

12 September 2019

Response to the Victorian paper on the health and wellbeing of people with intersex variations

This paper is a formal response to the *Health and wellbeing of people with intersex variations Information and resource paper* published by the Department of Health & Human Services in Victoria earlier this year (Department of Health & Human Services 2019).

The report contains important and helpful reporting on a range of issues, including respect for and acknowledgement of our diversity as a population, and accurate reporting of issues in relation to law reform. We warmly commend the Victorian government, including the Department of Health and Human Services for developing this document, in particular in a context where other jurisdictions in Australia have not done so. However, the document also exhibits hyperbole and lacks evidence in support of claims made in relation to medical practices.

1 Historicity and authorship

We have read with some concern descriptions of the background paper as historic and as written by intersex community members. The paper, as with 2013 decision-making principles published by the Victorian government, is flawed and developments to date should not be described as historic. The document was authored by consultants at the request of the government, and we congratulate them for their work. Input was obtained from a variety of different sources, and this is vital for the 2019 paper and for future work – but the 2013 predecessor guidelines were substantively based on deeply flawed “ethical principles” by three Victorian clinicians (Gillam, Hewitt, and Warne 2010), and the current paper contains consequential flaws, including on matters relating to evidence, consent, research, and descriptions of opinion and belief.

Hyperbole does not serve us well when this document is a single stage in a long-term process by which we hope that the Victorian government will come to terms with the need to protect the human rights of people born with intersex variations in medical settings, and act on that need. Similarly, we hear repeated claims of leadership by different Australian governments on intersex issues. We are seeing a trend towards consideration of the needs of intersex populations, but this work is sadly often grounded in misconceptions (notably the ideas that intersex people are necessarily queer and/or transgender), and consideration

does not mean action. We have yet to see implementation of the demands of the community Darlington Statement (AIS Support Group Australia et al. 2017). We will have a historic moment at the point where we have a legal prohibition of deferrable medical interventions, effective rights-affirming oversight of decision-making, and standards of care – all developed with meaningful community involvement.

2 Evidence

The paper highlights concerns with Victorian “decision-making principles” published in February 2013 which purported to ensure that:

All decisions about the healthcare of all infants, children and adolescents with intersex conditions in Victoria should be made while supporting patients and parents, and according to the current best practice medical management, human rights, ethical and legal decision-making principles in this resource. The final decisions should be those that reach a balance of the principles in light of the individual circumstances of the case, and that are in the best interests of the patient (Department of Health 2013, 1).

The 2019 paper states that:

the principles are supported by Victorian clinicians and by some members of the intersex community but have also been criticised for allowing 'non-therapeutic' reasons to guide decisions about whether genital surgery may be appropriate.

Similar to the discussion in the earlier section, a lack of publicly available data about the treatment and care of people with intersex variations makes it difficult to assess the practical application and effect of both the Charter of Human Rights and Responsibilities and of the principles. This lack of implementation evidence and data on current Victorian practices and inconsistencies in publications between the department and clinicians has also been criticised (Carpenter, 2016a & b). (Department of Health & Human Services 2019, 19).

This statement appears to us to conflate several things. It is good that the State is attempting to improve medical practice, and we support aspects of this approach. However, it is also clear that this approach is not one that can change medical practices to ensure that they meet human rights norms – and the reasons for this are evident in the stated critique: both the 2013 guidelines and the 2019 Health and Wellbeing paper suffer from a lack of transparency about actual clinical practices, and they lack evidence of implementation.

These omissions have a significant impact on the utility of the background paper. Without information on actual current and historic procedures, trends in procedures, and claimed indications, the report is incomplete. Some of this data we have reported in national statistics and Family Court cases (Carpenter 2018; Intersex Human Rights Australia 2019). The report itself illustrates a fundamental problem with lack of transparency and accountability.

We examine some reasons for a lack of evidence to underpin clinical practices in a later part of this response, on research.

3 Who consents?

The report presents multiple statements (for example, in headline bullet points on page 15) that “the state’s Charter of Rights protects people with intersex variations against medical treatment without full, free and informed consent”. Similarly, a “systems approach” diagram (page 38) defines outcomes as including “self-determination”.

However, these statements obscure the role of parental decision-making and fails to distinguish between medical interventions necessary for health and medical interventions based on social, cultural or psychosocial rationales.

Recognition of the role of substitute decision-making is made on page 8, where it is noted that, actually, informed consent is provided by “people with intersex variations **or their legal guardians**” (our emphasis). These include consent in relation to interventions that the report describes as “contested” where the Family Court has described those interventions as “therapeutic”.

As expressed in the Darlington Statement, and as evidenced by recent Family Court cases such as *Re: Carla* (2016), the current model of court oversight has failed people with intersex variations. Parents should never be put in the position of being asked to consent to some forms of medical intervention.

4 Opinion and belief

While suggesting that the February 2013 decision-making principles should lead to decision-making according to current human rights and ethical principles, the report quotes a later, July 2013, submission to a Senate inquiry by the Royal Children’s Hospital that states:

It is our opinion that early surgery has psychological benefits for the child, as it allows them to grow up with more normally appearing genitalia, which reduces psychosocial and psychological stigma associated with DSD and also minimises parental anxiety (Royal Children’s Hospital, 2013).

This position is incompatible with the human rights of the child, and expresses a general position in favour of early intervention, before the subject is able to consent. This is stated clearly as an “opinion” because it lacks evidence.

A later 2016 global clinical update states:

There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery...

Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization (Lee et al. 2016).

The report contrasts the RCH Melbourne opinion with a quotation from IHRA that expresses a belief:

We believe that cosmetic genital surgeries, and the sterilisation of children who are assigned a sex that does not match to their gonads, must end...Medical interventions based on psychosocial adjustment or genital appearance should no longer be considered 'therapeutic' (Carpenter, 2013b).

This position is an ethical position grounded in human rights norms, supported by the 2013 Senate committee inquiry, and shared by a broad range of human rights institutions, but framing this as a matter of opinion against a belief acts to diminish the standing of the human rights concern.

5 Contradictory policies by the Victorian government and clinicians

While the Victorian government asserts recognition of the rights of children with intersex variations, other publications by the same government department and by clinicians in the State contradict these assertions.

For example, in addition to the example in the previous section, these include a Victorian government website continues to state:

*Potential for cosmetic surgical correction of **ambiguous genitalia** for virilised[sic] females should be discussed with the endocrinologist. Most surgical correction is now delayed until 6 months of age or later (Victorian Agency for Health Information and Safer Care Victoria 2018)*

That Department's current page on congenital adrenal hyperplasia (CAH) was developed with a medicalised parent-led group. It problematises genital appearance and proposes that surgery "may" be required. These surgeries share commonalities with those in *Re: Carla*. The web page states:

Children with non-salt-losing CAH are usually healthy, but may be born with genital abnormalities [sic] resulting from an excess of androgen. In girls, non-salt losing CAH is usually diagnosed at birth because the clitoris is large and the labia are partially fused. Sometimes, however, the changes [sic] may not be very obvious. In cases where the diagnosis is not made at birth, the growth of the clitoris continues and becomes much more obvious as time goes by...

Girls with CAH may need surgery to reduce the size of the clitoris to normal, separate the fused labia and enlarge the vaginal entrance. The technical name for this operation is ‘clitoral recession or reduction and vaginoplasty’. It is done either in one or two stages. The clitoral reduction or recession is done in the first few months of life. The vaginoplasty is sometimes done at the same time as the clitoral reduction, but may be left until adolescence (Department of Health & Human Services 2014)

A report of the Urology Clinical Committee, 2018 to the Medicare Benefits Schedule Review Taskforce which called for an increase in fees payable for paediatric vaginoplasties (Medicare Benefits Schedule Review Taskforce 2018). The document also provides important information on masculinising genitoplasties. The committee was chaired by a urologist at Monash.

These contradictions are not adequately addressed in the report.

6 The 2013 guidelines and 2010 “ethical principles”

A revision of the 2013 guidelines is prioritised in a “systems diagram” (page 38) as a potential future output. In our view, this is misguided, for both process and outcome reasons.

The guidelines are substantively derivative of 2010 “ethical principles” by Gillam, Warne and Hewitt, in particular in its framing of medical interventions as means of avoiding particular categories of risk, including psychosocial risks. For example, the “ethical principles” include the following “psychosocial risks” that could be minimised through medical intervention:

- *Risk that child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding with associated negative consequences*
- *Risk of social or cultural disadvantage to child, for example, reduced opportunities for marriage or intimate relationships or reduced opportunity for meaningful employment and capacity to earn an income (Gillam, Hewitt, and Warne 2010)*

The initial version of the 2013 guidelines included the following risks:

- *risk that the child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding and associated negative consequences*
- *risk of social or cultural disadvantage to the child, for example, reduced opportunities for marriage or intimate relationships, or reduced opportunity for meaningful employment and capacity to earn an income (as cited in Community Affairs References Committee, Senate of Australia 2013, 95).*

The process employed to develop those principles was inappropriate, in that the three clinical authors excluded discussion and consultation with other stakeholders and interests, and discarded all prior ethical analysis of medical interventions on intersex people. By doing this, the process was ethically and methodologically at odds with the broad engagement evident in current Victorian consultations on ways forward.

The three clinical authors employed Rawls' reflective equilibrium method of constructing new principles, a method of creating coherence between moral principles, beliefs and actions. There is no substantive literature on the application of this methodology. This method appears to rely on multiple stakeholders with different moral principles, beliefs and perspectives coming together to share different perspectives, when the actual process involved three clinicians with similar moral principles, beliefs and perspectives, and no voices of individuals with intersex variations, or parents were involved. With such a narrow group of participants, coherence between any set of beliefs is easily attainable, but it provides no guarantee of a valid, meaningful and defensible position.¹

Indeed, the ethical principles were immediately challenged by other clinicians for these reasons. Dreger, Sandberg and Feder stated:

The authors have opted to ignore the existing DSD ethics literature in an effort to arrive at principles putatively unburdened by previous ethical engagement.” and “This article seems largely to be responding to the major DSD debate of a decade ago, namely over genital surgeries in infancy. Many have now recognized that the central challenge in DSD care is not centered on the surgeries per se, but rather finding a way to help families (and healthcare professionals) overcome the shame and anxious secrecy that may shape minds and force hands in ways that ultimately harm all involved (Dreger, Sandberg, and Feder 2010).

The guidelines themselves are overly complex, appear to be disregarded or overlooked in practice. They have received a mixed reception largely due to their ability to perpetuate customary practices, and their perpetuation of a lack of transparency and accountability regarding clinical practices. The guidelines should not be amended or revised; they should be replaced as part of a larger reframing of policy and practice protecting the human rights of people with intersex variations. Such reforms must recognise the failure of clinical self-regulation, and ensure effective legal protections and independent oversight.

7 Contested and deferrable medical interventions

The “systems overview” in the Health and Wellbeing paper (page 38) distinguishes between “medically essential”, “deferrable” and “contested” medical interventions, primarily intended to characterise interventions on infants, children and adolescents who lack agency. “Medically essential” interventions includes interventions that are “immediately necessary to avoid serious, urgent and irreparable physical harm”, but also interventions that “otherwise carr[y] a demonstrable long-term health benefit that cannot be managed through less invasive, irreversible or major surgical means”. The latter interventions are safely deferrable as they only become necessary at particular life stages.

¹ This position has been developed in discussions between Morgan Carpenter and Angus Dawson (head of Sydney Health Ethics), and between Morgan Carpenter and two co-authors of the 2010 ethical principles – Lynn Gillam and Jacky Hewitt.

“Contested” interventions are described as those which “may carry a long-term health benefit but are not currently medically essential and may be managed over time through less invasive, irreversible or major surgical means” These concepts of medical necessity and contested interventions require significant work, and underpinning with sound evidence.

In 2017, the Committee on Bioethics of the Council of Europe commissioned a report examining the rights of children in biomedicine (Zillén, Garland, and Slokenberga 2017). The report authors made extensive comments and citations, including citing clinical literature showing that:

(1) “quality of life” studies on patients into adulthood are lacking and are “poorly researched”, (2) the overall impact on the sexual function on children surgically altered is “impaired” and (3) the claim that gender development requires surgery is a “belief” unsubstantiated by data...

On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion

The report of the Committee on Bioethics also stated that no clinically-accepted standard of care:

has emerged to explain, as a matter of science, how infant surgery will be certain to coincide with the child’s actual identity, sexual interests, and desires for bodily appearance

The authors found that:

- *surgery ... in infancy [is done] on the assumption that parental rearing could steer gender development.*
- *all evidence-based reviews concur that gender identity and sexual orientation of children with differences in sex development cannot be predicted with accuracy*
- *the medical literature has not addressed the implications of whether clinicians and parents have a right to assign these identities surgically and irreversibly on children (Zillén, Garland, and Slokenberga 2017)*

These points have not yet been adequately addressed.

8 Research

The Health and Wellbeing paper fails to identify problems with clinical research evaluating medical interventions performed by staff involved in conducting the research. This research lacks the rigour of independence, and skews research agendas towards clinical objectives

that do not match those of the studied population. Participation in clinical research can be expected to be skewed, omitting individuals who are dissatisfied with surgical outcomes or otherwise do not maintain a relationship with clinical bodies.

In 1998, Chase identified:

the “epistemological black hole” which precludes follow-up of intersex surgeries: the purpose of surgery is to hide intersexuality, therefore intersexuals must be lied to about their histories and surgeries, and thus follow-up cannot be done (Chase 1998)

A 2016 global clinical statement remarks that disengagement is frequent, due to dissatisfaction and withheld medical information:

The practice of withholding medical history details, along with the possibility of negative medical experiences, likely contributes to patients with DSDs frequently being ‘lost to follow-up.’ (Lee et al. 2016)

A 2018 post by the New Zealand Office of the Privacy Commissioner identifies variable progress in changes to this clinical paradigm of secrecy (Office of the Privacy Commissioner 2018). Australia and New Zealand share clinical institutions, so variable change is likely in Australia also.

All research has to have genuine, meaningful community participation, including a diversity of perspectives to ensure strong cross-community participation. Research methodologies and agendas must be transparent. Research must not be used to propose or facilitate human rights violations.

Research goals must take account of the factors detailed in the Darlington Statement, such as a focus on long-term outcomes.

9 Proposals for future action

Intersex advocates have been calling for reform of medical practices in Victoria and Australia for over two decades (see, for example, Briffa 2004). Our actions have included work at State and Territory, federal and international levels. In 2017, advocates from around Australia and Aotearoa/New Zealand collaborated on the Darlington Statement, a community consensus statement that sets out a common platform (AIS Support Group Australia et al. 2017). The demands in this Statement are comprehensive and integrated. In the context of medical interventions they include:

- **“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”
- **“mandatory independent access to funded counselling and peer support”** including integration of independent peer support and systemic advocacy organisations within multidisciplinary teams in hospitals (in referring to independence, we note that clinicians participate in the management of some groups).

- “appropriate **human rights- based, lifetime, intersex standards of care** with full and meaningful participation by intersex community representatives and human rights institutions”
- “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” (AIS Support Group Australia et al. 2017)

Reforms should address these concerns as an integrated package of measures. The development of guidelines is consequential to a legal and regulatory environment that recognises fundamental human rights principles.

Underlying human rights principles, including the right to bodily and mental integrity and the right to truth, are set out in the Yogyakarta Principles plus 10 (Yogyakarta Principles 2017). Detailed analysis of human rights principles relevant to the treatment of people with intersex variations in medical settings is laid out in the IHRA submission to the Australian Human Rights Commission in 2018, to its inquiry on protecting the human rights of people born with variations in sex characteristics in the context of medical interventions (Intersex Human Rights Australia 2018). A 10-page summary can be found in our submission to the UN Committee on the Rights of Persons with Disabilities (Intersex Human Rights Australia 2019).

10 References

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