomes (4) | 1 | 2016 | ~7 years old | F | - | - | - | - | X | X | X | X |
| 119 | NSW - 2023.04 - DSD Meeting Outcomes (5) | 1 | 2006 | ~16 years old | F | OC | - | - | - | - | - | - | - |
| 120 | NSW - 2023.04 - DSD Meeting Outcomes (6) | 1 | 2022 | <1 year old | U | X | X | - | - | - | - | - | - |
| 121 | NSW - 2023.06 - Complex Hypospadias (9) | 1 | 2021 | ~2 years old | M | - | - | - | - | X | - | - | - |
| 122 | NSW - 2023.06 - Complex Hypospadias (10) | 1 | 2021 | ~2 years old | M | X | - | - | - | - | - | - | - |
| 124 | NSW - 2023.06 - DSD Meeting Outcomes (1) | 1 | 2011 | ~13 years old | F | - | - | - | - | - | - | X | - |
| 130 | QLD - 1st request - 2022 - Case summaries | 1 | 2011 | ~11-12 years old | F | OC | - | - | - | X | - | X | - |
| 130 | QLD - 1st request - 2022 - Case summaries | 2 | Unsure | Puberty Age | F | OC | - | - | OC | X | - | - | - |
| 130* | QLD - 1st request - 2022 - Case summaries | 3 | 2022 | <1 year old | M | X | - | - | X | X | - | X | - |
| 130* | QLD - 1st request - 2022 - Case summaries | 4 | 2022 | <1 year old | F | X | X | X | - | X | X | - | - |
| 131 | QLD - 1st request - 2023 - Case summaries | 1 | 2015 | ~9 years old | F | - | - | - | - | X | - | X | X |
| 132 | QLD - 1st request - 2023 - Meetings | 1 | 2007 | ~16 years old | F | OC | - | - | - | X | - | X | X |
| 132 | QLD - 1st request - 2023 - Meetings | 2 | 2015 | ~9 years old | F | - | - | - | - | X | - | X | X |
| 132 | QLD - 1st request - 2023 - Case summaries | 3 | Unsure | ~8-9 years old | F | X | X | - | - | X | - | X | X |
| 132 | QLD - 1st request - 2023 - Meetings | 4 | Unsure | ~2 years old | F | X | - | - | - | X | - | X | - |

* Flagged case for technical review (see Table 8 for details)

**M -** Male gender of rearing
**F -** Female gender of rearing
**U -** Unknown
**(>M/F) -** Indicates change of gender/gender of rearing
**OC -** Older child, with involvement in decision or deferred until they can be involved
**X -** Observed in document or document linked to the patient

Table 9: A table outlining each of the FOI documents capable of analysis and the categories observed to inform findings.

EQUALITY