

Submission

Australian Human Rights Commission Inquiry

People Born with Variations in Sex Characteristics and Medical Interventions

Co - authored by the Executive Director and the Intersex Project Worker of A Gender Agenda (AGA) ACT.

A Gender Agenda (AGA) is a unique community organisation that was established in 2004 and since that time has been actively engaged in increasing public awareness and understanding of sex and gender diversity issues. It is incorporated under the *ACT Associations Incorporation Act 2001* and is registered with the Australian Charities and Not for Profit Commission.

AGA supports intersex, trans and gender diverse communities as well as their families, friends and allies. In addition to training and education, AGA provides advocacy, information and resources and is actively engaged in human rights and law reform. AGA is a vibrant peer based community organisation that holds regular community gatherings and also holds events that are open and inviting to the broader public.

AGA is making a written submission to the *Australian Human Rights Commission Inquiry - People Born with Variations in Sex Characteristics and Medical Interventions*, as we recognise there is an urgent need to support legislative change to protect the human rights of people born with variations of sex characteristics.

AGA's submission talks of themes and collective experiences of it's membership as a way to de-identify and respect anonymity.

AGA works within a human rights framework. We recognise that the health and wellbeing of community members born with variations in sex characteristics is intimately linked to discrimination and the denial of human rights. In particular, we recognise the significant mental health impacts on the intersex community as a result of unnecessary and intrusive medical interventions, as well as prejudice and stigma.

AGA recognises that understanding the lived experiences of people born with variations in sex characteristics is central to protecting their human rights. In September 2017 AGA was fortunate to employ an Intersex Project Worker funded through the Canberra LGBTI Community Consortium (the Consortium). This position has been fundamental in the respectful advances AGA has been able to make in this space, with regards to increasing intersex awareness, building trusting relationships with intersex led organisations and resourcing local community, including Government and non Government organisations.

AGA has been fortunate to hear stories of resilience and to celebrate the lived experiences of people born with variations in sex characteristics. We have also been privileged and saddened to hear of their experiences of confusion and despair, where bodily autonomy was non-existent for them and they now carry wounds of past medical, social and familial traumas.

AGA's work over many years has identified the importance of understanding the impact of the intersectionality of marginalisation and the systemic structures that discriminate and connect marginalised people. These intersectionalities must be made visible in beginning to address the discrimination and long-term physical and psychological implications of harmful and continuing medical practices imposed upon people born with variations in sex characteristics. AGA recognises that many people in our community live under multiple forms of disadvantage which occur due to gender identity, race, age, disability, sexual orientation and people born with variations in sex characteristics are no exception.

AGA identifies a great need for increased specific peer supports to further reach intersex communities, their families and supporters, as well as the provision of accurate and relevant information to assist professionals to work more effectively in this space. AGA recognises that the range of support systems afforded to others in our community, are for many intersex people intangible. Thus leaving many continuing to experience isolation, fear, shame, discrimination and secrecy, which ultimately impacts adversely on a person's social and emotional well-being.

AGA strongly affirms the Darlington Statement (2017) and the Yogyakarta Principles plus 10 (2017) and adheres to these practice guidelines that sit within a human rights framework. AGA primarily uses Intersex as is definitionally set out in the preamble of the Darlington Statement, recognising it as a term grounded in human rights discourse.

AGA recognises that some intersex people identify by more contentious and pathologising terminology but we continue to support the opposition to such terms as laid out in item 6 of the Darlington Statement. AGA also accepts that the term "People Born With Variations In Sex Characteristics" is a literal descriptor that should be able to reconcile individual preferences around terminology.

Understanding Lived Experiences

The lived experiences of Intersex members at AGA are similar to those described in Intersex: Stories and Statistics from Australia (Jones et al, 2015). Within that document approximately two-thirds of intersex people experienced medical intervention related to their intersex variation and a majority of that group reported negative outcomes and a lack of informed consent through the process.

For those who experienced medical intervention as minors, access to medical records was sporadic, limiting knowledge of their diagnosis or what procedures they underwent. A common query when some members first approach AGA, is whether or not their experiences or physical traits are indicative of an intersex experience.

This phenomena in particular is a common cause of distress and confusion. There is an anxiety when it comes to approaching intersex community without formal diagnosis, but often those without diagnosis need the most support through the uncertainty and isolation. This can be exacerbated in circumstances where people do not have familial connections whether due to ostracism or family members being deceased. There are often few other opportunities to find out about intersex status or experience.

Intersex members at AGA who have not been through medical interventions report a system that is often overbearing and predatory. Often choosing to defer or decline surgical intervention which can be seen as an act of non-compliance by the medical profession. The recent Australian survey of 272 adults born with atypical sex characteristics by Jones et al in 2016, found “strong evidence” of “institutionalised shaming and coercive treatment”. Of the study population,

“60% reported receiving medical interventions related to their intersex traits, and a majority experienced negative consequences, not simply medical or sexual: early school leaving (by 18% of respondents compared to a national average of 2%) was coincident with puberty and pubertal medical interventions” (Jones et al, 2016).

Information in medical practices appear to be regularly withheld, and alternative treatments and consequences of intrusive procedures are not always presented without significant prompting. Parents of intersex children report a similar experience where medical intervention is “aggressively” pushed. AGA has had experiences of parents feeling coerced or manipulated into medical interventions as a way of “correction” for their child. Some parents have reported seeking a specific medical procedure or treatment for their child but it was not unusual for multiple other interventions to be put forward, or even misrepresented and deemed necessary by the medical practitioner/s.

While many intersex members report negative experiences with the medical community, experiences within the intersex community are universally positive. Many members speak of a sense of isolation or shame before contacting AGA, reporting that connection to community has helped with self-acceptance. Perhaps most encouraging is that intersex members who have not gone through medical intervention report feeling more confident in advocating for themselves against medical intervention. Similarly parents report feeling more certain in their choices to not pursue intervention, and are more open and confident to encourage and invite earlier discussions about intersex with their child.

AGA strongly advocates for the need for more funding for peer support and systemic advocacy by intersex led organisations. AGA sees huge gaps in service provision for individual, parental and family counselling that could enable families and individuals to navigate difficulties with more informed resources and with appropriate support. Thus reducing stress, anxiety, further enabling parents to make decisions that are not based on social and cultural rationals.

Consent

While recognising that those who have reached an age of majority are legally capable of making decisions for themselves, AGA recognises a number of ways consent can be compromised by the power dynamic between doctor and patient.

When alternatives to medical interventions are not presented to the patient, the patient is only able to consent to one course of action, which is often not necessarily producing the best possible outcome for that person. Poor outcomes and consequences do not always seem to be openly disclosed based on the perceived necessity of interventions, therefore putting into question the legitimacy of informed consent in such circumstances. This consistently appears to be the experiences of intersex people with lived experiences who are AGA members. These experiences are also supported by research such as, “Intersex: Stories and Statistics From Australia” (Jones et al, 2015).

One such area for example, that has been of negligence to intersex people is medical photography. While the person in the photographs is seen as “an interesting case or unusual finding” it is another form of medical intervention. “The clinicians reap any benefits and little attention is paid to the person within the photograph” (Creighton et al. 2001).

To our knowledge there is no substantial data on the impacts that being photographed may have had on intersex people or on their families. Photographs of this nature however are particularly invasive and harrowing for intersex patients, “who are classically photographed naked”(Creighton et al. 2001).

Doctors must care for their patients and make their well being a priority. Doctors as with all caring professions, must adhere to privacy, respect and protect confidentiality. They need to avoid abusing their position and listen to patients and respect their views. Creighton et al. (2001), reported that feedback from patients at two UK adult intersex clinics highlighted major concerns over possible long-term psychological damage attributable to clinical photography.

Guidelines for consent must be widely available. There maybe times when photos for personal medical files may be helpful and should be taken by a trained medical photographer in a suitable environment. However obtaining images of patients with out their full informed consent is unethical and may have serious consequences, not only causing distress and suffering but also compromising the relationships for the patient to access necessary medical supports in the future. Creighton (2001) noted that most of the photos obtained to date however have been for

medical journals, teaching and conference presentations. It is essential that there are processes that ensure it is clear to the patient what the purpose of the photograph is for when obtaining consent. There are also often multiple photographs taken of one person that can be in circulation, used by different healthcare professionals to view, which also raises ethical and moral challenges. People born with variations in sex characteristics is in itself highly personal in nature, but this has them being exposed to invasive examinations and procedures to which most people are never subjected.

Photography highlights only one of the many serious issues faced by intersex people in medical systems. There is strong evidence for the need to develop standards of good practice based on a human rights framework to be implemented in medical settings, that is capable of addressing the lifetime needs of intersex people.

This reinforces why AGA supports many of the reforms highlighted in the Darlington Statement. It is necessary for advisory bodies to develop appropriate human rights based, lifetime, intersex standards of care. These standards must be informed by the lived experiences of intersex people and enforced with transparent oversight mechanisms. If it is found that such frameworks are not protecting the best interests of intersex people, AGA supports implementation of legislative frameworks to protect these rights.

As well as a shortage of referral pathways into intersex-competent services, specialists, or peer support capable of producing better outcomes for intersex people, the Darlington Statement also recognises the need for “patient right tool kits” to be developed that can support intersex people as they navigate healthcare services.

AGA recognises a lack of robust and consistent care for intersex people as a barrier to personal consent. Continuous care is undermined by a lack of adequate clinical transition pathways from paediatric to adult services and a shortfall of organised multidisciplinary care.

Consent for Children

AGA recognises the issue of non-consensual medical intervention on minors to be a key priority, based on the continuing damage and trauma that has been inflicted on those with intersex variation. In particular AGA acknowledges the historical context in which medical institutions have caused systemic harm to intersex people, including forced sterilisation, unconsented surgical alteration, and other coerced procedures. It is important to also acknowledge these medical procedures often have long term physical and psychological implications. The weight of these consequences is such that, to strip a person’s right to make decisions denies them essential autonomy, regardless of intent or outcome.

AGA wishes to note the aggressive push for medical interventions that have been experienced and shared by our intersex members. As stated previously, consequences and alternatives are

often not fully explored before commitment to medical intervention is expected. Individuals are not given enough direct information to understand what decisions are being made. Perhaps most egregious is a practice of bundling more than one procedure together, or misrepresenting one medical intervention as reliant on another. The experiences of AGA's membership is a pattern of blame and coercion that claims no unconsented medical procedures are happening. However AGA asserts that without transparent policies and statistics, this claim is unevidenced.

It is because of this environment that AGA strongly urges the immediate criminalisation of deferrable medical intervention on minors. Medical intervention must not take place until an individual reaches age of majority, or can establish competency. Legislation must take into account the likelihood of parents taking their children into jurisdictions where medical intervention continues to be legal. This legislation should not be understood in terms of taking rights away from intersex people or their guardians / carers, but protecting the right to bodily autonomy as laid out in the Darlington Statement, Yogyakarta Principles, and Universal Declaration of Human Rights (1948).

It is therefore important to note that AGA respects parents, carers, and families need some degree of discretion when it comes to the autonomy of a child. However these rights must not override the ability of a child to make decisions about their own body later on in life. AGA recognises a right to privacy, a right to support, a right to information, a right to raise a child as they see fit, and a right to act in the best interests of the child on matters of healthcare. These rights can be preserved while maintaining that an adult does not have the right to permanently modify a child's body. Parents who have engaged with AGA understand the importance of bodily autonomy and informed consent, and are more likely to try and stall medical procedures on behalf of the child.

There is evidenced information of harm from early surgical practices that came out in the Submission to the Senate Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia, Regarding the Management of Children with Disorders of Sex Development. A submission by the Australasian Paediatric Endocrine Group identified "particular concern regarding sexual function and sensation" as a consequence of recommended surgeries (Hewitt, Warne & Hofman, 2013).

Understanding Rationales for Intervention

Where a decision on behalf of a person who is unable to consent to an intervention that would result in a permanent bodily change, AGA supports an independent, effective human rights-based oversight procedure to determine individual cases involving those born with intersex variations and who are unable to consent to treatment. AGA also advocates that a legal definition of medical necessity must be established so that it is not at the discretion of a medical community that has propagated medical violence against intersex people.

AGA recognises that preserving bodily autonomy is about ensuring that the individual is able to make as many choices about their own body as possible. AGA strongly supports meaningful participation and consultation with intersex people in all issues and policies that affect intersex people. Intersex people need to be respected as the experts in their lives and that they are the experts in understanding the long term effects of medicalisation and medical interventions.

AGA maintains there is no demonstrable psychosocial benefit from medical intervention, and that an alleviation of experiences of shame, stigma, and discrimination can occur through education, peer support, and visibility efforts focused on bodily diversity. The definition of “deferrable” treatment must be grounded in what is life preserving and what is not, and recognise that permanent physical alteration carries lifelong consequences. Decisions made about quality of life should be reversible, or take into account options later on in life.

It is an ideal place in this submission to refer to a different learning medium to highlight the importance of why change in this space needs to occur as a priority.

AGA therefore makes reference to an award winning documentary called “Intersexion” (2011, <https://www.intersexionfilm.com>) which is about intersex people by intersex people . This is a documentary directed by Grant Lahood with presenter Mani Bruce Mitchell, who is New Zealand’s first ‘out’ intersex person. AGA highly recommends this documentary as it aims to “set the record straight”.

It talks about intersex variations, some of which are obvious at birth whilst others are only diagnosed later in life, if at all. It talks about the surgeries still commonly performed on intersex babies with the purported aim of helping them ‘fit in’, often leaving them devoid of sexual sensation for the rest of their lives. This “documentary will show everyone that the ‘shame and secrecy’ model hasn’t worked – and that intersex children can grow up to make informed choices about their own bodies (J.Kermode, 2013, review).

AGA suggests this documentary as essential for all people who are serious about supporting and championing for legislation change for those born with intersex variations and for their friends and families. The documentary is confronting and “ anyone who has supported campaigns against female genital mutilation will be left wondering why countries that condemn it still allow this sort of thing to go on. Others will wonder simply how such a big issue has been hidden for so long” (Kermode, 2013, review).

AGA position affirms the Darlington Statement (2017) and the Yogyakarta Principles plus 10 (2017) and supports the practicing guidelines that sit within a human rights framework.

Regulating Interventions

AGA is not aware of any consistent medical frameworks in Australia that takes into account the human rights of intersex persons. National Guidelines need to be established for a range of pivotal reasons and they must be set within a human rights framework that is capable of addressing the lifetime needs of intersex people..

Since 2013 there has been a global move towards the legal recognition of intersex variations with Australia, Germany and Malta all using different techniques to construct and regulate intersex embodiment. Garland and Travis (2018) completed research that compared and problematised these differing legal approaches. Their document presents the findings of the first qualitative study of the relationship between intersex embodied people and law. The research revealed that many of the approaches are grounded in ideas of formal equality that lead to the entrenchment of vulnerability and fail to build resilience for the intersex community (Garland and Travis, 2018).

Their study highlights the importance of engagement with the intersex community, as this has enabled a more contextual account of substantive equality, which facilitates new approaches to law and social justice. Their qualitative study revealed that “prevention of non-therapeutic medical interventions on the bodies of children was understood to be the key method to achieving equality for intersex embodied people” (Garland & Travis, 2018).

Garland and Travis state while it is fundamental for intersex-led legislative reform, they recognise that such an approach also warrants support through a mixture of formal and substantive equality methods such as anti-discrimination law, education and enforcement procedures.

Legal prohibition is necessitated by a continued lack of transparency and accountability. Reflecting item 7 of the Darlington Statement, AGA agrees there is a need 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.

Evidence of Outcomes

As results of intersex people being a minority, and due to the history of secrecy surrounding intersex diagnosis, statistically representative data on intersex people is lacking.

Research is needed on the lived experience of intersex people who have not undergone multiple surgeries in childhood, to better gauge the physical and social effect of the conditions themselves, apart from problems related to medical interventions. There is a lack of longitudinal studies on the psychological and physical impact of varying treatment models on intersex

people. As a consequence, many doctors, parents and individuals make decisions about medical care that are not evidence-based.

AGA has great concern for the lack of data and transparency that comes from medical institutions, which is also reflected in the Darlington Statement (2017). AGA supports the regular public disclosure of accurate summary data on all medical interventions, and disclosure of historical data.

AGA therefore supports the call for ethical research, including clinical, sociological and psychological research, led by community input. Clinical research, including longitudinal research, requires true, non-medicalised controls. It is only with evidence and research that we can build the frameworks and guidelines necessary to create optimal outcomes for intersex people, as well as find sustainable ways to support intersex people in our communities.

Privacy

There is a need to examine the importance of the meaning of privacy to intersex people before understanding the ways this privacy is exploited against the interests of intersex people. The Darlington Statement recognises that,

“stigma is often the result of misconceptions about intersex which is compounded by a lack of education and awareness.” (51, 2017) and 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”* (52, 2017) as well as *“high rates of early school leaving, poverty, self-harm and suicidality”* (53, 2017).

The need for privacy is the need for safety and security, to control disclosure, and to have access to all relevant information. In general patients have a right to access their own personal information and this should not be any different for intersex people

When intersex people are treated as a medical curiosity, this need for privacy is regularly ignored. Those who have experienced medical intervention often recount times where they were put on display, subject to needlessly invasive observation, or used as a training exercise for student doctors. However it is the practice of taking medical photographs that demonstrates the most egregious sense of entitlement to intersex bodies. AGA is not aware of any circumstances where such violations of privacy produced a better outcome for the individual, and as such strongly condemns these practices. In line with the Darlington Statement, *“Children with intersex variations should never be subjected to medical photography and display”* (32, 2017).

Experiences like above are in stark contrast to the lack of transparency and access when it comes to individuals own medical records, particularly paediatric records. It is not at all uncommon for someone approaching the intersex community at AGA to be unsure of their intersex status. Instead they are only able to piece together surgical scars and vague memories

to realise similarities with the public accounts of other intersex people. For many of these people paediatric records are long lost, unrecoverable, or deliberately withheld. If there is no further information available from their family, there is no certainty and no safety. Capacity to consent to further medical procedures is compromised.

AGA therefore supports the right of intersex people to have full access to medical records so that this persistent experience of stolen and lost information cannot continue. In line with the Darlington Statement item 34, "*Paediatric hospital records should be kept indefinitely. The medical records of people with whole-of-life medical issues should be kept indefinitely*".

As research has shown many intersex people suffer from the physical and mental effects of infant and childhood surgeries, as well as other 'normalising' treatments, medical photography, lack of counselling for individuals, parents and the family, and lack of transparency from doctors and other healthcare providers. It is of vital importance that privacy considerations are implemented and absorbed at all levels.

Accessing Services and Support.

AGA endorses the fundamental importance of peer support networks that help create a safe, caring and inclusive space for minority groups to connect with peers. These connections can also increase a sense of belonging and positive mental health by fostering meaningful relationships.

Peer support can provide vital space for intersex people to feel unconditionally welcomed and accepted. AGA is aware that Intersex people can thrive when they have access to peer support, and this has been an important strategic priority for the organisation to ensure this support is available for intersex people, as well as those who support intersex people in their lives.

It is the importance of this connection to community that makes it worth exploring the barriers intersex people can encounter in accessing support services. Often there is a geographical barrier, with some AGA members needing to travel from interstate rural or remote communities for opportunities to meet others. Sometimes intersex support fails to be distanced enough from political activism to feel like a safe space to explore intersex identity on a more individualistic basis.

There can also be a hesitancy in connecting to community where a sense of shame or secrecy becomes a barrier to accepting supports. This can be due to association with broader LGBTIQ+ community, or differences in language, understanding, and cultural background. Particularly AGA recognises that some groups reject the term intersex itself, or only choose to understand intersex in a medical context.

AGA therefore recognises the importance for intersex support to be run by those with lived experience to build trust with such communities, and calls for organisations led by intersex lived experience to be resourced to support other intersex people. We strongly acknowledge and recognise that intersex people are the experts in their lives and are also the experts in understanding the long term effects of medicalisation and medical interventions.

AGA has worked at trying to build respectful and trusting relationships within the intersex communities and we acknowledge this takes time and great care to ensure safety and confidentiality. For organisations and services to be able to support intersex people they need to ensure their organisations are welcoming and friendly and recognise that it does take time to build trusting relationships.

Organisations also need to take the time to understand the historical injustices and injuries suffered by intersex people, not only through the medical systems, but as a result of isolation, lack of bodily autonomy and discrimination. Services and allies need to understand specialist care for intersex health and that intersex status is about variations of biology, not gender identity or sexual orientation.

AGA acknowledges that LGBTIQ organisations can absorb a lot of funding and resources without adequate focus on intersex issues. Resources intended for intersex support must be distributed on a basis of engagement with lived experience, be they intersex led, or creating direct opportunities for engagement with intersex people.

Reflecting these values, AGA has prioritised increasing intersex resources and training that is informed by lived experience, and that encourages better widespread community engagement and elevated understanding. It is by creating paid opportunities for lived experience that we can ensure intersex peer support and activism is sustainable, accessible, and of the highest quality.

Well coordinated multidisciplinary care teams, established with the expertise of intersex voices and respectful consultation, could enable far better outcomes for intersex people. These must operate in line with transparent, human rights-based standards of care as per the Darlington Statement(23, 2017). This would enable professionals from a range of disciplines with different but complementary skills, knowledge and experience working together to deliver comprehensive healthcare when required. This would be aimed at providing the best possible outcome for the social, physical and psychosocial needs of intersex people and for their loved ones.

Support can be afforded by professionals with specialist knowledge and skills in the best outcome of care for intersex people. This can also enable data collection, and improved equality of outcomes as a result of better understanding and awareness of the needs of intersex people. It can also support adherence to national and local clinical guidelines and promote opportunities for education/professional development of team members .

Closing

Becoming accountable to the intersex community and their loved ones requires that we strive to privilege their experiences, needs and feelings and listen carefully to those who have been subjected to discrimination, invasive medical procedures and abuse and who have been robbed of bodily autonomy.

Becoming accountable requires commitment to seeking to understand the impact and effects of the trauma history and the repeated inhumane interventions many intersex people have been subjected to over time. We need to listen to their experiences in order to bring about understandings to inform and support a way forward. This understanding is obtained through ongoing research, reading, viewing and listening to accounts of the impact and effects of imposed practices on individuals, families and communities.

People born with variations in sex characteristics are a minority group who have been subjected to laws, unwarranted procedures and interventions by the majority. It is therefore important for champions and allies to always recognise the place of intersex people's quest and their advocacy endeavours over time.

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