

AIS SUPPORT GROUP AUSTRALIA INC.

Peer support, information, and advocacy for intersex people and families

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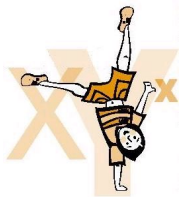
SUBMISSION TO THE AUSTRALIAN HUMAN RIGHTS COMMISSION: Protecting the human rights of people born with variations in sex characteristics

29 September 2018

The Androgen Insensitivity Syndrome (AIS) Support Group Australia Inc. (A0041398U) is a peer support, information and advocacy group for people with intersex variations, including AIS, and their families. We advocate for and support members (both in Australia and overseas) regarding issues associated with their lived experience of having intersex bodies. These issues include medicalisation, discrimination, stigma, social inclusion, infertility, disclosure, parenting and family dynamics, hormone therapy, gender identity, surgical intervention of children with intersex variations, sexual intimacy and associated human rights and psychological issues.

The AISSGA, which was established in 1985 at the Royal Childrens' Hospital Melbourne (RCH) and independently incorporated in Victoria in 2001, has been run by volunteers since its inception and receives no core funding from any Australian government or institution. Our organization was originally established for individuals with complete or partial AIS but progressively has become more inclusive to accommodate the need for peer support in the wider intersex community. Over time this has extended to:

- XY intersex variations, partial and complete gonadal dysgenesis, vaginal agenesis (also known as MRKH), 5a-reductase deficiency, 3b-hydroxysteroid dehydrogenase deficiency, 17-ketosteroid reductase Deficiency and 17b-hydroxysteroid deficiency;
- all other intersex variations;
- females, males, and non-binary identifying people;
- parents, siblings, family members, and partners;
- allied professional and service providers; and



- LGBTI community allies.

The AISSGA views intersex variations as natural expressions of the diversity amongst humans and rejects the philosophy that anything other than stereotypical binary expressions biological sex is considered disordered. We acknowledge that intersex is often viewed through a medical lens, that most of the words we have to know our bodies are medically-based, and that most of us come to know that we are intersex through a process of medical diagnosis. However the AISSGA subscribes to a 'social model of intersex' similar to the [social model of disability](#) presented by People with a Disability, and seeks to provide social pathways that enable intersex people and their families to be accepted, protected, self-determining, empowered, resilient, visible, and represented at all levels of society - to share a deep sense pride and belonging in our bodies and community.

The AISSGA respects the diversity and intersectionality within our community, acknowledging that people with intersex variations have diverse bodies, identities, ways of thinking and talking about their bodies, health needs, and experiences engaging in health and social settings. We also honour that parents may experience stigma differently and have differing concerns from their children. The AISSG Australia believes in a holistic model of health as per the World Health Organisation definition of 'health': "Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity".

The AISSGA provides support and advocacy services to members based around Australia. This work involves interacting with the medical, government and service provision sectors, yet our members still remain dangerously marginalised and many services are yet to become intersex inclusive or have only base-level understanding of the diverse needs of our community. Our volunteers are often called upon to educate service providers, liaise with medical professionals, conduct policy review and consult with other NGOs on top of providing peer support via phone, email, online and in person. Current medical frameworks do not provide adequate psychosocial support services for our community, or any resourcing for our organisation and AISSGA volunteers are often left to fill gaps in services left by other, highly funded organisations.

The AISSGA would like to thank to the Australian Human Rights Commission for the opportunity to participate in this critical project. The AISSGA has been calling for a



memorandum on medically deferrable surgeries where the individual is unable to provide full and informed consent since the 1990s. We have been calling for greater access to psychological services and the integration of peer support within multidisciplinary clinical teams for 15 years. We currently call for legislative protection of children with variations of sex characteristics, acknowledgement of previous harm caused from what were ostensibly experimental medical procedures, and the development of life-time standards of affirmative healthcare for all intersex persons.

At the time of writing, the AISSGA is not aware of a single referral of an intersex individual or parent from any Australian hospital in the past 10 years. Our critique of past and continuing medical treatment paradigms for all variations of sex characteristics means that our attempts at greater collaboration with hospitals has been met with ongoing resistance from clinicians and associated peak bodies who frame our concerns about human rights violations as being “bitter” and assert that medical practices have changed whilst not providing any transparency or evidence of treatment efficacy. At both organisational and personal levels such actions are dehumanising, demoralising, and contribute to volunteer burnout, additional stigma, family division, reduced health-seeking behaviours, and ongoing suffering within our community.

This submission has been written by the President of the AISSGA, Bonnie Hart in consultation with the AISSGA Committee of Management, and has been made available to all members through an internal call for submissions. The use of an online word processor allowed for individual member comment at every stage of the drafting. Individual member voices have been maintained, de-identified, and placed in *italics* and “inverted commas” throughout this written submission. It is of note that participation in this process was difficult for many, with some people noting that they felt too overwhelmed to contribute.



The AISSGA would like to make note of the following principles within this submission:

Darlington Statement

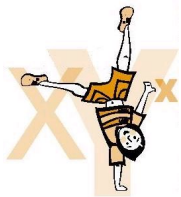
In 2017, representatives of the AISSGA, Intersex Trust Aotearoa/New Zealand, and Intersex Human Rights Australia (IHRA) in addition to independent intersex advocates published an Australian and Aotearoa/New Zealand consensus document - the [Darlington Statement](#), calling for a human rights approach to intersex clinical management, legal reform, an end to legal classification of sex, and improved access to peer support. The Darlington Statement was published after a consultation process that attempted to locate diverse representatives of the visible intersex community and human rights movement in Australasia. Invitations for EOIs from individuals with lived-experience were sent to all known intersex and diagnostic-specific support groups in Australia and Aotearoa and advertised on social media. Known clinicians and social-service providers working with intersex clients were asked to distribute the invitation in an attempt to locate isolated or marginalised voices. The process was conducted to provide a transparent framework for the human rights demands of the intersex community and to invite greater participation, dialogue, and action from medical, government, social service, and community sectors. The Darlington Statement acknowledges and is consistent with [Malta Declaration](#) of the Third International Intersex Forum in 2013. As such the AISSGA positions the Darlington Statement as the key document for policy reform in Australia and New Zealand and will make mention of the relevant clauses throughout this written submission.

2013 Senate Committee Report

The AISSGA also acknowledges the 2013 Senate Community Affairs References Committee report, [Involuntary or coerced sterilisation of intersex people in Australia](#). 15 recommendations were presented with bipartisan support from the contributing Senators. Unfortunately, no Australian government department has implemented any of the recommendations made. And following the outcome of the 2016 Family Court of Australia case [Re Carla](#), the AISSGA does not have confidence in the Family Court system to uphold the human rights of intersex people who are too young to make full and informed consent. As such, the following are the recommendations made by the report that are relevant to the current AISSGA submission:

- Recommendation 3

3.130 The committee recommends that all medical treatment of intersex people take place under guidelines that ensure treatment is managed by



multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.

- Recommendation 5

4.43 In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, the committee recommends that oversight of these decisions is required.

- Recommendation 6

5.30 The committee recommends that all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.

- Recommendation 9

5.38 The committee recommends that the special medical procedures advisory committee draft guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles. These guidelines should be reviewed on an annual basis.

- Recommendation 10

5.41 The committee recommends that complex intersex medical interventions be referred to the special medical procedures advisory committee for consideration and report to whichever body is considering the case.

- Recommendation 11

5.70 The committee recommends that the provision of information about intersex support groups to both parents/families and the patient be a mandatory part of the health care management of intersex cases.

- Recommendation 12

5.72 The committee recommends that intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases.

- Recommendation 13



6.11 The committee recommends that the Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients.

Human rights Principles

The AISSGA also acknowledges the Yogyakarta Principles plus 10 as strong guiding principles for the protection of people born with variations in sex characteristics with particular note to:

- Principle 32 on the right to bodily and mental integrity
- Principle 37 on the Right to Truth

The AISSGA also draws attention to the observations made by numerous UN Treaty bodies who have made condemnations of current clinical practices in Australia including obligations under:

- the International Covenant on Civil and Political Rights
- the Convention on the Rights of the Child
- the Convention against Torture
- the Convention on the Rights of Persons with Disabilities
- the Committee on Economic, Social and Cultural Rights
- the UN Human Rights Committee
- the Committee on the Elimination of Discrimination against Women



RESPONSE TO THE CONSULTATION PAPER

The AISSGA will respond to the individual questions as set out in the Commission's consultation paper.

1. Is the term 'people born with variations in sex characteristics' appropriate, or is there a better way to describe the people who are the subject of this Consultation Paper?

"This sounds OK to me"

"... considering how offensive and pathologising/inappropriate DSD is"

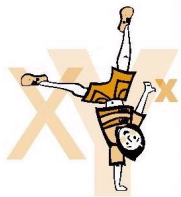
"Sure, it links in with some of the lingo used by international intersex groups and human rights institutions"

"I think we should also oppose terminology like "differences of sex development" because it "others" intersex bodies. By describing intersex bodies as "different", parents may be pressured into normalising their intersex child through surgical and hormonal intervention despite these interventions not being medically required and being deferrable until the child can decide for themselves what interventions they want (or don't want)."

Language is an important aspect of how people conceptualise and communicate about their intersex bodies in both social and medical contexts. Individuals may use some words when engaging with service provider, different language when accessing medical services, specific words with friends, family, or sexual partners. These definitions are deeply personal and using the wrong language can anger, confuse, or alienated a person with lived-experience. Importantly, people may not use language related to "sex characteristics" to describe themselves but the issues related in this submission and the AHRC's project will still relate to them.

In this submission we will refer to "intersex" and "variations in sex characteristics" interchangeably whilst acknowledging the people we are talking about may use any of the following language to describe their body:

- Intersex variation/condition
- Variations in sex characteristics
- Diagnostic-specific terminology (i.e. "a medical condition")
- Chromosomes or combine these with their sex/gender (e.g. "XY woman")
- Difference/disorders of sex development (DSD)



- Herm/hermaphrodite (generally derogatory, but reclaimed by some)

Language impact how individuals can access information or be referred to appropriate services or resources. DSD terminology is highly contested and often inappropriate within both community and clinical environments in terms of further pathologising intersex and clinical suitability of the umbrella term. We respect that some of our members may use DSD terminology and we include “DSD” on our website and promotional material so that peer support is inclusive and inviting to anyone with a variation of sex characteristics or parents, irrespective of the language they use. This is difficult as the term is so highly contested that some members of the community criticise the AISSGA for “endorsing” DSD which we do not. The inherent disordering associated with DSD, along with the predication that intersex can be “fixed” through medical intervention does not fit within our philosophical positioning of intersex bodies are healthy variation amongst humans. As such the AISSGA supports the 2013 Senate Committee’s recommendation that this term not to be used beyond the most specific clinical setting, and then this terminology should be phased out.

Language is also very age specific so people who have grown up with what is now outdated terminology still use older language to describe their variation, and respect should be given to all people regardless of the way they describe their bodies.

The Darlington Statement acknowledges:

3. The diversity of our sex characteristics and bodies, our identities, sexes, genders, and lived experiences. We also acknowledge intersectionalities with other populations, including same-sex attracted people, trans and gender diverse people, people with disabilities, women, men, and Indigenous – Aboriginal and Torres Strait Islander, Tangata Whenua – and racialised, migrant and refugee populations.

4. Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that are more diverse than stereotypical definitions for male or female bodies. For some people these traits are apparent prenatally or at birth, while for others they emerge later in life, often at puberty (see [UN definition](#)). We recognise our diverse histories and use the word intersex inclusively, and acknowledging our right to self-determination.



6. Our opposition to pathologising terminology such as “disorders of sex development”, not only because such labels are inherently disordering, but also because this promotes the belief that intersex characteristics need to be “fixed”.

52. We recognise that the stigmatisation and pathologisation of people born with variations of sex characteristics hinders self-acceptance, access to community, help-seeking, and accessing of services including healthcare.

59. We call for an end to the stigmatisation and unnecessary pathologisation of intersex bodies.

2. Broadly, how would you describe your experiences in the context of medical interventions?

“Monash Medical Centre - no pressure from specialist, yet no clear expertise either. Provided with some options, but we were not confident that there weren't other options which we just weren't being told about. My experience was that I had to do a lot of my research so that I could ask the right questions”

“inappropriate interventions (surgical and hormonal) still occur in hospitals as verified by the RCH last year. These are not medically required, non-consensual and deferrable. For example clitoral reductions... clearly these interventions should not occur and would not be acceptable to anyone that does not have an intersex variation - the very definition of discrimination”

“I grew up being taken to a hospital by my mum during the school holidays where lots of men would look between my legs, put their fingers in my vagina, and talk about how abnormal I was. At age 11 my undescended testes were removed and I began a life-long journey with HRT. I have since seen my consenting signature on the medical records, but I'm not convinced I fully knew what was happening and certainly did not understand the long term effects of the surgery. We were simply doing “what had to be done”. I was told I would never be able to have sex and vaginoplasty was recommended. Fortunately my parents decided to wait and see if it was necessary instead opting for a course in vaginal dilation which I began at 13. It was a painful,



bloody and completely unsupervised practice aimed at allowing me to successfully accommodate a future fictitious husband and hence make me a more normal female”

“As an older member of the community I know that many older people have been used as guinea pigs for clinicians to gain credibility in their field with little or no respect being afforded to the individual. Many older intersex people have little or no records of surgery as a child and live a life of limbo in relation to their bodies adding to mental health issues and the inability to ever gain bodily autonomy and of course never bodily integrity.”

“We can build on this to debunk claims by clinicians at the RCH that more research and data is needed. What data is needed to determine that reducing the size of a baby girl’s clitoris is ok? Or why is data required to know that babies should not be given hormone treatment without their consent to influence their gender identity and sexual orientation. Intersex conversion therapy needs to be prohibited. ”

The AISSGA has witnessed a huge variation in the experiences of its members in relation to medical interventions. Medical paradigms are experienced differently between individuals with intersex bodies and parents. There is no consensus in treatment protocols and experiences of medical interventions are different between older and younger members within the group. Some members have ongoing health implications associated with childhood surgeries or subsequent revisions, whilst others take HRT. The AISSGA is aware of ongoing psychological themes of shame, isolations, and lack of support experienced as a result of overt medicalisations.

3. What are the current Australian sources of information and education about the experiences of people born with variations in sex characteristics?

“AISSGA members, AISSGA publications/pamphlets, internet, research papers from Australian doctors/researchers”

“IHRA, and there’s also some community-based research, which gives first-hand accounts of people’s stories. We need more Australian community-based and participatory research”



“Current available information is insufficient and the AISSGA needs to be resourced to provide better education services which are delivered peer support groups and not clinicians.”

“School programs such as “All of Us” made by the Safe Schools program go a way to addressing the experiences and needs of people growing up intersex. Also educational documentaries made by people with intersex variations about their lives, such as Orchids: My Intersex Adventure.”

4. Are there gaps and/or inconsistencies in sources of information and education that are available about the experiences of people born with variations in sex characteristics? If so, what is the impact of this?

“Yes. I've discovered that people with Turners are still being told by Dr's that there are no educational and informational resources. Previous studies that came at a very dear price are not even being referred to”

“It seems to me that it very much depends where a person resides (which hospital they are referred to) as to the kind of experience available to them. The impact of this is that many people don't have choice as to where they source information, and information is not readily accessible”

“No one hospital or team can say with any accuracy or knowledge what any other hospital or team is doing. There are lots of fine words about changed practices, but no evidence of those changes. Instead, we keep seeing evidence that things haven't changed”

“Life long data is not in abundance because of hospitals refusal to share data”

Navigating the vast amount of information relating to living with and diagnosis of a variation in sex characteristics can be overwhelming. Clinical evidence and terminology is not consistent and can be technically inaccessible to many. Intersex people remain largely hidden in society and media coverage can be sensationalistic and inaccurate. Legal information around intersex can other intersex men and women into a third sex classification. LGBTI organisations generally have a focus on sexual behaviour and gender identity issues and can conflate notions of intersex with



queer identities. Searching the internet for information about variations in sex characteristics can be frightening as there is much misinformation, conflicting data, outdated and stigmatising language, medical photography, and a huge lack of affirmative, celebratory intersex narratives and role models. Without access to peer support, many parents and individuals may become lost in the huge amount of information and the most clinically focused, prolific, sensational, conservative, or risk-focused information may be privileged. This is exacerbated in that intersex-led organisations remain marginalised both socially, medically, and financially, and are hence limited in their capacity to provide readily accessible information about the real-lives of healthy intersex people, guides surrounding treatments and decision making. Distribution of existing resources produced by peer-led intersex organisations is also limited due to lack of resourcing and clinical referral pathways.

5. How is the consent of a person born with a variation in sex characteristics currently sought prior to a medical intervention?

“As a teenager I experienced no consent. Consent was only apparently required via my father and stepmother. I was not included in anything during my DR's appointments.”

“Some experiences show coercion and a denial of the child's right to bodily autonomy and integrity. Deferrable procedures should be deferred, not imposed on children. The High Court also confirmed that parents cannot consent to irreversible non-therapeutic medical interventions, so why is this allowed for children with variations of sex characteristics?”

“My 13 year old daughter gave informed consent and we as parents also consented. Information was provided by one specialist, age appropriate for my 13 year old, psychological assessment was conducted to ensure she was not coerced, etc.”

“I kind of consented, as an adult, but it wasn't an informed consent. I was isolated, had no support and no idea what the long term consequences of medical interventions were, and really wasn't able to make good decisions. They had big consequences not only for my physical health, but also for my mental health.”

“I did say yes to the surgery I received as a teenager, but I had no idea about the impact it would have on my body and my life, and the lifelong follow ups and



treatment the surgery brought about. That information didn't get discussed, or only in a very cursory manner. If I had of known all the facts, I would have said no."

"Consent is treated as a discrete moment in time, an understanding of what they are doing to you and the reasons. The thing is that what was communicated to me when I had my surgery did not match up to what I experienced as a result of the surgery. Not having treatment was not even considered as an option."

The AISSGA is not aware of any consistent approach to obtaining consent between hospitals or clinicians. Clinical guidelines or individual hospital practises are not communicated by hospital to our support group. Our current understandings come from the anecdotal accounts of members who are engaging with hospitals.

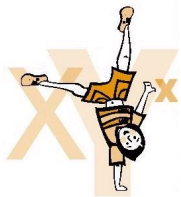
6. How do current guidelines or protocols relating to the medical management of people born with variations in sex characteristics deal with the issue of consent, including the ability to withdraw any consent given at any time?

"It doesn't! Not when the child is an infant and deferrable procedures are still being conducted."

"Consent should be fully informed, many surgeries are done without knowledge of potential long term consequences as studies have not been conducted to assess harmful effects and patients may not be aware of this."

"Consent for an infant or child should only be given by the child once a child can give informed consent except where a surgery is not deferrable as it would be deemed life threatening."

"Parents should not be able to consent to medical interventions that are not medically required and deferrable. "



"I felt pressured to consent to my irreversible surgery. Withdrawal did not feel like an option. This was because I was a child and children don't have the ability to speak their mind fully or understand all the implications."

7. What practices/safeguards are in place to ensure any consent obtained remains informed?

"Independent arbiter to determine what is in the best interests of the child. Interventions that are not medically required and that are deferrable should not be permitted."

"I can only think of the surgeon asking a patient immediately prior to surgery if they know what the surgery is for."

"Consent is more than what happens on the way into an operating theatre. It's about exposure to information, to peers, to different perspectives, and especially to affirmative perspectives that can help tackle shame and secrecy in constructive ways"

8. What could enhance the capacity of people born with variations in sex characteristics or their caregivers to provide full and informed consent?

"A holistic team which supports the individual and family in a biopsychosocial aspect."

"Impartial information, advice and support from a well resourced, intersex led peer support agency."

"Advice given over an extended period. Not a one-off 10-minute conversation."

The AISSGA believes all interventions on intersex bodies that medically-deferrable should be deferred to a time where the child or adult is able to provide full and informed consent. All individuals involved in the decision-making process must be made aware of that enough time to make decisions and a variety of options are open to them including the option of no treatment. The clinical situation must be de-escalated and the individual or family must be provided psychosocial support at



every stage. Issues related to medical necessity and psychosocial rationales must be clearly separated. Honest articulations of the evidence related to treatment outcomes including mixed results, uncertain risk factors, success and complication ratios must be clearly presented. A variety of sources of information relating to the intersex variation, including information related to social understandings of intersex and peer support. In order to have adequate time to process the information, parents and intersex children under the age of 16 must have multiple stages of consultations with a focus on psychological support and connection to peer support in between clinical sessions. Before consent is accepted the individual or parent must be able to clearly demonstrate both the desired outcome, risk factors associated with intervention, alternative options, and contingency plans for ongoing psychological and peer support for the individual.

9. To what extent should parents and carers be involved in making decisions on behalf of their child? How can parents and carers be best supported to make these decisions?

“Parents and carers need to be involved in these decisions for young children, however, the extent should reduce as the child is able to understand more and make decisions for themselves. Parents and carers need easy access to social workers and other health supports, a holistic team as mentioned above, individuals with lived experience and support groups in order to be able to come to informed decisions.”

The parent must be provided with both psychological and peer support at every stage of the decision-making process. It is the view of the AISSGA that the bodily integrity of individual with a variation in sex characteristic must be maintained wherever possible so that the person can have full control and autonomy over decisions around non-reversible interventions. Parents must be able to consent to interventions where there is a clear and evidenced medical necessity associated with their child's physical health which are clearly separated from any perceived psychosocial or cultural beliefs.

10. What, if any, legal oversight mechanism(s) should be in place to guide decision-making about medical interventions involving a person born with



a variation in sex characteristics where the person does not have the legal capacity to provide consent?

“First - do no harm, second - do not alter a person’s body for aesthetic purposes (only where medical intervention is necessary for physical health) and certainly do not make alterations to a person’s body that are irreversible except where extreme medical situations exist. Legal oversight could consist of a panel of specialists, including social workers, psychologists, etc, and most importantly, people with lived experience, perhaps something like the mental health board for involuntary admissions.”

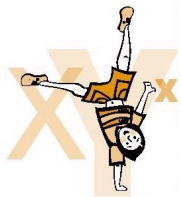
“We need to be mindful of surgeries that get carried out but are part of another related surgery. “

“I understand a legal oversight may add more stress to families seeking to access medical interventions for non-urgent procedures. But frankly, if the reason a family wants surgery on their child is because they’re worried about what others will say or that their babysitter will refuse to change their child’s nappy, then they need to have a good, long hard think about the environment the child is being exposed to rather than the child’s natural body.”

The AISSGA believes in light of the past and current harms caused to individuals within clinical environments from what are essentially unevidenced, experimental procedures on intersex individuals, oversight is necessary. The AISSGA believes that the Family court system has failed to protect the bodily integrity of unconsenting minors and as such, an independent body comprised of specialist clinicians, ethicists, psychologists, human rights experts, and intersex representatives from peer-led community organisations is necessary.

The Darlington Statement acknowledges:

22. We call for 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. The pros and cons for and against medical treatment must be properly ventilated and considered, including the lifetime health, legal, ethical, sexual and human rights implications .



11. If such a mechanism existed,

- o how could this mechanism adequately address different interventions and different variations?**

“Consideration on a case by case basis, and communication with each family/individual involved.”

“An oversight mechanism must ensure that decisions are compatible with human rights norms”

“ Perhaps by bringing in specialist advisors for each case, for example person with the same or similar variation to the one being discussed?”

- o how can it best respect the future capacity of a child to consent?**

“By firmly adhering to no surgery that is not medically necessary for the physical health of a child - do no harm.”

“By preserving every decision possible for the child, by maximising the freedoms and rights of the child, by ensuring that the child knows what is going on and has been exposed to different options”

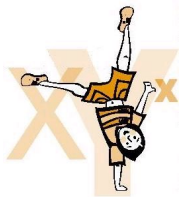
- o should there be distinct processes for children with parents and for adults who lack legal capacity?**

“A board/panel could address both.”

12. Would a legal definition of medical necessity or therapeutic treatment be helpful and, if so, what should the definition be?

“I believe it would be helpful. A definition should include what is NOT a medical necessity, eg. aesthetic alteration which serves no health purpose at the time.”

“Do no harm.”



“Yes it would be helpful. I feel many doctors would say that a child being able to use a toilet or a dressing room to change clothes without feeling embarrassed is a ‘medical necessity’.”

The AISSGA believes such definitions would be useful.

13. What are the permissible rationales/considerations that should be taken into account when determining whether or not to undertake a medical intervention on behalf of those who lack the capacity to consent?

“Whether the intervention is serving a serious medical need at the time re the health of the person. Intervention should not be undertaken with only a future view in mind about what might be easier for the individual. Interventions should serve a very definite purpose in the present.”

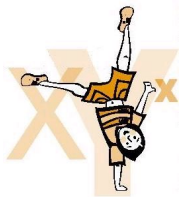
“Include deregistration.”

“If a child is likely to be in pain or couldn’t urinate properly or if there’s a risk they’ll be really unwell or even die, then surgery is a must.”

The AISSGA asserts that rationales must be associated with clear medical necessity or medical emergency. Any rationale that is based on gender stereotypes, social or cultural norms, cost-effectiveness, clinical competence or convenience, limiting psychological distress, parental bonding or is presented as a “fix” without access to ongoing peer or psychological support must be considered insufficient.

14. Should all non-emergency and/or deferrable medical interventions that alter a child’s sex characteristics, where the child does not have legal capacity to consent, be prohibited by law? If so, should this prohibition be civil or criminal?

“Yes, should be prohibited, both civil and criminal. The rights of the child are paramount.”



"Yes"

"Like 20 years ago"

"It should be a criminal offence"

"If it's not a criminal offence, it will be ignored"

"Include deregistration."

"I strongly agree with this statement."

The AISSGA calls for all non-emergency and/or deferrable medical interventions that alter a child's sex characteristics, where the child does not have legal capacity to consent to be prohibited by law? Any breaches should be considered criminal acts in a manner similar to acts of female genital mutilation. Additionally there must be no statute of limitations placed on litigation relating to past, current, or future medical interventions.

The Darlington Statement acknowledges:

7. We call for the 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. We call for freely-given and fully informed consent by individuals, with individuals and families having mandatory independent access to funded counselling and peer support.

9. We call for effective legislative protection from discrimination and harmful practices on grounds of sex characteristics .

10. We call on governments and institutions to acknowledge and apologise for the treatment of people born with variations of sex characteristics, and provide redress and reparation for people born with variations of sex characteristics who have experienced involuntary or coercive medical interventions. There must be no time limit on access to redress and reparation.



15. What are the current approaches to the management of people born with variations in sex characteristics? What are these based on?

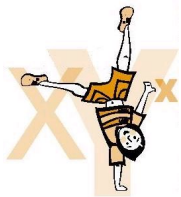
“They are based on heteronormative ideals about what women and men’s genitals are supposed to look like, how they are supposed to be use, and who they are supposed to be used with. They make a lot of assumptions that people are going to be straight and into having “normal” sex or being embarrassed about having a big clit”

“I received my treatments a few decades ago. I’ve had many doctors tell me that there’s been many changes since, including better diagnostic tools and processes. However, when you bare down on into it, you’ll discover doctors are still performing operations on babies and children with ambiguous genitals for purely cosmetic / social reasons.”

“I know that parents-to-be are terminating embryos which have intersex variations at an increasing rate, usually after consulting with their doctor. So you don’t have to be ‘born’ to have been affected by social attitudes and medical paradigms which negatively impact people with intersex variations.”

16. Do any medical guidelines exist that are considered best practice in Australia or internationally, either for the general management of people born with variations in sex characteristics, or for specific variations?

The Victorian decision making guidelines exist and we have been made aware that these are endorsed by the APEG-DSD Subcommittee. These guidelines still permit psychosocial rationales for surgery which the AISSGA strongly opposes and as such the AISSGA does not consider the Victorian guidelines as best practice. These guidelines are out of date and the AISSGA has not be consulted regarding any review processes. Any review process should be accompanied by appropriate resourcing to ensure meaningful engagement with intersex community representatives.



17. Should there be national guidelines to guide medical interventions involving people born with variations in sex characteristics?

“Yes - standards of care”

“Standards of care that ensure that treatment meets human rights norms”

“National guidelines are important, but they still just guidelines which physicians could choose to ignore willy nilly.”

The AISSGA calls for lifetime standards of care to guide clinical and psychological interventions associated with variations in sex characteristics.

The Darlington Statement acknowledges:

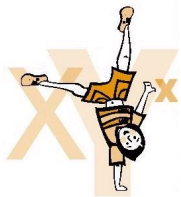
15. We acknowledge the long-term physical and psychological implications of harmful and continuing medical practices, and limited access to support and peers.

16. Current forms of oversight of medical interventions affecting people born with variations of sex characteristics have proven to be inadequate.

a. We note a lack of transparency about diverse standards of care and practices across Australia and New Zealand for all age groups.

b. We note that the Family Court system in Australia has failed to adequately consider the human rights and autonomy of children born with variations of sex characteristics, and the repercussions of medical interventions on individuals and their families. The role of the Family Court is itself unclear. Distinctions between “therapeutic” and “non-therapeutic” interventions have failed our population.

17. We call for the implementation of advisory bodies to develop appropriate human rights-based, lifetime, intersex standards of care with full and meaningful participation by intersex community representatives and human rights institutions.



18. We call on the Australasian Paediatric Endocrine Group and other medical/health bodies to stand alongside intersex-led community organisations to develop human rights-based lifetime standards of care .

19. We recognise that intersex people have health and medical needs, sometimes related to having an intersex variation, and sometimes not. We recognise that for people with an intersex variation, misconceptions and associated stigma can act as barriers to treatment. Current practices are often based on the needs of other populations.

20. We recognise access limitations in rural, regional and remote settings.

21. We call for resourced access to necessary and appropriate health, medical and allied services and treatment, including surgeries and hormone treatment, psychosocial, psychosexual and psychological support, and including reparative treatments. Standards of care must support reparative treatments, and must not require conformity with stereotypical and clinical norms for female or male bodies, women and men, nor impose inappropriate psychiatric eligibility assessments.

23. Multi-disciplinary teams must operate in line with transparent, human rights-based standards of care for the treatment of intersex people and bodies. Multi-disciplinary teams in hospitals must include human rights specialists, child advocates, and independent intersex community representatives.

24. Some people need pap smears, some people need prostate examinations or mammograms, and some people need a combination of these. National screening programs and computerised systems must recognise the needs of people born with intersex variations.

25. We call for an end to the use of IVF and other forms of genetic selection to de-select variations of sex characteristics.

26. We call for access to reproductive services and fertility counselling for all intersex people, with protection of our reproductive autonomy, regardless of whether or not our capacity for fertility is considered to be in line with our legal sex.

18. If so:



o what factors should the guidelines take into account?

“Acceptance of bodily diversity and respect for body integrity. Psychological and emotional impacts of surgery should be acknowledged and taken into account. Not make assumptions about what is best for people without asking them.”

“It sounds a bit hippy dippy but part of the treatment paradigm ought include scope to develop self love, self value, self esteem in patients and an understanding that difference is not only OK, but could actually be a boon.”

o what should be the legal status of the guidelines?

“I would love if the guidelines are strictly enforced. Doctors have disregarded the ongoing calls for changes from the intersex community and our allies for decades. This is attitude is belligerent and uncaring, and in many cases downright criminal.”

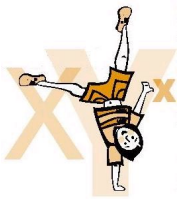
o what should be the process, including consultation, for drafting the guidelines?

“Collaborative process with intersex people, families, clinicians and community representatives.”

“Intersex people must have a seat at the table. We’ve been left out of the conversation about what happens to our bodies for too long.”

The AISSGA calls for the guidelines to be drafted by specialist clinicians in consultation with peer-led intersex organisations, human rights experts, ethicists, and psychologists. Consultation must be obtained from people with lived experience for the scope of variations in sex characteristics that the guidelines covers, where possible multiple perspectives on the same variation should be sought. Appropriate resourcing must be made available to individuals and community groups to participate in both the drafting and consultation. The guidelines once approved must be reviewed every 2-3 years due to quickly changing terminology and to allow for the incorporation of new qualitative or quantitative evidence or community consultation.

o what should be the oversight mechanism for decisions made under the guidelines?



"I feel strongly about included people with lived experience in any decision making bodies."

"An impartial mechanism - a committee comprised not just of doctors! - should oversee the implementation of the guidelines."

The AISSGA calls for peer-led intersex organisations and community representatives, and additionally, parent representatives to be included in any oversight mechanism established to ensure that decision making protects the best-interest of the child and is within a human-rights framework.

19. What are the current Australian sources of data on:

- o the number and nature of medical interventions involving people born with variations in sex characteristics?***

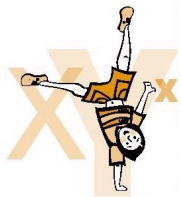
"As all information is held by the medical fraternity it's impossible to ascertain anything in relation to data also many older Intersex people are unaware of their variation as families hid this information for fear of shame & stigma."

"Irreversible surgical and hormonal interventions on children and adolescents must be very carefully considered, if not banned altogether unless of a medical (not a cosmetic!) necessity."

- o long-term outcomes of medical interventions involving people born with variations in sex characteristics?***

"As organisations such as AISSGA did not exist until 30 years ago many older Intersex people have not been part of any peer support group, if they were informed by their parents or guardians or if they had to discover their variation by themselves with no support they soldier on by themselves with their variation and if they are lucky they find a G.P. who Has some understanding of their variation but more times than not this is not the case. With an estimated range of 1.7% of the world having an Intersex variation it appears surprising how little doctors are informed of Intersex variations."

"I'm not happy with the medical interventions I received in the long term. The surgery I had was done for very flimsy reasons, and my level of health and wellbeing has been compromised significantly by the interventions I received - not improved!"



The data associated to long-term clinical outcomes is highly unsatisfactory with small sample sizes, using individuals who are not intersex as controls. An attempt to “fix” intersex characteristics in childhood and a disconnect between pediatric and adult services can mean that true outcomes of surgery are not known. Many adults accessing our support group do so in their early twenties after leaving the family culture surrounding their intersex variation, do not have in depth knowledge of the procedures they received as children, nor the words to talk about their bodies in empowered and affirmative ways. Often such adults if they are experiencing negative outcomes, can become disenfranchised and alienated from medical services. The interrupting and often traumatic experiences associated with diagnosis and intervention can result in reduced performance at school, poverty, family stress, and complex psychological issues that are often not the focus of clinical studies.

The AISSGA is not aware of any long-term data for people born with variations in sex characteristics beyond the qualitative data and stories held and shared within our intersex community. Unfortunately we know that mental health outcomes are extremely poor for individuals who did not provide consent to or have had complications or iatrogenic effects from medical interventions associated with their intersex variation. We experience high levels of suicidal ideation within our community and AISSGA members provide front-line suicide intervention. Belongingness has been evidenced as a strong protective factor against suicide and as such the peer support provides both intervention and protection from suicide and self-harm.

The AISSGA rejects research aimed at confirming the efficacy of current clinical interventions that does not take into account, or is conducted at the expense of investigating of the true effects of past (and continuing) interventions. As such, the AISSGA calls for greater community based participatory research.

The Darlington Statement acknowledges:

37. We call for the implementation of adequate clinical transition pathways from paediatric to adult services.

39. We recognise the trauma and mental health concerns caused by the unnecessary medicalisation of intersex people, as well as stigmatisation of intersex characteristics that has resulted in a legacy of isolation, secrecy and shame.



46. We acknowledge that intersex people are the experts on our own lives and lived experience. Intersex people are experts in understanding the long term effects of medicalisation and medical interventions.

o long-term outcomes of people born with variations in sex characteristics not undertaking medical interventions?

"I've heard stories from people with intersex variations similar to mine who haven't had any medical interventions whatsoever and they're in a much better place physically and mentally than I am."

The AISSGA is not aware of any long-term research conducted for intersex individuals who have not experienced medicalisation. Within our community groups we have access to individuals and family members who have not received medical interventions, we hear their stories.

20. How adequate are the current Australian sources of data for each of these areas?

"All very inadequate"

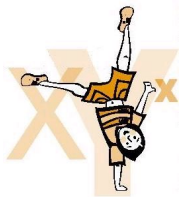
"Current sources of data are scant and usually the participant pool is small."

21. What barriers exist to nationally consistent data collection?

"Many intersex people are not willing to disclose personal information for research purposes."

"Disclosure is traumatic. Each time it requires revisiting harmful experiences."

"Our trust in researchers and scientific or medical research has been abused time and again."



The Darlington Statement acknowledges:

29. We call for regular public disclosure of accurate summary data on all medical interventions to modify the sex characteristics of children, and disclosure of historical data.

22. How can medical practices best respect the privacy of people born with variations in sex characteristics?

“Don’t take photographs of their genitals when they are under anesthetic”

“Not require people born with an intersex variation to be automatically placed on a national database of health record.”

“I think many doctors - particularly ones working in hospitals in charge of teams who treat children with intersex variations - have built careers on communicating information about their patients at conferences and in journals. In some of these publications, their medical photographs are displayed in a highly pathologising and freaky manner. This use of our stories as a learning exercise for other physicians might be acceptable but again negates our agency and leaves us out of the conversation.”

The Darlington Statement acknowledges:

32. Children with intersex variations should never be subjected to medical photography and display.

23. Have you faced any difficulties accessing your medical records?

“Yes. My Paediatrician denied me access. Knowing that he had inappropriate non consensual photographs of me naked due to being part of a hormone study!”

“I had to steal my records when the doctor was out of the room. I thought he was lying to me and I needed to know for sure. I was right”



"I tried to get my medical records and found out that the hospital had destroyed them after 10 years"

"As an older person I was told that my health records were destroyed, meaning that I have no record of any surgery prior to the age of 21 as I was a state ward before that time and I was not in a position to even enquire."

24. How can access to medical records and histories be improved? By providing patients/families with records throughout processes - this would assist with information/education provision and allow families to revisit records in their own time as their understandings evolve.

"Make it illegal for Dr's to refuse to provide their records! Make medical records the intellectual property of the person who they are about!!!"

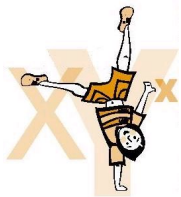
"Automatic & Unobstructed Freedom Of Information Rights"

"Make sure that medical records for any childhood diagnosis or intervention is maintained in perpetuity."

"I got my medical records through a FOI application. There was so much blacked out it was almost impossible to work out who had done what. This was done to protect everyone else who made those decision, not my right to know the truth about what had happened to me and what the reasons were."

"I managed to receive my redacted medical records from the hospital where I was treated as a child and an adolescent via the Freedom of Information provision. It was extremely illuminating and I could work out what information had been removed anyway."

The AISSGA believes it is essential that individuals be able to access full and complete records relating to physical and psychological interventions they experienced as a result of the variation in sex characteristics as any stage of life. These records must be easily accessible without prohibitive bureaucratic obstructions or financial cost to the patient. The records should be maintained in perpetuity, particularly when interventions were received during childhood when full and informed consent may be



contested. Penalties or litigation pathways should be available to patients in circumstances where records have been, lost, stolen, destroyed, or altered.

The Darlington Statement acknowledges:

33. We call for respect for the privacy, integrity, and security of our medical records .

34. Recognising the difficulty that some intersex people have in accessing childhood medical records, we call for full access to medical records. Paediatric hospital records should be kept indefinitely. The medical records of people with whole-of-life medical issues should also be kept indefinitely.

25. *How can people born with variations in sex characteristics and their families and carers be more adequately supported?*

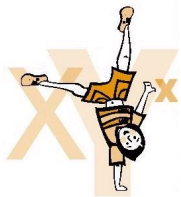
“Provision of a holistic multi-disciplinary team which remains connected with the family - not just with each other. The care-team should include social workers who have contact with support groups and can provide families with multiple options for contact going forward.”

“Funding for support groups to provide peer support services!”

“There needs to be more understanding and awareness of intersex variations and the issues they present in the community. Also, treating intersex as merely a medical problem which must be treated by surgery or hormonal treatment only is reductive. We need people with whom we can talk to and receive support from, and a more holistic approach to wellbeing.”

“With Intersex organisations being one of the least funded groups of all medical variances the information you are seeking in this document itself is strained, peer support groups need substantial funding so that a national approach can be made.”

The AISSGA calls for increased psychosocial interventions to address issues relating to people born with variations. Peer support is evidenced in clinical consensus statements and multiple random control trials as being effective at promoting good



physical and mental health outcomes and should be acknowledged and included as such within clinical multidisciplinary teams. Adequate training and education about the diversity of bodies contained under the intersex umbrella, including the specific concerns for some of the more common variations, and the human rights issues that face our community should be included in all new medical, health, psychological, sociological, social work, and community services related studies and ongoing professional development opportunities for practicing professionals should be available so that referral pathways to affirmative peer support and information is available. Additionally, sex education delivered in schools must provide at least the most basic description of intersex so that individuals are not erased in this context and discussion around intersex issues is open, nonpathologising, and supported. Peer-led intersex organisations should be consulted in the drafting of any such educational material. Individuals with lived-experience who are open and willing to speak about their experiences have often spent many years in reflection and resilience and therefore must be considered experts in intersex issues.

The Darlington Statement acknowledges:

31. We call for improved and ongoing education of health, welfare and allied professionals in issues relating to intersex bodies, including human rights issues.

40. We recognise the fundamental importance and benefits of affirmative peer support for people born with variations of sex characteristics.

41. Our peer support organisations and other peer communities need resourcing and support to build communities and networks inclusive of all intersex people. No intersex person or parent of an intersex child should feel they are alone, irrespective of their bodily variation or the language they use.

42. We recognise the needs and lived experience of youth, and of people coming from varied cultural and faith backgrounds. We recognise these experiences as valid and legitimate.

43. We recognise the fundamental importance and benefits of peer support for parents, caregivers, and families of people with variations of sex characteristics. We recognise the importance and benefits of peer support for friends, partners, and others who support intersex people in their day-to-day lives.



48. We encourage all organisations and bodies that support the intersex movement to recognise this Darlingtong statement

53. We acknowledge the impacts of stigma, trauma and unwanted medical interventions on access to education and on employment, and consequences that include high rates of early school leaving, poverty, self-harm and suicidality.

54. We call for the inclusion of accurate and affirmative material on bodily diversity, including intersex variations, in school curricula , including in health and sex education.

55. We call on education and awareness providers to develop content with intersex-led organisations, and promote delivery by intersex people.

26. How can psychological and peer support be more integrated into decision making processes?

“Having those with lived experience connected with hospitals/care teams and available for consultation, and better yet, a mandated consultation requirement. Perspective needs to shift to those with lived experience being experts.”

“I was never offered any psycho-social support when I was being treated as a teenager by medical professionals for my intersex variation. When I asked to meet others like me, I was told that was impossible. I feel like my life could have been radically reshaped by the (missed) positive experience of meeting others or by having conversations with professionals that helped me to love and accept my body and myself.”

The AISSGA strongly promotes that community experts with lived-experience are included in any oversight, ethics committees, or decision making structures to ensure that the knowledge of how living in society with a variation of sex characteristic is considered beyond technical or theoretical considerations. Community-based participatory research should be considered in clinical and research contexts.



The Darlington Statement acknowledges:

30. We call for more research, including clinical, sociological and psychological research, led by community input. Clinical research, including longitudinal research, requires true, non-medicalised controls.

44. Peer support must be integrated into human rights-based multi-disciplinary medical approaches, teams and services.

27. What barriers exist to connecting individuals to support services?

“There seems to be a disconnect between medical professionals and support groups, and this results in families and individuals not receiving the best care and advice that is possible. Ultimately, the consumer suffers because those in positions of power don’t hold the consumers needs/rights/best interests as paramount.”

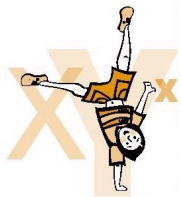
“Lack of information provided by clinicians and stigma around intersex, people don’t want to talk about it.”

“Stigma and misinformation.”

“Doctors don’t tell you about support groups.”

“There’s often a question of what’s actually out there that could help me? We’re so used to struggling through without any help whatsoever. We may not be aware there are support services which could be valuable.”

The AISSGA is aware that individuals face both internal and external barriers to accessing support. People with variations in sex characteristics or parents may experience a sense of shame about their bodies and the idea of contacting an unknown group of people may be too much for them to handle on top of all the medical information or social adjustments they are contending with. Language barriers and misinformation around “intersex” or diagnostic-specific language might prevent individuals from realising that intersex peer support is a service that is designed for them and is proven to be beneficial. Unfortunately the AISSGA does not



currently have the resourcing to do outreach to locate people with variations of sex characteristics or their parents in health or social spaces. This could be potentially mediated by trusted individuals, such as specialist clinicians, social workers, psychologists, or genetic counsellors, providing current contact details for peer support alongside recommendations, endorsement, and evidence of the of the associated benefit from peer and psychosocial support. The AISSGA does not believe the mechanisms of referral to peer-led support groups is currently working as the AISSGA is not aware of a single referral to our support group from any Australian hospital in the past decade. Unfortunately, members of the AISSGA have reported meeting Australian people with variations of sex characteristics at international intersex support group conferences who have been directed to not contact the AISSGA because we are “too bitter”, presumably as a result of our criticism of practices and condemnation of the harmful, experimental interventions experienced by our members. This is obviously counterproductive and severely limits peer support to online interactions or to those that have the financial capacity to travel internationally to connect with others like themselves. The AISSGA believes that peer support delivered by peer-led intersex organisations should be integrated within multidisciplinary team so that referrals are seamless and meeting others with bodies similar to the individual is normalised within a clinical framework.

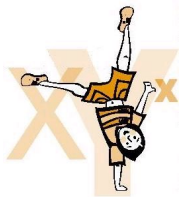
The Darlington Statement acknowledges:

51. We acknowledge that stigma is often the result of misconceptions about intersex which is compounded by a lack of education and awareness.

52. We recognise that the stigmatisation and pathologisation of people born with variations of sex characteristics hinders self-acceptance, access to community, help-seeking, and accessing of services including healthcare.

28. What barriers exist for individuals in accessing support services?

“Lack of awareness. Individuals would expect that professionals and specialists would inform them of all supports available, however it is often a family’s own research and inquiry which broadens their knowledge of supports. Therefore the medical profession is a barrier in this sense.”



“Overcoming differences in language to realise that intersex services are inclusive of all variations in sex characteristics, beyond individual diagnostic-specific groups.”

“Often no one knows more than the people with an intersex variation or their families. They look to support services for help but it’s rarely available.”

“Individuals with intersex variations are often burdened by shame and stigma. They are reluctant to ask for help, even when they desperately need it.”

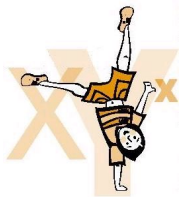
The time of diagnosis for an individual or parent can be intensely stressful and uncertain. Often there is a lot of new and highly specialised medical information to navigate and inconsistencies in data and the range of information available over the internet can be overwhelming. Individuals or parents in this situation may also be navigating social difficulties understanding or talking about the variation as a result of the stigma associated with their variation. Making contact with an unknown person or organisation at this stage may be increasingly difficult. Any tension between medical and social models of intersex may also be difficult to navigate, particularly if the benefits of peers support are not explained by clinicians and recommendations for psychosocial support made as a first tier intervention.

29. How can peer support groups and organisations be adequately resourced and supported?

“By being welcomed as a valued source of information into the medical arena and seeing the unique and important role they can play with supporting people.”

“Government needs to provide funding and health services, need to promote support groups and actively seek our advice.”

“Peer support organisations are invaluable for people with intersex variations. They offer a unique and life-affirming source of advocacy, support and information for people with intersex variations. These organisations are under resourced and led by volunteers, who do a great job but quickly get burned out. With greater funding and resourcing, these organisations could really help the intersex community greatly.”



Peer-led intersex organisations must be funded to provide high-quality peer-support, information, and advocacy services. Hospitals, clinicians, psychologists, counsellors, and social workers must actively promote the benefit of peer support and facilitate referral pathways. Adequate funding must be made available to peer-led intersex organisations in order to provide services to people with variations in sex characteristics and their families, so that these organisations can operate with integrity, independent of other health, government, social service, and LGBTI institutions. Funding must be allocated at both federal and state levels in both health and community budgets as the issues affecting intersex people are intersectional. Service providers that wish to connect their clients or access the resources or services provided by peer-led intersex organisations must be prepared to pay for the associated costs.

The Darlington Statement acknowledges:

27. Intersex-led organisations must be resourced to develop patient rights and human rights toolkits for intersex people and our families to improve access to healthcare, and ensure enjoyment of the highest attainable standard of physical and mental health.

45. We call for public, governmental, and philanthropic support for funded, affirmative peer support.