

National Dialogue on the Protection and Promotion of the Human Rights of INTERSEX PEOPLE



Foreword

Firstly, we would like to take this moment to honour Sally Gross, an anti-apartheid and intersex activist who founded Intersex South Africa. Sally, who worked tirelessly to ensure visibility and redress of the ongoing human rights violations of intersex people in South Africa, secured the first known mention, globally, of intersex in national law through the inclusion of “intersex” within the definition of “sex” in the *Promotion of Equality and Prevention of Unfair Discrimination Act*, which governs the judicial interpretation of the *Equality Clause*. She subsequently helped to draft legislation on the *Alteration of Sex Descriptors and Sex Status Act 49 of 2003*, which allows intersex citizens to change their sex descriptors on their identification documents.

Almost four years after Sally’s passing, we continue to hear intersex South Africans recount experiences of violations in all spheres of life; within their families, within rural and traditional settings, within medical settings, in schools and in prisons. We honour them as well, for daring to be visible in the face of pervasive ignorance, violence, discrimination and stigma. We honour them for telling and retelling their stories, for refusing to be silenced, for being prepared to stand up for the next generation of intersex children. We remember the words of former President Nelson Mandela, when he said, “there can be no keener revelation of a society’s soul than the way in which it treats its children”, and invite you to commit to working together to end intersex infanticide and genital mutilation.

We are inspired and encouraged by the victories that intersex activists everywhere have managed to secure despite seemingly insurmountable odds. As we release this report, we invite you to interrogate the current legislative protections we have, and the continuing human rights violations against intersex people, and to reflect on our collective responsibility today. How do we make manifest constitutionally guaranteed rights in the lives of the average intersex person? What gaps exist that we need to address legislatively? What are the issues that need a more nuanced approach? What is our own personal role?

The National Report reflects some of the conversations that took place on 11 December 2017. We release it in the hope that it will increase awareness of issues facing the intersex community, and stimulate civil society, parents, and other actors to urgently address violations with the urgency they deserve, working hand in hand with intersex activists to co-create solutions. We hope this moment also marks the beginning of a joint sustained effort with government to address the human rights violations against intersex people, and we pledge to continue this work until every intersex child and adult is free from violence and harm based on their sex characteristics.

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1 Iranti Director Jabulani Pereira, Deputy Minister of Justice John Jeffreys, Deputy Director of the Foundation for Human Rights Hanif Vally, Crystal Hendricks from Intersex South Africa and Joshua Sehoole, Iranti's Advocacy Manager, at the National Engagement. Photo by: Gugu Mandla ©Iranti

KEYNOTE ADDRESS

**by the Deputy Minister of Justice and Constitutional Development
the Hon JH Jeffery, MP, at the National Engagement on the Promotion and
Protection of the Human Rights of Intersex Persons, at the Protea Hotel Parktonian**

11 December 2017

The UN's Free and Equal Campaign tell us that up to 1,7% of the world's population are intersex – that's roughly the same percentage of the population as those who have red hair. That means that up to two million babies are born every year with intersex traits – intersex traits, that research tells us, can take at least 40 different congenital variations.

When I watched one of Intersex South Africa's [videos](#) I was particularly struck by some of the observations and experiences. Francina Phiri said:

"The change I would like to see in South Africa is for intersex people to be recognised and not isolated."

Babalwu Mtshawu, speaking about parents of intersex children:

"They need to get as much information about their child's condition before making any decision. And they do not have to make decisions for their children."

And Tebogo Makwati said:

"The system itself doesn't give room for such conversations to happen which is a challenge and leads to a lot of misinformed decisions being made by parents."

Francina, on what we can do to raise awareness, said:

"I would like to have a campaign where school children are educated about intersex people."

Crystal Hendricks summed it up well when she said:

"We have accepted ourselves and we are just waiting for South Africa to come to the party."

That's why we are here today. Today's meeting is exactly that – a step closer to us all coming to the party.

There is no doubt that intersex people face appalling stigmatization and discrimination, as children and as adults. In certain regions of the world when an intersex variation is visible at birth it may result in infanticide, abandonment and the stigmatization of families. In addition, what used to be called "normalising" surgery, to make very young children look more typically male or female, has been standard practice for decades. Today, we know it is intersex genital mutilation.

IGM practices have been described as non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical treatments that would not be considered for so-called "normal" children, without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs.

In a 2016 interview in the UK's The Guardian parents talk of their experiences after the birth of their intersex children. They talk of a lack of knowledge and peer support. They speak of being pressured, nearly coerced, into surgery and being led to believe that they are acting the best interests of their child.

One said:

"One of the doctors described it to us as your baby being born with an extra nose on their face. Would you leave it there, or would you fix it?"

Another said:

"We were of a mind to leave all treatment for as long as possible, so that we could involve him. No one ever asked us, are you OK with this? It was just, this is what we're going to do. Abnormality, disorder, problem – these are all the words that are thrown at you."

So what is the world doing about it? The United Nations, as part of the Free and Equal Campaign, has urged states;

- To prohibit medically unnecessary surgery and procedures on the sex characteristics of intersex children, protect their physical integrity and respect their autonomy.
- To ensure that intersex people and their families receive adequate counselling and support, including from peers.
- To prohibit discrimination on the basis of intersex traits, characteristics or status, including in education, health care, employment, sports and access to public services, and address such discrimination through relevant anti-discrimination initiatives.
- To ensure that human rights violations against intersex people are investigated and alleged perpetrators prosecuted, and that victims of such violations have access to effective remedy, including redress and compensation.
- To enact laws to provide for facilitated procedures to amend sex markers on the birth certificates and official documents of intersex people.
- To provide health care personnel with training on the health needs and human rights of intersex people and the appropriate advice and care to give to parents and intersex children, being respectful of the intersex person's autonomy, physical integrity and sex characteristics.
- To ensure that intersex people and organizations are consulted and participate in the development of research, legislation and policies that impact on their rights, and
- National human rights bodies should research and monitor the human rights situation of intersex people.

In 2013, Australia adopted the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act – the first law to include intersex status as a stand-alone prohibited ground of discrimination. The Australian Senate has also carried out an official inquiry into the involuntary or coerced sterilization of intersex people.

In 2015, Malta adopted the Gender Identity, Gender Expression and Sex Characteristics Act – the first law to prohibit surgery and treatment on the sex characteristics of minors without informed consent. The Act states that it is unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent: Provided that such sex assignment treatment and/or surgical intervention on the sex characteristics of the minor shall be conducted if the **minor** gives informed consent through the person exercising parental authority or the tutor of the minor. In exceptional circumstances treatment may be affected once agreement is reached between an interdisciplinary team of healthcare professionals and the persons exercising parental authority over the minor. The Maltese Act also specifically makes mention of a person's "self-determined gender identity".

The Chilean government recently issued guidelines to doctors opposing corrective surgery, allowing them to refuse a parent and not face legal consequences and the parents of an adopted intersex boy are currently taking legal action against doctors and social services in South Carolina for performing surgery which was not medically necessary. In 2013, Germany became the first European country to allow parents to register newborns as neither female nor male, if the child was born with characteristics of both sexes. Last month Germany's constitutional court ruled that binary gender designations violated the right to privacy. The court ruled that the current system, which does not provide for a third option - besides the entries female or male - is unconstitutional. The Court gave the legislature until the end of next year to either allow the introduction of a third gender category or dispense with gender in public documents altogether.



2 Keynote speaker Deputy minister of Department of Justice John Jeffrey welcomed the delegates at the National Intersex Meeting. Photo by: Lungile Maquba ©Irant

In September last year, at the 73rd Session of the United Nations' Committee of the Rights of the Child, the Committee considered the second periodic report of South Africa and adopted the present concluding observations on 30 September 2016. The Committee expressed its concern at the high prevalence of harmful practices in South Africa, which include child and forced marriage, virginity testing, witchcraft, female genital mutilation, polygamy, violent or harmful initiation rites and intersex genital mutilation. The Committee also mentioned ukuthwala. The Committee urged South Africa to guarantee the bodily integrity, autonomy and self-determination of all children, including intersex children, by avoiding unnecessary medical or surgical treatment during infancy and childhood. In our reply to the Committee the South African delegation acknowledged that we are aware of the need to stop the practice of intersex genital mutilation. In his address to the Committee, Zane Dangor from the Department of Social Development, said that as a government we do recognise that intersex traits are sex characteristics and not medical conditions, but at the same time we recognise that there are still practices where newborns and young children are having surgeries performed on them which are harmful.

Intersex rights activists commended South Africa as the very first state to officially recognise the essentially harmful practices on intersex children at the UN. Mr Dangor continued to say that –

“So we are now beginning a process in its early stages, to acknowledging that it's happening, to engage with universities, particularly the university children's clinics and other medical practitioners around the fact that this is not a medical condition, that surgeries performed at a very young stage are harmful and that it needs to stop. So we will be engaging with all the relevant stakeholders on that.”

Today's meeting is an example of this vital engagement with stakeholders.

From a legislative point of view, we have the Promotion of Equality and Prevention of Unfair Discrimination Act, 2000, where we inserted the definition of “intersex” in 2005, under the definition of “sex”, as one of the prohibited grounds upon which one may not be discriminated against - the first country in the world to do so. We have the Alternation of Sex Description and Sex Status Act, 2003. I can also advise that intersex is also specifically mentioned in our new Prevention and Combating of Hate Crimes and Hate Speech Bill, so as to criminalize any hate crimes or hate speech aimed at intersex persons. With regards to possible new legislation

to prohibit surgery on intersex children, this is something that government and relevant stakeholders will have to engage on further. I will, in any event, undertake to raise the issue with the Ministries of Health, Home Affairs and Social Development and this is also something that can be placed on the ongoing agenda of the National Task Team on LGBTI Rights.

In the meantime, in addition to raising awareness, more thought could be given to ways of informing and empowering parents of intersex newborns.

As intersex activist Hida Viloria writes -

"My goal was that a parent who might have recently had an intersex child or have one in the future would see my interview and think, "Oh, being intersex is fine and this person has been able to grow up happy and successful and feel good about themselves. There's no reason I have to cut up my child's body in this non-consensual, irreversible way. I'll just let them grow up and decide later on if they want to change anything about their body, the way most people get to decide."

There are many ways of raising awareness and specifically empowering parents. For example, the Department of Justice and Constitutional Development has a radio programme, *Let's Talk Justice*, which broadcasts to 65 community radio stations countrywide has been such a success that it is already in its third season. In the programme, a different justice related topic is covered every week and it is broadcast at 18h05 on Tuesdays and Thursdays. Perhaps an episode, focusing specifically on intersex issues, is something that can be explored.

Consideration should also be given to one of the Chapter 9 institutions, perhaps the South African Human Rights Commission or the Commission for Gender Equality, or both, to conduct public hearings and/or an investigation. Ultimately the message we want to get it out is best said by Babalwa Mtshawu, when she said in the video clip:

"There is nothing wrong with us. We are human beings like everybody else and we are just trying to live a normal life."

I wish you the best today's engagement - may it be the first of many to come.

I thank you.

NATIONAL INTERSEX MEETING REPORT

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KEYWORDS

Atypical sex characteristics – another term used to describe intersex traits.

Concealed method of care – is a medical intervention method which emphasises the nurturing of intersex children into a fixed gender/sex through early surgical and hormonal intervention, secrecy and parental reassurance. The concealed care method developed through the theoretical work of Dr Money who theorised gender as neutral at birth, and that healthy gender development is dependent on the appearance of fixed/unambiguous male/female genitals.

Intersex people – are persons born with sex characteristics, such as chromosomes, gonads, or genitals that, according to the UN Office of the High Commissioner for Human Rights, do not fit typical binary notions of male or female bodies. Intersex is an umbrella term used to describe a wide range of natural bodily variations. In some cases, intersex traits are visible at birth while in others, they are not apparent until puberty. Some chromosomal intersex variations may not be physically apparent at all.

Informed consent – permission granted in full knowledge of the possible consequences, typically that which is given by a patient/guardian for treatment with awareness of the potential risks and benefits of a procedure. The South African Sterilization Act defines consent as;

“consent given freely and voluntarily without any inducement and may only be given if the person giving it has

- a. *been given clear explanation and adequate description of the*
 - i. *proposed plan of the procedure; and*
 - ii. *consequences, risks and the reversible or irreversible nature of the sterilisation procedure;*
- b. *been given advice that the consent may be withdrawn any time before the treatment;*
and
- c. *signed the prescribed consent form*

Intersex genital mutilation (IGM) – cosmetic surgeries performed on intersex infants/babies. These surgeries are often coerced, uninformed and unnecessary aimed at altering the sexual and reproductive anatomy to suit social classifications of male and female. The surgeries are performed without the informed consent of the minor (and in some cases, without that of their parents). IGM surgeries are irreversible causing permanent infertility, permanent pain, incontinence, loss of sexual sensation, and lifelong mental suffering, including depression. IGM may include other harmful medical interventions/treatments which may not be considered necessary for “normal” children without evidence of benefit for the child concern but justified by societal and/or religious standards.

I. Introduction

Statistics suggest that between one in one thousand to one in two thousand people globally are born intersex. To put it in terms far more graspable, the upper estimation of the number of intersex people in the world is similar to that of redheads. Some statistics suggest the number for South Africa may be much higher, with an estimate of one in five hundred, or as high as one in two hundred.

South Africa, thanks mainly to the pioneering work of Intersex activist and founder of *Intersex South Africa* (ISSA) Sally Gross, was the first country in the world to explicitly include intersex people within the definition of 'sex' in its anti-discrimination laws. Along with this the *Alteration of Sex Description and Sex Status Act 49 of 2003* is arguably the cornerstone of legal recognition for transgender and intersex people in the country. Indeed any doubts that South African law would not see the provisions of the Constitution as intersex inclusive were put to rest when Gross submitted amendments to the *Judicial Matters Amendments Act* which saw the *Promotion of Equality Act* and *Prevention of Unfair Discrimination Act 4 of 2000* amended at Section 1 to state the following:

16. Section 1 of the *Promotion of Equality and Prevention of Unfair Discrimination Act, 2000*, is hereby amended— (a) by the insertion in subsection (1) after the definition of "HIV/AIDS status" of the following definition: " 'intersex' means a congenital sexual differentiation which is atypical, to whatever degree;"; and (b) by the insertion in subsection (1) after the definition of "sector" of the following definition: " 'sex' includes intersex;".

Regardless of these protections the response of healthcare professionals broadly as noted in several studies suggests that as infants, intersex people in South Africa, continue to be subjected to 'medically sanctioned' non-consensual coercive genital surgery, more commonly known globally as intersex genital mutilation (IGM). *Organisation Intersex International*, a global network of intersex organisations, defines intersex genital mutilation as "conducted on new born babies when their external genitals do not look 'normal' enough to pass unambiguously as male or female. Surgery is carried out upon the genitals of new born babies, infants and children for cultural or religious reasons [where] medical needs are also cited as a justification for the surgery, but the evidence of actual need is slim at best."

Worldwide intersex people, from birth, face stigmatisation and discrimination. In Africa and Asia in particular concern for intersex people also centres on infanticide, abandonment and stigmatisation of and by families. Due to the nature of medical treatment, intersex traits are often treated as shameful perpetuating the idea that they should remain unspoken. For many intersex people though, their bodies are not a medical condition. South African intersex activist Crystal Hendricks believes that the continued pathologisation of intersex infants, regardless of international calls by the UN and WHO to end IGM, perpetuates issues regarding infanticide and broader societal stigma. Indeed, South Africa is one among a host of countries internationally, regardless of constitutional protections, continues to practice IGM.

Known as the 'I' in LGBTI intersex people are often included at least linguistically in campaigns for gender and sexual orientation rights. But intersex activists stress that there is a difference for them in that "they face discrimination due to biological differences, and intersex people can be heterosexual, or same-sex attracted, or might transition, just like anyone else". Intersex people are at pains to stress that they are not a novel gender or sex classification and while many intersex people experience similar discrimination to transgender people their concerns are different. Moreover, while intersex people benefit from "actions to reduce gender inequality and the stigmatisation of gender non-conformity...intersex people only share with each other an experience of being born with stigmatised atypical sex characteristics".

As noted, as a rule, Western medicine treats intersex individuals as ill or abnormal and attempts to 'treat' this by assigning an intersex person one of two sex/genders as quickly as possible in order to conceal the intersex body. This concealment is often done through surgical and medical means. Notably "interventions are rarely life-sustaining measures in a narrow sense, since intersex individuals generally have completely healthy bodies". These invasive procedures are justified by societal and cultural norms and belief. It is widely held that due to IGM and the pathologised and stigmatised nature of being born intersex the discrimination that intersex individuals endure also remains invisible. The intersex movement more broadly is of the opinion that

IGM qualifies as an on-going human rights violation. Several UN Committees, the World Health Organisation (WHO), the UN Special Rapporteur on Torture and the UN High Commissioner for Human Rights (UNHCHR) have all criticised IGM as a serious human rights violation. Following representations to the United Nations Committee of the Rights of the Child (CRC) by Iranti, the Aids and Rights Alliance for Southern Africa, Gender Dynamix, the Legal Resources Centre, as well as a shadow report by international NGO StopIGM.org, attention was drawn to the continuing violations of the human rights of intersex persons. The CRC made the following binding recommendations to the state;

- (d) *To guarantee the bodily integrity, autonomy and self-determination of all children, including intersex children, by avoiding unnecessary medical and surgical treatment during infancy and childhood.*
- (e) *To build capacity of all professional groups working for and with children to prevent, identify and respond to incidents of harmful practices and to eliminate customary practices and rituals which are detrimental to children.*

The following is a report on the outcomes, themes and issues of a multi-stakeholder National Intersex engagement meeting held by Intersex South Africa, the Foundation for Human Rights, the Department of Justice and Constitutional Development and Iranti-org.

II. The Global Discussion: FGM, IGM and Circumcision

The surgical alteration of an infant or child's genitals is treated very differently dependant on sex and gender and the society in which this alteration takes place. Intersex births are primarily treated as a medical emergency, in the majority of cases, the doctor assigns the child a sex - either male or female - and operates accordingly to make it so. There is a growing global resistance this kind of 'normalising' intervention. In the case of assigned female children or children born with vaginas, it is mostly considered, particularly in the Global North, an intolerable violation to undertake any form of non-therapeutic genital cutting no matter how minor. This type of intervention is also often framed as child abuse and/or a form of gender-based violence. Arguments in support of this form of cutting are dismissed as inadequate on moral grounds or fallacious on religious grounds. This type of intervention is branded Female Genital Mutilation (FGM) or, euphemistically, Female Genital Circumcision (FGC). In many countries, FGM is, actually, illegal although this does not stop the practice. In fact, some research suggests that the legal injunction against it has only made the practice more dangerous by driving it underground.

Male circumcision or male genital cutting, targeting those assigned male at birth or people with penises, is treated entirely differently from either intersex or female genital cutting. Though there is apparent overlap in the three practices regarding physical invasiveness and possible adverse consequences, male circumcision is viewed far more favourably and unproblematically globally. There is almost nowhere in the world that male circumcision is prohibited, in many cases, it is not even regulated, and in some cases, it is actively promoted as "a form of partial prophylaxis against certain diseases". FGM and male circumcision have significant overlap in practice, purpose and cultural meaning. Brian Earp goes so far as to argue that in some cases forms of FGM "including forms that are legally prohibited in Western societies, are demonstrably less harmful than the most prevalent forms of male circumcision". Regardless, when the two are spoken of "as being potentially comparable, the reaction is often incredulous."

The debate regarding FGM is profoundly polarising between those who see it as traditional and cultural and those who view it as an abuse of women's rights. In the Global North FGM is mostly frowned upon and considered a barbarous crime. It is often used as a marker of the progressive nature of Western nations versus their African, Asian and Arab counterparts. Notably, this seems to apply solely to FGM whereas attitudes towards male circumcision and indeed even intersex surgeries are far more positive. Indeed, for many, this approach in the Global North is considered hypocritical given their perceived failure "to challenge other unnecessary surgical interventions — such as male circumcision or cosmetic surgery — in their own communities and cultures".

For intersex infants “factors are not equally weighted, and interpretation of the “best” assignment has been influenced by heteronormative assumptions and sex stereotypes – that is, assumptions that the child will grow up to be heterosexual and to desire “traditional” (penile-vaginal) intercourse”. In most cases, this decision is based on whether the infant has a “worthy penis”. Commentators have begun to agree that the recent shift in rhetoric on IGM from world bodies such as the UN and WHO has begun to align IGM with FGM as a form of inexcusable morally and ethically unjustifiable intervention. Activists, particularly in the Global North, have been at pains to draw the parallels between FGM and IGM, “with both types of procedures giving rise to lifelong physical and psychological suffering, and neither type conferring any medical benefit”. Naturally, given the apparent divide, between the Global North and Africa/Asia over these issues this shift has happened at significant risk to the global anti-IGM campaign.

FGM is a complicated issue for the Global North in that in some senses it has become the litmus test “of whether there are absolute rights and wrongs that are the basis of international human rights standards, or whether universalism is ‘barely disguised ethnocentrism’”. African and Asian activists though they may not even support the practice have been deeply critical of the Western approach noting how it is often inaccurate, sensationalised and overgeneralised or simply doesn’t apply to most cases. Some commentators have noted the possibility of a shift with regards to FGM seen in for instance the 2012 UN General Assembly resolution cosponsored by two-thirds of the general assembly including the Africa group, to ban FGM worldwide.

Globally across these three surgeries, perhaps also to depoliticise some of the apparent cultural issues, the move has been to push for a model of informed consent based on age and ability to give said consent. The most prominent argument for delaying the procedure and working from a model of informed consent is that a significant proportion of all who experience non-consensual coercive genital surgery in the three categories described, report feeling a sense of violation of their sexual autonomy mainly when it takes place as infants with have no comparable recourse. While those whose genitals have not been altered as infants can remedy their situation by choosing to undergo surgery at the age of mental maturity. In light of this Brian D Earp and Rebecca Steinfeld suggest the best model may be one where all forms of non-consensual coercive genital surgery, regardless of sex or gender, are discouraged until individuals can choose for themselves under “conditions of valid consent”. The emerging consensus for many is that non-consensual coercive genital surgery, “should hinge, not on the apparent sex of the subject—as judged by their external genitalia—but rather on considerations of medical necessity, informed consent, and respect for the bodily autonomy of all person”. Earp and Steinfeld suggest that what is necessary is a gender-neutral approach to genital cutting. The advantages of this would be:

- 1) *It deflects accusations of sexism by recognising that boys and intersex children – just like girls – are vulnerable to genital alterations that they may later come to resent seriously.*
- 2) *It reduces the moral confusion that stems from Western-led efforts to eliminate only the female “half” of genital cutting rites in communities that practice both male and female forms in parallel.*
- 3) *It neutralises accusations of cultural imperialism and anti-Muslim bias by avoiding racially tinged double standards*

This is because the same moral concern would apply to medically unnecessary genital cutting practices that primarily affect white children in North America, Australasia and Europe, as to those affecting children of colour (and immigrants) from Africa, the Middle East and Southeast Asia”

In essence, this would mean the application of consistent principles in the choice of “non-therapeutic bodily modifications as ‘cultural’”. This would have several implications some of which might bear out well in a South African context given the already established cultural practice of undertaking male circumcisions, for instance in Xhosa culture, at a particular age.

III. South Africa

In 2018 in its briefing to the UN's Children's Rights Committee, the South African Department of Social Development conceded that the government was aware of the issues surrounding IGM in the country and the need to halt the practice. Intersex rights activists noted that this made South Africa the first state to officially recognise at the UN the harm perpetuated by IGM on intersex children. In his address to the committee at the UN, Zane Dangor, adviser to Social Development Minister Bathabile Dlamini, said:

"As a government, we do recognise that being intersex is a sexual characteristic and not a medical condition. But at the same time, we recognise that there are still practices where surgeries are being performed on new-borns and young children, which are harmful..So we are now beginning a process in its early stages to acknowledging that such surgeries performed at a very young stage are harmful and that it needs to stop."

It is notable that the Department's attention was drawn to the practice after the Children's Rights Committee had highlighted IGM as a significant concern with regards to South Africa. This highlighting was as a direct result of advocacy efforts by intersex organisations and allies. This step forward does not negate the broader issues that currently trouble intersex advocacy within South African society, in particular, the fact that intersex often remains confused with gender identity. The critical issues for intersex people "are not the existence of binary sex and gender categories, but what is done to intersex people, to make them conform to narrow stereotypical classifications".

1. Language and Framing of Intersex in South Africa

In part, the perpetuation of stigma towards intersex people can be attributed to the adding of the 'I' to LGBT. This allows for misconceptions either with regards to homosexuality or increasingly transgender identity. South Africa's history with regards to notions of intersexuality is in some ways unique, as Amanda Lock Swarr has explored. The use of the Zulu term 'stabane' as a derogatory moniker to indicate someone who is perceived to have both a penis and a vagina. Those identified as such rarely have intersex bodies but rather "there is a widespread assumption and co-created understanding that those who self-identify as lesbian or gay or engage in particularly gendered same-sex encounters may be intersexed".

This is not merely 'the fault' of a Global Northern advocacy model of LGBTI politics but also South Africa's historical experience with regards to the use of medicine as a tool to discipline bodies perceived to be unruly and pathologised, in particular, Black bodies. As Lock Swarr argues

"This racial juxtaposition and its longevity in South African medicine extends earlier connections between racist science and intersexuality by using claims of the common occurrence of intersexed bodies among black South Africans to reinforce assertions of racial difference and white superiority. Under apartheid, the uniform collection of medical statistics concerning black people was discontinued to facilitate the impression of control over disease among blacks and to mask the fact that withholding medical services was a means of population control. Consequently, medical statistics, such as those that racialise intersexuality, are extremely suspect. The effects of medical claims about intersexuality were part of apartheid discourses that pathologised black South Africans by exaggerating sexual difference".

It is in part this framework that has perpetuated the notion that those who have same-sex desire must have some form of intersexuality. Indeed reports of people in some locations being stripped or forced to face examination, alongside infanticide are not uncommon. These physical examinations serve three intertwined purposes:

"First, they iterate the assumption that same-sex sexuality must have a physical explanation; second, they facilitate the impression that sexual acts require both a penis and a vagina; and third, they serve as a public and violent reminder of the possible consequences of defying compulsory heterosexuality".

These issues - the prevalence of the term 'stabane' and the medicalisation of Black bodies during apartheid, including the perception that intersexuality is more common among Black people than white people, are in many ways particular to South Africa and the meaning of intersex today. Markedly they weave together

a strange conglomeration of class, race, sexuality and gender. Perhaps most visible, which this report will address later, in the experience of South African sports star Caster Semenya's experience.

2. Infanticide

"When an intersex baby is born, it is viewed as a sign that the ancestors are angry about something. The traditional birth attendants I have spoken to have justified the strangling of these babies as 'an act of love'. They believe that, in doing this, they are saving the mother from too many questions from the community."

Some cultures believe that intersex infants are 'bad omens', a sign of witchcraft, a punishment from God and a curse on the family they are born into. In these instances, it is often understood to be preferable to kill the child, by twisting its' neck, than allowing the mother to raise it. Birth parents are often told that their child was stillborn and not to ask further questions. Instead of being buried, the body of the infant has been known to be crushed to make muti. Midwives have done this "over a number of years" because it is their "cultural belief". An infant that is not killed may be abandoned in a hospital or left in the place they were born. It is not only infants that are killed. If an intersex child survives birth but is later found to be intersex by rural or traditional communities this can also put the child's life in danger. In informal research carried out by Northern Cape LGBTI organisation LEGBO between 2008 and 2010 it was discovered that of the 90 traditional birth attendants and midwives interviewed 88 admitted to having 'gotten rid of' ostensibly intersex children after their birth.

It must be noted though that the killing of intersex infants is not restricted to South Africa but is also practised elsewhere on the continent and perhaps more broadly. Julius Kaggwa executive director of SIPD Uganda, an organisation that advocates for intersex rights: "In many African countries, the traditional way of dealing with perceived sexuality 'abnormalities' has largely been staying silent – and wishing them away through various kinds of traditional rituals, which often meant killing the intersex infants." Moreover as a perceived 'cultural practice' infanticide can go fairly hidden, in that the numbers are largely unknown because the babies are dumped with no intention of being found. Mothers can retain their place in communities and society and avoid stigma often through taking this route or pleading ignorance regarding the actions of midwives or birth assistants.

What these behaviours indicate is a profound degree of stigma and fear regarding the birth and meaning of intersex children for communities. For children that do survive, parents often experience deep shame, and it is common for them to not talk to their children about their intersex status. Parents also often question their child's sexuality and identity and, indeed, their own. This stigma and secrecy are self-perpetuating in that it is difficult for intersex individuals to come out and speak on their own behalf, this particularly true for Black intersex people from rural communities. As intersex activist Nthabiseng Mokoena recalls:

"[I]n African culture, unfortunately, the birth of a child is the mother's responsibility, and if there is something 'wrong' with the child the blame goes to the mother, and so she felt extremely isolated after giving birth to me. And she said to me: 'All that I ever ask is that you not feel the same pain that I went through after giving birth to you, and it's not that I was ashamed that I gave birth to a child like you it's because people put me in that position.'"

It is essential to urgently address intersex infanticide, child abandonment, familial stigma and other concerns in rural and traditional settings across the country.

3. Healthcare

In the Western model of medicine, intersex is seen as a Disorder of Sexual Development (DSD). Operations based on a DSD diagnosis, in essence, IGM, often leave individuals with "severe physical and psychological damage in the aftermath of medical interventions, sometimes to the point of life-threatening organ damage". In medical settings intersex people are often made aware that their bodies are *wrong* rather than *different*, this is then conceptualised as a disorder.

Framing intersex traits as an abnormality

Crystal Hendricks noted that the lack of information allowed doctors to act from a “concealed-centred method of care”. The concealed-care method of care is rooted in the notion that a child can be nurtured into a specific gender and that ambiguous genitalia must be surgically and medically fixed clearly as either male or female. The concealed-care method is supported by various unethical medical behaviours including misrepresentation of the medical impact of atypical genitalia. This misrepresentation allows medical professionals to frame atypical genitalia/intersex characteristics as a medical problem and an abnormality requiring invasive genital mutilation rather than a natural variation/sex characteristic.

The characterising of intersex traits as an “abnormality” and as disorders is problematic as it directly encourages, supports and results in intersex genital mutilation and prevents affirming access to healthcare. There needs to be a conceptual shift in how intersex variations are seen, named, discussed and framed, to more neutral medical terms that are neutral and descriptive rather than negative and implicitly directive.

Crystal Hendricks noted that this entire medical approach is based on “normalisation” and isolation of intersex children, rather than a celebration of natural human diversity. Hendricks noted that growing up and having your body framed within a model of “abnormality” induces depression, shame and a sense of being a “liar”.



3 A private doctor apologised for the medical profession’s current treatment of intersex variations, and spoke about the need for doctors to be more informed on intersex issues. Photo by: Lungile Maquba @Iranti

Lack of competent, affirming healthcare: Nthabiseng Mokoena’s Story

When I was 19, I started having pains in my abdominal region, my family took me to a doctor who referred to me as “it” and said that they had made a mistake by raising me as a girl and he quickly advised surgery, I could not go through with it if it meant “becoming a boy”. We had to find a doctor that was more knowledgeable on intersex healthcare, we spent two years searching for a doctor in the North West province that could assist me and my search did not yield any results. I contacted an NGO and they referred me to a doctor at Chris Hani Baragwaneth Hospital in Soweto, 250 kilometres from where I lived. Once every month I would have to travel to Soweto for “healthcare”.

That was the one of the worst experiences of my life, I would have to undress and the doctor would bring his medical students into the room to give them a lecture on “disorders of sexual development”, with me as the exhibition. I stopped seeing this doctor, I used painkillers to cope with the pain and only had the courage to see another doctor only 6 years after that experience. I later realised that this is a typical experience for most intersex persons in the country, you either had surgery as a child and had to deal with the consequences by yourself for the rest of your life or if you were lucky enough to escape surgery as a child, you had to deal with the difficulty of accessing healthcare as an adult.

Access to healthcare is still difficult for the average South African, access to healthcare for an intersex person is even worse, there are only a few hospitals in the country that can cater for the needs of intersex persons with care and understanding.

My work as an activist also involves a lot of media visibility, and it is not easy being visible. The first time I appeared in a national magazine, I had to spend an entire month avoiding calls or being alone in public. The hate mail was tremendous and people were more curious about my genitals than the issues I was trying to raise. In time I became used to the public sneers and the curiosity over my gender. I soon realised the social stigma that surrounded being intersex, I knew the secrecy we were all raised under but I did not expect that speaking out would involve isolation and literal threat to my life at times. Stories of intersex primary school children being undressed in front of their classmates by their teachers suddenly did not become shocking, they became a reality of being intersex and living in the townships. For these reasons I decided to stay as an activist and know other activists such as Sally, if not for mentoring at least for support.

The framing of intersex traits as abnormalities and disorders increases cases of inadequate access to healthcare due to pathologisation.

Intersex Genital Mutilation (IGM)

Intersex people experience a wide range of human rights violations in the South African context, these include, as discussed, IGM or medically unnecessary surgeries, cosmetic in nature and harmful to intersex babies and adults. These surgeries would not be considered for non-intersex children without evidence of medical benefits or good reason.

These surgeries are justified using societal norms driven by religious and cultural perceptions of sex and gender. These medical interventions include masculinisation or feminisation, sterilisation, experimentation, and denial of needed healthcare. In the past medical practitioners attempted to, wherever possible, make the child more “male-like” thus preserving male privilege in accordance with prevailing values. These days, medical practitioners are more likely to attempt to make the child more “female-like” because current surgical procedures are far more likely to produce a pleasing long-term outcome when removing tissue and making a vagina than they are when introducing the tissue needed to make a phallus.

“It is important to note that these medical and surgical interventions do not constitute a single intervention. Many people assume this. But we are talking about a number of surgeries over a period of time with severe consequences that include loss of sexual sensation, loss or impairment of reproductive capabilities, extensive scarring, continual pain, incontinence, life-long dependency on artificial hormones, depression, self-harm and mental trauma”

The surgery to make an intersex child into an “unambiguously female child” is done as early as is possible, premised on earlier surgery resulting in the child healing with minimum scarring and minimal recollection of these invasive practices. However even in new-borns, scars do not grow, further regular surgeries are inevitable until the child themselves stop growing in their early twenties. Babies who have “neo-vaginas” constructed will immediately have to begin vaginal dilation and must continue that for the rest of their lives. That means that a parent will have to insert a dilator into their baby’s vagina at first daily and then on a weekly until their child is old enough to do it themselves. This entails the therapeutic sexual penetration of one’s own child, with the accompanying psychological effects.

All typical forms of IGM are still practice in South Africa today. The South African Association of Paediatric Surgeons lists 7 paediatric centres which still practice IGM, these hospitals include; The Red Cross War Memorial Hospital in Cape Town; Chris Hani Baragwanath Hospital; the Department of Paediatric Surgery at Free State University, Tygerberg Hospital, East London Hospital and the University of KZN's Paediatric department.

Dimakatso's story



4 Dimakatso Sebidi from ISSA (Intersex South Africa) presents on issues faced by Intersex persons. Photo By: Lungile Maquba @Iranti

At the meeting, Dimakatso gave an account of her story. She spent several of her formative years in hospital. As a child, she was never told what was wrong with her. At Chris Hani Baragwanath, there were a multiplicity of doctors who would check up on her, and she had multiple surgical interventions. Even at home, it was difficult as the people at home did not know what being intersex was. And because of the "concealed-method of care" model used by the doctors all she was told was that she had kidney problems. Her right to privacy was violated continuously in multiple ways as people always wanted to know what was "in her pants". From birth she was told she was undergoing surgeries and continuously taking medication, to be "fixed". As she grew up, she became increasingly suicidal as she felt she "did not belong anywhere". She attempted suicide multiple times.

Through Dimakatso's story, a few issues arise. As a child, she was not given full information about her body and her intersex status. This lack of information led to her being unable to understand what was being done to her body and the reasons for these interventions. She underwent non-consensual genital mutilating surgery and other sterilising procedures, the imposition of hormones, forced genital exams and was put on medical display. Further, her family was not given information for them to help her understand what was going on with her body. The lack of knowledge made it difficult for Dimakatso to accept her body and relate to it in a healthy manner. As a result, she suffered through various psychological trauma.

IGM is an on-going and common practice in South Africa even though globally there has been a definite shift to understanding it as non-consensual, cosmetic, medically unnecessary and harmful. IGM practices are known to cause permanent psychological, physical and social issues for intersex people. Indeed, this has been recognised by several UN Bodies and Committees as "constituting a harmful practice, violence and torture or ill-treatment"¹.

¹ Bauer, Markus, and Daniela Truffer. 2016. 'Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report to the 2nd Periodic Report of South Africa on the Convention on the Rights of the Child (CRC)'. StopIGM.org. http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ZAF/INT_CRC_NGO_ZAF_24911_E.pdf. p.5

Not only has South Africa done very little more curtail this but the state directly funds these procedures through their support for public university clinics, Regional Children's hospitals and paediatric hospitals.² IGM is also widely advocated by South African medial associations along with private doctors and surgeons. The 2016 *Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report* shows concrete examples of how IGM is practiced and supported across various medical settings in South Africa, spoken about at key paediatric conferences as a viable practice, promoted as necessary to normalisation, advertised on urology websites and a preferred method of 'treatment'.³ The recent acknowledgement by the South African government, therefore, a critical win.

Children and infants who do undergo IGM in South Africa, particularly those from more impoverished communities, struggle post-surgery. This is due to the ongoing need for medication such as hormone replacement therapy and visits to the hospital which can become a financial burden to families.⁴ There is also a notable lack of follow up care for children and infants who do experience IGM. Due to cost and distance, some infants do escape cosmetic interventions and are able to live without medical interventions until much later in life⁵. As Dr Kevin Adams, a senior specialist plastic surgeon at Groote Schuur Hospital and the Red Cross Children's Hospital in Cape Town, explains that IGM is still a common practice it part because it is "largely based on tradition and not scientific evidence...The issue is a complex one. Personally, I try engage with parents to avoid surgery but I come from a different generation [he is 50] and the truth is that many of my older colleagues disagree with me".⁶ He suggests that a way to avoid this might be the creation of interdisciplinary teams much in the same way transgender healthcare is managed in the public sector.

*"But if we saw these patients as part of interdisciplinary teams, involving social workers, psychologists, psychiatrists and others, I think we would see less of these surgeries – and less of their negative consequences... The more professionals involved, the more likely we are to make the right decision and the more likely we are to defend patients' rights."*⁷

For intersex activists globally intersex bodies are, like other bodies, mostly healthy. While some may experience health issues, being intersex in and of itself is not a health problem or indeed a medical condition.⁸ In fact, if illness or disease does develop in relation to being intersex it is often the physical and mental effects of surgery or 'normalising' treatments, and, such as in Mokoena's case, exposure to medical photography and medical students that is considered to be the main cause. The lack of transparency intersex patients experience from healthcare providers only exacerbates these situations. This medical curiosity in particular often prevents intersex people from seeking appropriate medical care. They are "more likely to be subject to abuse due to the scarcity of knowledge, lack of doctors and medical hunger for 'cases'"⁹.

According to South African intersex activist Crystal Hendriks despite the growing number of visible intersex people globally and in South Africa "people like her are not spoken about and are treated as if they "need to be fixed" through medical intervention"¹⁰

2 Bauer, Markus, and Daniela Truffer. 2016. 'Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report to the 2nd Periodic Report of South Africa on the Convention on the Rights of the Child (CRC)'. StopIGM.org. http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ZAF/INT_CRC_NGO_ZAF_24911_E.pdf, p.5

3 Bauer, Markus, and Daniela Truffer. 2016. 'Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report to the 2nd Periodic Report of South Africa on the Convention on the Rights of the Child (CRC)'. StopIGM.org. http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ZAF/INT_CRC_NGO_ZAF_24911_E.pdf.

4 Bauer, Markus, and Daniela Truffer. 2016. 'Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report to the 2nd Periodic Report of South Africa on the Convention on the Rights of the Child (CRC)'. StopIGM.org. http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ZAF/INT_CRC_NGO_ZAF_24911_E.pdf, p.5

5 Christian Ghattas, Dan. 2013. 'Human Rights between the Sexes A Preliminary Study on the Life Situations of Inter* Individuals'. Publication series on democracy 34. Heinrich böll Foundation p. 42

6 Green, Amy. 2018. 'Government Urged to Ban Intersex Genital Mutilation'. *Health-E*. January 15. <https://www.health-e.org.za/2018/01/15/government-urged-ban-intersex-genital-mutilation/>.

7 Green, Amy. 2018. 'Government Urged to Ban Intersex Genital Mutilation'. *Health-E*. January 15. <https://www.health-e.org.za/2018/01/15/government-urged-ban-intersex-genital-mutilation/>.

8 Organisation Intersex International Australia. 2014. 'Making Your Service Intersex Friendly'. OII Australia and ACON. <https://ihra.org.au/wp-content/uploads/key/OII-Australia-Inclusive-Service.pdf>, p. 4

9 Husakouskaya, Nadzeya. 2013. 'Rethinking Gender and Human Rights Through Transgender and Intersex Experiences in South Africa'. *Agenda* 27 (4) p. 18

10 Green, Amy. 2018. 'Government Urged to Ban Intersex Genital Mutilation'. *Health-E*. January 15. <https://www.health-e.org.za/2018/01/15/government-urged-ban-intersex-genital-mutilation/>.

IGM is not only practised on intersex infants. In South Africa it is also used to treat non-intersex infants who experience 'muti' mutilations: "excision of body parts for incorporation as ingredients into traditional medicine and concoctions".¹¹ In 1999 an infant whose penis had been cut off in a 'muti' attack was taken to Chris Han Baragwanath Hospital. Doctors decided the best course of action would be to perform gender reassignment surgery on the infant. In the proceeding years, the toddler refused to wear dresses or play with girl's toys. In an interview with South African newspaper the Sunday Times, his mother stated that although they thought they could change him after the operation, the child became "more like a boy than ever".¹² In this instance, the doctors involved conceded to have failed. The case suggests, quite clearly that, surgeries are undertaken without consent which can have a radical effect on a child's life have a very real likelihood of creating increased trauma and psychological issues rather than the perceived opposite.¹³

Transphobia and Homophobia

Doctors routinely assure parents that surgical treatment will result in a normal child. By normal, they also intend a child that is heterosexual with a normative gender identity.¹⁴ The self-reinforcing nature of the concealment model makes it difficult to discuss intersex issues or access alternative paradigms for thinking through gender, sex and sexuality. The concealment model has kept intersex people separate from each other. In turn, those intersex adults who do speak out are often considered "gender radicals" rather than a group of people whose bodies deserve the right to exist without interference until they consent to it.¹⁵ Ultimately then "doctors" decisions to recommend genital-normalising surgery and parents' decisions to approve it may be based on cultural norms rather than on medical need¹⁶. While extent of this consideration in a country such as South Africa has yet to be ascertained, it likely plays a significant role in parent's decision-making.

Power Dynamics within medical spaces

Any departure from the "traditional/normative" standards of sex characteristics often raises anxieties. In a society where the normative understanding of sex characteristics and gender is still a binary, any deviations from these set binary understandings are often characterised as "abnormal".

IGM exists within this paradigm of a need to "normalise" intersex children and have them fit into either male or female categories. The binary gives rise to a sense that anything which does not fit must be corrected. In other words, intersex children, because of their deviation from the norm are pathologised, and their bodies are framed as needing "medical correction".

This binary logic persists because the medical space is often seen as an objective and neutral space. However, the medical space is often infused with social and cultural understandings of what it means to be male/female/man/woman. In other words, science/medical field/psychology often reproduce social constructions of "normality".

In the South African context, where a medical practitioners' own biases are compounded by issues of race, gender, language and the rural-urban divide, which all exacerbate the power imbalance between doctors and patients, it is essential that the medical/psychological space move away from a hierarchal approach to medical care to being person-centred. Rather than the doctor/patient relationship being top/down power dynamic, it must move towards being more of a dialogue where the best interests of the patient are the primary concern.

Rather than medical decisions being left to medical professionals, the making of a decision about a patient's health must be a process within which the medical professional must be a facilitator rather than the chief decision maker.

11 Bauer, Markus, and Daniela Truffer. 2016. 'Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report to the 2nd Periodic Report of South Africa on the Convention on the Rights of the Child (CRC)'. StopIGM.org. http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ZAF/INT_CRC_NGO_ZAF_24911_E.pdf p. 11

12 Staff Reporter. 1999. 'Lifting the Veil on Intersexuality'. *The M&G Online*. August 13. <https://mg.co.za/article/1999-08-13-lifting-the-veil-on-intersexuality/>.

13 Staff Reporter. 1999. 'Lifting the Veil on Intersexuality'. *The M&G Online*. August 13. <https://mg.co.za/article/1999-08-13-lifting-the-veil-on-intersexuality/>.

14 Tamar-Mattis, Anne. 2006. 'Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants'. *Berkley Journal of Gender, Law and Justice* 21 (1): p. 84

15 Tamar-Mattis, Anne. 2006. 'Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants'. *Berkley Journal of Gender, Law and Justice* 21 (1): p. 84

16 Tamar-Mattis, Anne. 2006. 'Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants'. *Berkley Journal of Gender, Law and Justice* 21 (1): p. 84

(in)Accessibility of medical information

In the 1950s Dr John Money, a leading psychologist on sexuality, developed what has come to be called the “optimum gender rearing” system in the treatment of intersex children. A primary pillar of this medical model of care was that in intersex cases settling the assigned gender of the child early was central to ensuring that the child grew up as either a stable and good boy or girl.¹⁷

This method relied primarily on concealment, also known as the concealment model, through surgical and medical interventions. This often meant that doctors were not candid and open about a child’s intersex condition. Thus manipulation of information by doctors became a common practice. The practice of manipulation and misinformation to secure stable/fixed sex continues.

Participants noted that the misinformation facilitates the continued violation of intersex children. Additionally, the lack of and manipulation of information by doctors was one of the drivers of invasive medical and surgical interventions on intersex children. This is compounded by the fact that South Africa still has a large number of its populations living in rural areas. This often means a lack of access to information that is accurate and understandable. This lack of information usually means that when parents enter the medical space, they over-rely on medical professionals and do not question the decisions doctors make concerning their children’s bodies. The lack of information often means that a child’s intersex variation is shrouded in secrecy, fostering a sense of shame.

Intersex adults are also often denied access to their medical records and accurate information about what interventions happened to them as children, putting in place barriers to seeking redress and reparations. Access to medical information is vital to the protection of the human rights of intersex people.

Psychological Trauma

Psychologist, Dr Bosworth noted that we could learn from the HIV/AIDs epidemic and the role of secrecy in framing the virus as a stigma. He pointed out that the more you label things as a secret, they are constructed as something wrong and to be hidden. The secrecy and stigma which follows intersex traits often becomes inherent in the person’s sense of identity and creates a sense that there is something wrong with them. It changes how a person sees themselves and how they value themselves resulting in mental health traumas such as depression and other mental health issues. People in these minority groups often manifest various forms of psychological distress including anxiety, depression and problems within the context of forming intimate relationships.

Nadzeya Husakououskaya points to a disjuncture. For intersex patients, the ‘truth’ must be found in the body

“Intersex people are not treated as those who need any psychological assistance, and they usually go straight to the surgeon in frequent cases of normalising surgeries, or to the endocrinologist. Their need for support is not taken into account”¹⁸.

More generally for intersex people, there are fewer medical professionals with the requisite knowledge to assist. As noted medical curiosity is a common experience, which prevents intersex people from seeking healthcare, even general healthcare or psycho-social support.¹⁹ Children with intersex traits are subjected to repeated genital traumas which are kept secret both within the family and in the culture surrounding it. They are frightened, shamed, misinformed, and injured. These children experience their treatment as a form of sexual abuse²⁰. This is not surprising, considering practices like regular vaginal dilation. Although many physicians and researchers recommend counselling for their intersex patients, patients rarely receive psychological intervention and are usually reported as being “lost to follow-up.”

17 Intersex Society of North America “What’s wrong with the way intersex has traditionally been treated?”, available at <http://www.isna.org/faq/concealment>, accessed January 2018.

18 Husakououskaya, Nadzeya. 2013. ‘Rethinking Gender and Human Rights Through Transgender and Intersex Experiences in South Africa’. *Agenda* 27 (4) p. 18

19 Husakououskaya, Nadzeya. 2013. ‘Rethinking Gender and Human Rights Through Transgender and Intersex Experiences in South Africa’. *Agenda* 27 (4) p. 18

20 Alexander, Tamara. 1997. “The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse.” <http://www.isna.org/articles/analogue>



5 Trauma counsellor Casey Blake spoke about this engagement assisting her with approaches to counselling for parents of Intersex children. Photo by: Gugu Mandla ©Irantí

In cases where the intersex traits are identifiable at birth, a child is subjected to extensive testing physically, genetically, and surgically, to determine the gender most appropriate for rearing. Although the child is repeatedly examined through puberty, there is often no explanation given for these frequent medical visits. Because both parents and physicians view these treatments as necessary and beneficial to the child, the child's trauma in experiencing these procedures is often ignored. The underlying assumption is that children who do not remember their experiences are not negatively affected. However, medical procedures may be experienced by a child or adolescent as a trauma, with the medical personnel considered as perpetrators in collusion with the parent. The long-range effects of these events may have serious and adverse effects on future development and psychopathology²¹.

Like victims of child sexual abuse, intersex children are routinely misinformed about their experiences. Parents may be encouraged to keep the child's intersex status from him or her, and are often misinformed themselves regarding the procedures being enacted on their children as well as the possible outcomes for their child²².

"In addition to the laws, there would be a need for educative approaches so as to enable parents to know that there are other options than surgery at birth. Work also needs to be done to address the stigma that families and children may often be faced within communities."²³

One thing that is clear about genital normalising surgery or IGM is that it more often than not causes the problems it purports to solve. For instance, it can be much more difficult for children to conceal multiple surgeries and their after-effects from their peers than their intersex body.²⁴ It is as Anne Tamar-Mattis suggests the "failure of imagination—the inability to envision a happy, productive life for a visibly intersex person - is both cause and consequence of the surgical "erasing" of intersex bodies.²⁵

21 Alexander, Tamara. 1997. "The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse." <http://www.isna.org/articles/analog>

22 Alexander, Tamara. 1997. "The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse." <http://www.isna.org/articles/analog>

23 Collison, Carl. 2018. 'SA Joins the Global Fight to Stop Unnecessary Genital Surgery on Intersex Babies'. *The M&G Online*. October 27. <https://mg.co.za/article/2016-10-27-00-sa-joins-the-global-fight-to-stop-unnecessary-genital-surgery-on-intersex-babies/>.

24 Tamar-Mattis, Anne. 2006. 'Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants'. *Berkley Journal of Gender, Law and Justice* 21 (1): p. 72

25 Tamar-Mattis, Anne. 2006. 'Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants'. *Berkley Journal of Gender, Law and Justice* 21 (1): p. 83

4. Legal Structure SA

Anti-Discrimination Legislation

*“Since 2000, I’ve drafted amendments bearing on intersex for the Alteration of Sex Descriptions Bill and the Promotion of Equality Act, and these have been lobbied into law. Getting intersex into the Promotion of Equality Act is the weightier of the two. Lobbying persuaded the SA Human Rights Commission that intersex is a serious human rights issue”.*²⁶

The promulgation of the *Judicial Matters Amendment Act of 2005* changed the legal status of intersex people in South Africa theoretically guaranteeing them protection. Theoretically, it secured protections on the basis of intersexuality for South Africans. For activist Sally Gross one of the critical issues with which the way this was achieved was the stealth nature of its entry into the statute book. Evident perhaps by the fact that though the amendment has far-reaching implications, not just for intersex people in South Africa, it has remained mostly invisible. Gross suggests that this is a testament to the “entrenched culture of shame, secrecy and stigmatisation” when it comes to intersex issues in South Africa.²⁷

At the level of the state, the South African government has repeatedly been made aware of intersex issues particularly with regards to IGM since at least 1999.²⁸ In 2004 the South African Human Rights Commission explicitly considered legislation as a means to eliminate IGM.²⁹ This did not result in the tangible outcomes hoped for and as this report has noted IGM has primarily continued as an acceptable practice unabated. Most disturbing is that much of these practices take place at University clinics and state hospitals. In light of this, there is an argument to be made that not only does the South African state do nothing about IGM but directly funds its continuation.³⁰

Despite existing anti-discrimination legislation, violations against intersex persons in medical and other settings continue, showing the need for specific legislation criminalising IGM and making provision for access to redress.

Solutions to address intersex marginalisation and violations will need a multi-pronged process, which will implicate some stakeholders. In the engagement, it became clear that all solutions and interventions would need to be centred around a shared understanding of what informed consent means in the context of children and there would need to be a normative move towards understanding intersex variations as sex characteristics and not medical conditions. Proposals regarding the use of legislation follow.

Consent by children and bodily integrity

Creating legal interventions, which will deal “normalising” intersex surgeries or IGM, require a holistic analysis of existing legislative frameworks which protect the rights of children. South African law understands the concept of “evolving capacity” in children. Thus the age of consent for medical procedures begins at 12 years of age for children. Section 129(2) of the Children’s Act³¹ provides;

“A child may consent to his or her own medical treatment or the medical treatment of his or her child if-

- a. *The child is over the age of 12 years; and*
- b. *The child is of sufficient maturity and has the mental capacity to understand the benefits, risks, social and other implications of the treatment.”*

26 Gross, Sally. 2009. ‘Intersex and the Law’. *The M&G Online*. September 19. <https://mg.co.za/article/2009-09-19-intersex-and-the-law/>.

27 Gross, Sally. 2009. ‘Intersex and the Law’. *The M&G Online*. September 19. <https://mg.co.za/article/2009-09-19-intersex-and-the-law/>.

28 Bauer, Markus, and Daniela Truffer. 2016. ‘Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report to the 2nd Periodic Report of South Africa on the Convention on the Rights of the Child (CRC)’. StopIGM.org. http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ZAF/INT_CRC_NGO_ZAF_24911_E.pdf.

29 Roelf, Wendell. 2004. ‘Intersex Children Must Be Protected from Temptation of Parents to “fix” Them Surgically’. *lol.Co.Za*. December 26. <https://web.archive.org/web/20041226061403/http://www.capetimes.co.za/index.php?fSectionId=271&fArticleId=2329017>.

30 Bauer, Markus, and Daniela Truffer. 2016. ‘Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report to the 2nd Periodic Report of South Africa on the Convention on the Rights of the Child (CRC)’. StopIGM.org. http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ZAF/INT_CRC_NGO_ZAF_24911_E.pdf.

31 2005

Section 129(3) provides similarly in relation to surgical operations and additionally stipulates that a parent, guardian or caregiver may “duly assist”. This may be interpreted to mean that non-consensual and cosmetic surgeries may not be done on an infant until they are over the age of 12 years and can, with the assistance of their parent, guardian or caregiver, make an informed decision and give full consent. This proposed interpretation is in line with the principle of the *best interests of the child* and would go a long way in limiting the cases of coercive IGM surgeries which result in forced sterilisation. In addition, it is important to note that even from 12 years old, **consent given based on only negative, pathologizing information, without positive, affirming language and information cannot be characterised as full, free and informed consent**³². Training and education on informed consent, bodily diversity and the right to bodily integrity and autonomy, are therefore necessary to ensure that healthcare professionals can provide medical information and healthcare services in-line with human rights standards.

The Constitution is the primary document which recognises specific rights in relation to children in Section 28. However, children are also entitled to other rights in the constitution including the rights to life, dignity, equality and most importantly bodily and psychological integrity.³³ The South African Constitution provides that “[t]he child’s **best interests** are of paramount importance in every matter concerning the child.”³⁴ In giving effect to the rights of children contained in Section 28 of the Constitution, the Children’s Act provides that “all proceedings, actions or decisions in a matter concerning the child must

- a. *(respect, protect, promote and fulfil the child’s rights set out in the Bill of Rights, the best interest of the child standard set out in section 7 and the rights and principles set out in this Act, subject to lawful limitation;*
- b. *respect of the child’s inherent dignity;*
- c. *treat the child fairly and equitably.”*

Section 7 further stipulates the factors to be considered when determining the best interests of the child, including;

- (g) *the child’s*
 - i. *age, maturity and stage of development;*
 - ii. *gender;*
 - iii. *background; and*
 - iv. *(any other relevant characteristics of the child;*
- (h) *the child’s physical and emotional security and his or her intellectual, emotional, social and cultural development”.*

In ***AB and Another v Minister of Social Development and Another*** the court articulated the right to bodily integrity as the right to one’s own physical self-autonomy including a person’s right to reproductive autonomy.³⁵

Because of the invasive nature of intersex genital mutilations and their impact on the reproductive abilities of intersex children once they become adults, it can be argued that the practice of IGM surgeries is unconstitutional. Because IGM surgeries and other hormonal interventions limit the ability of intersex children to make choices around their bodies, it can also be argued that depriving them of making these decisions later in life is a violation of their Section 12(b) rights to bodily and psychological integrity.

32 Mokoena, N. (2015). Intersex youth: Can we say that consent is truly free, full and informed?, Page 3.

33 Section 12(2) of the Constitution.

34 Section 28(2) of the Constitution of South Africa.

35 *AB and Another v Minister of Social Development* [2016] ZACC 43, paras 306 – 318.



6 Mr Sebidi (Dimakatso's father) sits on a panel discussion on challenges of being a parent of an Intersex child.
Photo by: Gugu Mandla @Iranti

The minority judgment in the same case is instructive of how the stifling of a person's [including children] ability to make decisions concerning their health[care] can be a violation of their psychological integrity, **provided the consequences are of an offensive nature.**

In determining whether a practice prevents a person or a group of persons from making a "decision" concerning their reproductive health the court set out the following test;

- a. Does the impugned law or conduct prevent or inhibit a person or group of persons from making a decision?
- b. If the answer to (a) is yes, does the decision concern reproduction?
- c. If the response to (b) is yes, does preventing or inhibiting the decision detrimentally affect the psychological integrity of the person or persons concerned?

IGM surgeries and non-consensual medical interventions violate the child's best interests as they inhibit the child's ability to make decisions about their bodily autonomy and their right to make future decisions concerning their future reproductive capabilities. In other words, the practice of IGM not only violates the child's bodily autonomy and physical integrity but also deprives them of the future ability to make decisions around their reproductive possibilities.

In remedying this violation government can take several steps to stop this practice. Government is obligated in terms of the Constitution and various legislative enactments to "respect, protect and fulfil the rights in the in the Bill of Rights".

The steps taken by the government are multi-fold including – as suggested in the engagement;

- Issuing a moratorium on IGM surgeries in tertiary hospitals
- Enacting legislation & directives laying out restrictive criteria/guidelines on instances in which surgical intervention can be considered on newborn intersex babies.
- Instituting enquiries into the practice of IGM surgeries in tertiary hospitals
- Ensuring victims of IGM have access to redress and reparations

However, the use of legislation which does not speak directly to IGM leaves out a few critical considerations specific to intersex children. Both the Sterilisation Act and the Children's Act do not define nor distinguish between a medical condition and natural sex characteristics. As Zane Dangor notes, the lack of distinction between these two concepts in relation to intersex children often means that sex characteristics, which are no more than mere biological differentiation are diagnosed and pathologised through being characterised as a medical condition.

Further, neither Acts allow for a mandatory deferral of medical intervention in non-emergency cases involving intersex variations. A compulsory deferral of medical and surgical intervention in such cases would prevent medical interventions when a child born with an intersex variation, until they reach an age of maturity where they can take an informed decision about which medical interventions they want, if any.

The Sterilisation Act

IGM often happens without the informed consent of the child, and sometimes of the parents because of the "concealed-care" medical model used by medical professionals. Parents are not put in the position to make informed decisions about the medical interventions their children are subjected to.

Tshego Phala of Webber Wentzel noted that there needs to be an extensive decision-making process through which decisions on surgical interventions on babies with intersex variations are put through.

One of the suggestions Mx Phala put through was that all decisions, which involve invasive surgical interventions, must be taken by a panel consisting of various medical professionals and an intersex representative, and must centre the best interests of the child. In other words, the decision-making process would include critical stipulations, which would measure any decision against the **best interests of the child** standard.

"The "best interests of the child" is a notion which as a cornerstone in relation to decisions which involve children. This notion exists internationally and is a guideline which should be standard in any decision concerning the child."³⁶

Internationally there has been conclusive evidence, which reveals that there is no underlying medical purpose for any of the surgeries, which are conducted on intersex children. In the preliminary research, there is no medical research, which has proven that IGM surgeries are medically beneficial for intersex children.

However, even the reasons which are often stipulated as medically beneficial, i.e. that IGM surgeries help in the prevention of cancer, have been shown to be primarily driven by binary notions of gender and the parent's fears of the stigma and shame around intersex bodies.

As a result, these surgeries violate a number of rights of intersex children; they violate their right to privacy, bodily and psychological integrity and self-determination. They also violate the child's right to reproductive health.

Tshego Phala noted that a lot of IGM practices conducted on intersex children often resulted in forced sterilisation. Currently, our laws provide that procedures which result in sterilisation cannot be performed on children below the age of 12 unless there are serious health risks which are linked to the need to sterilise. Additionally, the consent of the parent is required, and the reason for the sterilisation must be based on medical fact and not societal and cultural fears and constructs. Further, the head of the hospital has to convene a panel which consists of a psychologist, a nurse and a medical doctor.

In summary, the current Sterilisation Act requires that procedures which result in the sterilisation of children under the age of 12 must adhere to the following criteria;

- The reasons for the sterilisation must be based on medical fact and not societal constructs and fears;
- The parent of the child must consent;
- The head of the hospital must convene a panel consisting of a psychologist, a nurse and a medical doctor
- The head of the hospital must then write a report giving reasons as to why the sterilisation process was medically necessary.

36 Interview with Tshego Phala

Because IGM results in the forced sterilisation of intersex children, the Sterilisation Act can be used in combating non-medically necessary surgeries on intersex children. Although the issue of IGM surgeries needs to be addressed through the enactment of targeted own legislative provisions and should not rely on other ill-suited legislation, the Sterilisation Act provides an immediate and interim solution through which intersex children and their families can begin to enforce their rights.

5. Social and Cultural Marginalisation

The Deputy Minister of Justice and Constitutional Development acknowledged that the inclusion of intersex persons needs to be a multi-departmental effort. This is because intersex persons are excluded in multiple and intersecting ways through discrimination in education, healthcare provision, employment.



1 Delegates engaged on a group discussion on ways of tackling health issues of Intersex persons

Because misinformation, stigma and shame shroud the reality of intersex variations and because intersex characteristics manifest in a multiplicity of forms, there needs to be intersecting solutions to the multitude of intersex experiences that exist. Though not exhaustive, below are some of the themes identified by the participants and speakers which any interventions would need to address in concrete form.

Sport

In 2009 South African middle-distance runner Caster Semenya rocketed to fame not because she had won gold in the women's 800m race at the World Championship in Athletics in Berlin but because of accusations regarding her sex. Semenya's time was remarkable, and sceptics argued that it was not possible for her to run that fast and be female. After winning Semenya was subject to what is commonly called a 'gender test' which is, in fact, a sex test. It was also later revealed that pictures were taken of her genitals.³⁷ The test results were leaked by an Australian newspaper, a severe breach of ethics.³⁸ Semenya was cleared by the IAAF in July 2010 to compete as a female competitor.³⁹ The Caster Semenya story is but one moment in the ongoing political issues around intersexuality and race. The response of South African sports bodies and politicians

37 Bailey, Candice. 2009. 'Intersexuality Quite Common'. *Iol.Co.Za*. September 19. <https://www.iol.co.za/news/south-africa/intersexuality-quite-common-459039>.

38 Bhuka, Vidhya. 2011. 'Questioning Gender: The Representation of Race and Gender in Global and Local Print Media Responses of the Caster Semenya Saga'. Department of Media Studies, Johannesburg: University of Witwatersrand. <http://hdl.handle.net/10539/10742> p. 4

39 Bhuka, Vidhya. 2011. 'Questioning Gender: The Representation of Race and Gender in Global and Local Print Media Responses of the Caster Semenya Saga'. Department of Media Studies, Johannesburg: University of Witwatersrand. <http://hdl.handle.net/10539/10742> p. 5

was as worrying. For instance, South African politician Julius Malema, claimed that intersexuality did not exist.⁴⁰ Furthermore, conflicting stories suggest that Athletics South Africa also requested the test or at the very least consented to it. Though this was denied.⁴¹

Sporting history is replete with stories of women, in particular, being banned from competition after medical testing revealed intersex traits. The scientific basis for this exclusion is at best questionable. Medical papers also suggest that some athletes have gone so far as to undergo sterilisation and/or clitoridectomies (a form of Female Genital Mutilation) in order to continue competing.⁴² Intersex people are capable of high levels of sporting achievement. Intersex traits are singled out for investigation, particularly among female athletes, while other genetic differences are not,⁴³ which is a clear form of discrimination.

Though the support for Semenya has shifted since 2009, it is clear that sports bodies need to consider how they might protect their athletes particularly those who may be intersex in future. This is particularly true when issues of race exacerbate the situation as was clear given the way in which Semenya, unlike other white athletes in the past who have experienced similar issues, was thrust into the public eye. A firm supportive stance on these issues from South African sport bodies including a moratorium on sex/gender testing is needed.

Movement Funding

Comparatively across the African continent, the intersex movement is vastly underfunded. There is a need for capacity building and institutional funding alongside access to healthcare. As Julius Kaggwa from SIPD Uganda notes compared to funding the fight against homophobia or the plight of child soldiers in Africa “complete indifference [is shown] to life-threatening genital mutilations and infanticide that intersex children suffer”.⁴⁴

The **American Jewish World Service (AJWS)**, **Astraea Lesbian Foundation for Justice (Astraea)** and **Global Action for Trans Equality (GATE)** released the findings of their global surveys of intersex and trans organizations in 107 countries in two new reports, *The State of Intersex Organizing (2nd edition)* and *The State of Trans Organizing (2nd edition)*. More than 450 trans groups and 50 intersex groups participated in the surveys. The reports conclude that, despite exponential growth in LGBTI funding in recent years, intersex and trans groups are deeply under-resourced and continue to be neglected by international funders. Key findings include⁴⁵:

- Almost no intersex groups receive funding from donor governments.
- Fewer than 1 in 5 intersex groups have full-time paid staff. Even those with paid staff struggle to provide a living wage given their budget constraints.
- Nearly 8 in 10 trans and intersex groups report needing support with fundraising and grant-writing, and roughly three-quarters report needing support in healing from trauma and preventing burnout.

We urge the South African government, and South African funders to increase their support for intersex groups so they can continue – and expand – their vital work. This financial support is essential in ensuring an enabling environment for intersex-led organisations to engage meaningfully with interventions developed and implemented that address violations of the human rights of intersex people.

40 Swarr, Amanda Lock, Sally Gross, and Liesl Theron. 2009. ‘South African Intersex Activism: Caster Semenya’s Impact and Import’. *The Politics of Embodiment* 35 (3): p. 660

41 Bailey, Candice. 2009. ‘Intersexuality Quite Common’. *Iol.Co.Za*. September 19. <https://www.iol.co.za/news/south-africa/intersexuality-quite-common-459039>.

42 Carpenter, Morgan. 2015. ‘Intersex Rights and Freedoms’. <http://morgancarpenter.com/wp-content/uploads/2015/11/carpenter-morgan-2015-intersex-rights-freedoms.pdf>. p.29

43 Pride in Diversity, and Organisation Intersex International Australia. 2014. ‘Employers Guide to Intersex Inclusion’. Pride Diversity and OII Australia. <https://ihra.org.au/wp-content/uploads/key/Employer-Guide-Intersex-Inclusion.pdf> p. 15

44 Larsson, Naomi. 2016. ‘Is the World Finally Waking up to Intersex Rights?’ *The Guardian*. February 10. <http://www.theguardian.com/global-development-professionals-network/2016/feb/10/intersex-human-rights-lgbti-chile-argentina-uganda-costa-rica>.

45 [Published on Oct 31, 2017] <https://www.astraeafoundation.org/stories/global-surveys-trans-intersex-groups-reveal-critical-funding-gap/>

State and Civil Society Approaches and Awareness

In part due to the nature of LGBTI or SOGIESC rights, where intersex is rhetorically included in the concept of sexual orientation and gender identity construction and LGBTI identity construction, it is often believed that intersex people are transgender or non-binary. This can act as a barrier to disclosure for intersex people. It can also lead to lack of respect for an intersex person's experience and actual identity as a heterosexual man or a woman.⁴⁶ Intersex concerns are marginalised if not visible, "a conceptual void that is also mirrored in the absence of funding".⁴⁷

It is also important to be cognisant of "pinkwashing" - the promotion of the gay-friendliness of a state or political entity in an attempt to downplay or soften aspects of it considered negative. This practice includes in an illusion of intersex inclusion within "LGBTI" initiatives where there is rarely any substantive address of the concerns, needs or violations against the intersex community, a conflation of sexual orientation and gender identify with intersex status, and the instrumentalising of intersex issues for the benefit of LGBT communities. In June 2016, Organisation Intersex International Australia pointed to contradictory statements by Australian governments, suggesting that the dignity and rights of LGBT and intersex people are recognized while, at the same time, harmful practices on intersex children continue⁴⁸.

In August 2016, Zwischengeschlecht described actions to promote equality or civil status legislation without action on banning IGM, and including bans of IGM without sanctions and without access to redress for survivors, including adequately prolonging statutes of limitations, as forms of pinkwashing⁴⁹. The organization has previously highlighted evasive government statements to UN Treaty Bodies that conflate intersex, transgender and LGBT issues, instead of addressing harmful practices on infants⁵⁰. Pinkwashing has severe consequences, including fuelling the underfunding of the intersex movement, and unnecessarily prolonging intersex genital mutilations and other violations against intersex people.

It is important that states and civil society are educated when engaging on intersex issues and do so with the meaningful engagement and leadership from intersex activists and communities.

Research

Due to the fact that being intersex is so widely stigmatised and suppressed the need for research is dire. Secrecy about issues such as infanticide may be a stumbling block in substantive research. That, and a scarcity of resources. The research, mentioned in this report on infanticide in the Northern Cape, is one of the limited studies available and even this has struggled to find financing for completion.⁵¹ The effects of this, as one researcher notes can be dire, "if nothing is being done about it, this thing is going to keep happening again and again and again. The thing is, traditional healing is as old as creation, and it does good. Both Western and African medicine have brought us all a lot of good. But with this thing, people are using tradition and culture to protect something which is humanly unacceptable behaviour."⁵²

The lack of available research also affects the possibility of legislation. Karabo Ozah, an attorney at the University of Pretoria's Centre for Child Law, asserts the importance of accepted practices and statistics in considering legislation.

46 Pride in Diversity, and Organisation Intersex International Australia. 2014. 'Employers Guide to Intersex Inclusion'. Pride Diversity and OII Australia. <https://ihra.org.au/wp-content/uploads/key/Employer-Guide-Intersex-Inclusion.pdf> p. 16

47 Christian Ghattas, Dan. 2013. 'Human Rights between the Sexes A Preliminary Study on the Life Situations of Inter* Individuals'. Publication series on democracy 34. Heinrich böll Foundation p. 7

48 "[Submission: list of issues for Australia's Convention Against Torture review](#)". Organisation Intersex International Australia. June 28, 2016.

49 Seelenlos. 2016. "'Intersex legislation' that allows the daily mutilations to continue = PINKWASHING of IGM practices'. August 28. <http://stop.genitalmutilation.org/post/Intersex-politics-that-ignore-the-daily-mutilations-PINKWASHING-OF-IGM-PRACTICES>

50 "[TRANSCRIPTION > UK Questioned over Intersex Genital Mutilations by UN Committee on the Rights of the Child - Gov Non-Answer + Denial](#)". Zwischengeschlecht. May 26, 2016.

51 Collison, Carl. 2018. 'Intersex Babies Killed at Birth Because "They're Bad Omens"'. The M&G Online. January 24. <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens/>.

52 Collison, Carl. 2018. 'Intersex Babies Killed at Birth Because "They're Bad Omens"'. The M&G Online. January 24. <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens/>.

Educational Environments

The lack of education around, and awareness of bodily diversity, in particular intersex traits, creates a hostile and discriminatory environment for intersex youth in schools. The issue of bullying and ostracism in schools is of particular concern to intersex youth. There are no systems and structures in place to ensure consistent and sustainable interventions of teachers on behalf of intersex youth. In many cases, the lack of an organised support system capable of meeting the needs of intersex youth forces intersex learners to enter into a hostile school environment.

There is no mention of gender, sexual, or bodily diversity in the school curriculum. Gender identity, gender expression, intersex variations and sexual orientation are rarely discussed in a manner which ensures inclusivity and a balanced, informed understanding in schools. This has serious consequences for intersex individuals who are not educated about gender and body diversity in their school curriculum. Intersex youth may feel pressured into conforming to the existing sex stereotypes, and the limited non-pathologising information available can pressure youth to undergo invasive and medically unnecessary procedures to do so. This has a detrimental effect on the mental and sexual health of intersex youth as they go through puberty and may result in depression, self-harming and other life-risking behaviour. Intersex persons whose bodies (sex characteristics) do not appear stereotypically female or male are also generally only exposed to sexual orientation terminology or to stigmatising terms that conflate incorrect assumptions about biology and sexual orientation (e.g. *stabane*⁵³). Additionally, they may be exposed in medical settings to highly technical and pathologising medical language (e.g. "disorder", "disease", "malformation", "pathologic", "defect" and "abnormality") about their bodies. This undermines a positive sense of self and causes depression, anxiety and confusion about one's body, identity and belonging. Early social affirmation of body diversity as a healthy manifestation of human diversity, and access to intersex-positive language are crucial for the self-understanding, self-affirmation and healthy mental and sexual development of intersex children and youth.

In 2010 a principal at a school in Ga-Ntatelang village near Kuruman undressed a six-year-old child, who had ambiguous genitalia but preferred to use the girls' toilets, and forced the child to use the boys' toilets instead⁵⁴. This highlights other needs in addition to curriculum reform, including teacher training, privacy, the use of bathrooms, school uniform policy, sports in school, residential arrangements for boarders for example.

Official documents and sex status

It is obligatory to register an infants' sex/gender within a month of an infant's birth in South Africa. There are no special provisions for intersex children. The only sex/gender allowed is male or female. This may be altered at a later stage through the *Alterations of Sex Description and Sex Status Act 49 of 2003*. However, in practice, this remains difficult and in some cases impossible due to negligence and ignorance on the part of Department of Home Affairs staff. There are very few support structures to which intersex families or children can turn when this situation happens. Given the general stigmatisation and silence around intersex existence children and parents often do not have the necessary tools to manage cases such as this.

While South Africa recognises the right of intersex persons to change their sex description, the change is limited to one of two binary categories of male or female. The *Alteration of Sex Description and Sex Status Act 49 of 2003* provides that intersex persons can change their sex description only if they live as their "preferred" sex for an uninterrupted period of two years.

However this requirement is often hard to fulfil as the period will always be interrupted if one is required to move in a world where they carry an "M" identity document but identify as "F", or vice versa, and is a violation of the right to bodily autonomy and self-determination. An additional obstacle in the form of the new smart card ID documents is that whereas in the old green barcoded ID the sex description was a sequence of numbers, the smart card currently explicitly displays either an "M" or an "F".

53 Swarr, A.L. (2009). 'Stabane', intersexuality, and same-sex relationships in South Africa. *Feminist Studies* 35(3): 524–548.

54 John, Victoria. (2012). Gentle man's brutal murder turns spotlight on intolerance. *Mail & Guardian Online*, 28 June 2012. Available at <http://mg.co.za/article/2012-06-28-gentle-mans-brutal-murder-turns-spotlight-on-intolerance>.

Consequently, a change in how the sex descriptor is indicated might be necessary for intersex persons who do not wish to be either “F” or “M”. South Africa may need to follow countries such as Germany and Argentina which provide for a third-gender gender marker or have removed the gender marker entirely for official documents.⁵⁵ It is essential to note however, that reforming legal recognition without addressing substantive issues like intersex infanticide, IGM and access to redress may exacerbate the violations in medical settings experienced by intersex people, and this should therefore not be prioritised above more urgent interventions, or done in isolation⁵⁶.

6. Responsibility of Chapter Nine Institutions

Much of the work of advocating for intersex rights in South Africa is done through NGOs. Most intersex work is, as has been noted, underfunded, and done with transgender work or broader LGBT work, which can have negative consequences for perceptions of what intersex means within broader society and indeed for state institutions.⁵⁷ The reliance on funding and the grouping with LGBT issues has often had negative consequence on organisations in that one or two overly committed individuals often run them. LGBTI or trans NGOs often perpetuate offensive behaviour such as expecting intersex people to prove they are intersex⁵⁸. Indeed as Mokoena points out “we are usually people that were ashamed of our bodies, are isolated, have life-long trauma and are easily taken advantage of by people claiming to have our best interests at heart”.⁵⁹ It cannot be overstressed that intersex people though they can be LGBT can also not be. While NGO involvement is necessary, it is not sufficient, and Chapter Nine institutions also have a role to play. There is a great need for public education about intersex issues, legal intervention and perhaps most importantly institutional change. The simple step, by these institutions, of treating intersex existence as a fact that is an essential part of human diversity, visible globally, is a rights issue and not a pathology would have far reaching consequences. This would mean a possible change in the very approach and function of this institutions. Generally, as institutions established to safeguard democracy Chapter Nine bodies should be considering the following:

- Including intersex infanticide in national studies regarding infants and children. The absence of these figures at a state level perpetuates the silence around intersex existence⁶⁰. Educational drives have been useful particularly in the Northern Cape where the issue of infanticide with regards to intersex infants continued to make headlines from 2015.⁶¹
- It was one of Sally Gross’s great hopes that a modest directorate be set up to address intersex issues within the “Department for Women, Children, and Persons with Disabilities with a mandate to engage with other Departments regarding the rights and needs of the intersex, [which] could achieve a great deal at minimal cost”⁶²
- Medical school content and interventions particularly at public university hospitals and clinics
- Ensure that human rights violations against intersex people are investigated and alleged perpetrators prosecuted and that victims of such violations have access to effective remedy, including redress and compensation.⁶³
- Active engagement with intersex needs and people.
- Include the voices of intersex people and groups in newspaper, TV and radio campaigns.⁶⁴ Especially when those campaigns are not intersex or LGBT specific
- Support intersex inclusion in health and human rights initiatives.
- Change language and frame of reference. Intersex status is distinct from sexual orientation, gender identity and gender expression.

55 Nandi, Jacinta. 2013. ‘Germany Got It Right by Offering a Third Gender Option on Birth Certificates’. *The Guardian*. November 10. <http://www.theguardian.com/commentisfree/2013/nov/10/germany-third-gender-birth-certificate>.

56 Seelenlos. 2016. “Intersex legislation” that allows the daily mutilations to continue = PINKWASHING of IGM practices. August 28. <http://stop.genitalmutilation.org/post/Intersex-politics-that-ignore-the-daily-mutilations-PINKWASHING-OF-IGM-PRACTICES>

57 Mokoena, Nthabiseng. 2015. ‘Remembering Sally, and the Intersex Movement in South Africa’. *Intersex Day*. October 22. <http://intersexday.org/en/remembering-sally-south-africa/>.

58 Mokoena, Nthabiseng. 2015. ‘Remembering Sally, and the Intersex Movement in South Africa’. *Intersex Day*. October 22. <http://intersexday.org/en/remembering-sally-south-africa/>.

59 Mokoena, Nthabiseng. 2015. ‘Remembering Sally, and the Intersex Movement in South Africa’. *Intersex Day*. October 22. <http://intersexday.org/en/remembering-sally-south-africa/>.

60 Collison, Carl. 2018. ‘Intersex Babies Killed at Birth Because “They’re Bad Omens”’. *The M&G Online*. January 24. <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens/>.

61 Collison, Carl. 2018. ‘Intersex Babies Killed at Birth Because “They’re Bad Omens”’. *The M&G Online*. January 24. <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens/>.

62 Gross, Sally, and Rosemary Lennox. 2017. ‘Diversity in Nature’. *Intersex South Africa*. October 1. <http://www.intersex.org.za/>.

63 Free & Equal: United Nations for LGBT Equality. 2018. ‘Fact Sheet: Intersex’. United Nations Human Rights Office of the High Commissioner. Accessed March 17. https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf.

64 Free & Equal: United Nations for LGBT Equality. 2018. ‘Fact Sheet: Intersex’. United Nations Human Rights Office of the High Commissioner. Accessed March 17. https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf.

- Include intersex issues in education and service access policies, and in employment, diversity and inclusion, and anti-bullying strategies.
- Consider whether and where your institution needs to collect data on sex, gender and title. Recognise the diversity of intersex people.
- Put people with intersex variations and intersex-led organisations front and centre when talking about issues related to intersex.⁶⁵
- Share intersex issues on social media.⁶⁶
- When creating surveys with a wish to include intersex people, the question might be:

Intersex is a term for people born with atypical physical sex characteristics. There are many different intersex traits or variations. Do you have an intersex variation? Yes/No⁶⁷ Or Were you born with a variation of sex characteristics (this is sometimes called intersex)?⁶⁸

- Intensify the collaboration with and support of intersex individuals and organisations
- Take into consideration intersex individuals and issues across all areas of work be it health issues, education, gender democracy, labour, migration, sex work, etc. and to examine project proposals as to whether they include and enable intersex individuals to participate.⁶⁹
- Use the term intersex. Stigmatising language leads to poor mental health, marginalisation, and exclusion from human rights and social institutions. The term intersex promotes equality and human rights for people born with atypical sex characteristics.⁷⁰
- Consider how you can manage any school or workplace dress codes to support bodily diversity associated with intersex and other differences. Lead by example.⁷¹
- Before you ask anyone for information on sex or gender, ask yourself if, when and how this information is relevant. While it might be important, along with other demographic data, for some statistical, and diversity and inclusion, purposes, it may not be required for other purposes⁷²
- The provision of documents that are intersex inclusive such to raise awareness in all sectors of the institutions work

Chapter 9 institutions such as the Commission for Gender Equality, the South African Human Rights Commission and Public Protector in particular need to act as a catalyst⁷³ around intersex issues

- Consider extending the institutional language to all sexes as opposed to 'both sexes' or 'different gender and sexes.'
- Introduce legislation to prohibit IGM, and legislation more generally should be screened with implications for intersex people⁷⁴
- Streamlining of Act 49 along with the implementation of protocols to guide frontline Home Affairs service staff⁷⁵, and considering amendments to make it in line with international human rights standards. Act 49 has never been implemented in South Africa in accordance with its own provisions "and consequently undermines its progressive potential and other national and international rights".⁷⁶
- Intersex people should always be consulted in the development of legislation and policies that impact on their rights.

65 Carpenter, Morgan. 2012. 'Intersex for Allies'. *Intersex Human Rights Australia*. November 21. <https://ihra.org.au/allies/>.

66 Carpenter, Morgan. 2012. 'Intersex for Allies'. *Intersex Human Rights Australia*. November 21. <https://ihra.org.au/allies/>.

67 Carpenter, Morgan. 2012. 'Including Intersex People in Forms, Studies and Surveys'. *Intersex Human Rights Australia*. May 25. <https://ihra.org.au/forms/>.

68 Carpenter, Morgan. 2012. 'Including Intersex People in Forms, Studies and Surveys'. *Intersex Human Rights Australia*. May 25. <https://ihra.org.au/forms/>.

69 Christian Ghattas, Dan. 2013. 'Human Rights between the Sexes A Preliminary Study on the Life Situations of Inter* Individuals'. Publication series on democracy 34. Heinrich böll Foundation p. 30

70 Pride in Diversity, and Organisation Intersex International Australia. 2014. 'Employers Guide to Intersex Inclusion'. Pride Diversity and OII Australia. <https://ihra.org.au/wp-content/uploads/key/Employer-Guide-Intersex-Inclusion.pdf>. p. 11

71 Pride in Diversity, and Organisation Intersex International Australia. 2014. 'Employers Guide to Intersex Inclusion'. Pride Diversity and OII Australia. <https://ihra.org.au/wp-content/uploads/key/Employer-Guide-Intersex-Inclusion.pdf>. p. 17

72 Pride in Diversity, and Organisation Intersex International Australia. 2014. 'Employers Guide to Intersex Inclusion'. Pride Diversity and OII Australia. <https://ihra.org.au/wp-content/uploads/key/Employer-Guide-Intersex-Inclusion.pdf>. p. 19

73 Gross, Sally, and Sylvia Tamale. 2011. 'And Intersexed Activists Journey'. In *African Sexualities Reader*, 245–237. Cape Town: Pambakuza Press p. 237

74 Gross, Sally, and Rosemary Lennox. 2017. 'Diversity in Nature'. *Intersex South Africa*. October 1. <http://www.intersex.org.za/>.

75 Williams, Denise. 2012. 'Silent Discrimination'. *Timeslive*. November 27. <https://www.timeslive.co.za/news/south-africa/2012-11-27-silent-discrimination/>.

76 Hurt, Sally. 2015. 'South Africa: The State versus Identity'. *MambaOnline - Gay South Africa Online*. February 17. <http://www.mambaonline.com/2015/02/17/south-africa-state-versus-identity/>.

- Prohibit discrimination on the basis of intersex traits, characteristics or status, including in education, health care, employment, sports and access to public services, and address such discrimination through relevant anti-discrimination initiatives.⁷⁷
- National human rights bodies should research and monitor the human rights situation of intersex people.⁷⁸
- Reaching intersex populations means using tailored channels, not merely appealing to those identifying as LGBTI as this is unlikely to attract many intersex people⁷⁹
- Collection of stats and research, appropriate counselling, workshops for medical professionals, getting intersex issues covered from a rights perspective in medical-school curricula and the like, protocols for classification of sex at birth, making provisions for intersex people if admitted to hospital to ensure dignity in treatment, dignified treatment when in contact with the prison system and correctional affairs⁸⁰

77 Free & Equal: United Nations for LGBT Equality. 2018. 'Fact Sheet: Intersex'. United Nations Human Rights Office of the High Commissioner. Accessed March 17. https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf.

78 Free & Equal: United Nations for LGBT Equality. 2018. 'Fact Sheet: Intersex'. United Nations Human Rights Office of the High Commissioner. Accessed March 17. https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf.

79 Carpenter, Morgan. 2012. 'Including Intersex People in Forms, Studies and Surveys'. *Intersex Human Rights Australia*. May 25. <https://ihra.org.au/forms/>.

80 Gross, Sally.N.D. 'Intersex Initiative: Response on the Mistreatment of Caster Semenya'. *Intersex Initiative*. Accessed March 17. <http://www.intersexinitiative.org/media/castersemenya.html>.

IV. Recommendations

There is an extensive body of work from a variety of international and regional organisations, which has set out the need for legislative and other interventions to eradicate the continued human rights violations of intersex children and adults. It is vital that in addressing these violations and working through solutions we involve and centre the people who experience violations.

Legal interventions

- Banning IGM surgeries in medical settings
- Enactment of self-standing legislation/directives to deal concretely with surgical and hormonal interventions on intersex children
- Amendment of Children's Act – include recognition the right to consent to surgical intervention by intersex children
- Amendment of Sterilization Act to cover intersex surgeries which may have a sterilising effect on children
- Definition of what would be considered medically necessary interventions on intersex children
- Making provision for redress and reparations for intersex adults, including adequately prolonging statutes of limitations
- Revision of the Alternation of Sex Description and Sex Status Act 49 of 2003

Medical and Health interventions

- Sensitization workshops for doctors and students including nursing students and assistants.
- Curriculum – inclusion of ethics and human rights modules in medical schools.
- Clear protocols on what must happen when a child with an intersex variation is born
- Clear medical definitions of "intersex", "medical necessary."
- Establishment of strategic contact points – a network of doctors & specialists consulting & supervising on alternative methods of medical intervention

Research

- Impact studies for intersex people in South Africa including longitudinal follow up studies and cross-sectional studies
- Auditing hospital logs for intersex-related surgeries with the intention of determining;
 - who is signing off on these studies;
 - how many surgeries are occurring annually; and
 - who is paying for them – including private medical aids where applicable

Community health

- Include awareness and education at prenatal clinics and community health workers in order to address the psychosocial needs of parents who receive information on intersex variations for the first time at the birth of their children.
- Training for traditional birth attendants, midwives and traditional healers on intersex traits

Awareness and Education

- Need to increase the knowledge people have about intersex people – speak to human rights-based organisations about intersex persons in order to have an understanding of how they can educate the communities they work with
- Self-education of activists and persons who work in the field of human rights – activists need to be able to speak from fact in order to limit confusion and misinformation about intersex variations, and avoid spreading misconceptions
- NGOs with national footprints – well known and host/create pathways of communication to communities
- Essential to create messaging, which is understandable across educational and classed backgrounds – "uncomplicate" the term intersex.
- Important to use important language context – it is important to understand how information in a rural setting is consumed versus urban context.
- Use of indigenous languages in messaging is vital
- It is essential that the distinction be made to limit conflation of sexual orientation, gender identity and intersex variations and ensure that the needs of the intersex community are adequately met

V. Conclusion

On the 16th September, 2015 was the first time that UN convened a discussion specifically to discuss the human rights of intersex people. The High Commissioner noted “When I started as High Commissioner a year ago, I knew little about intersex people. I don’t think I was alone in this: it reflects a general lack of awareness. Too many people assume, without really thinking about it, that everyone can be fitted into two distinct and mutually exclusive categories: male or female”⁸¹

This, unfortunately, continues to be the case both globally and in South Africa specifically. Addressing the rights of intersex people means both acknowledging the diversity of human bodies and shifting language. It means ensuring that infants are not subject to invasive and unnecessary surgical procedures to ‘normalise’ their bodies. Moreover, intersex people have the right to be informed about their intersex status and to make their own choices regarding their bodies, the right to determine their own identities.⁸² In essence, we are talking about the right to bodily integrity and self-determination. The notion that human beings are born into one of two distinct and separate sexes is deep-rooted and contributes to an ongoing taboo and stigma regarding intersex lives. This culture of silence perpetuates a legacy of shame and secrecy along with the invisibility of intersex lives. It also prevents families and individuals from pursuing a model of full, free and informed consent.

Addressing the needs of intersex South Africans means recognising diversity, understanding the history of medical gatekeeping particularly with its relationship to Apartheid notions of race and class and advancing legislation to address IGM and indeed the murders and death of intersex infants. As Rebecca Steinfeld and Brian Earp argue, and this is particularly true for Constitutional democracies, founded on a legacy of equality “Whatever specific policies are implemented, however, what is clear is that fundamentally different treatment of female, male, and intersex children—with respect to the preservation of their bodily integrity—will become increasingly difficult to justify in the coming years.”⁸³

81 Ra’ad Al Hussein, Zeid. 2015. ‘Opening Remarks by Zeid Ra’ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert Meeting on Ending Human Rights Violations against Intersex Persons’. OHCHR. September. <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E>.

82 Carpenter, Morgan. 2015. ‘Intersex Rights and Freedoms’. <http://morgancarpenter.com/wp-content/uploads/2015/11/carpenter-morgan-2015-intersex-rights-freedoms.pdf>. p. 29

83 Steinfeld, Rebecca, and Brian D. Earp. 2017. ‘Gender and Genital Cutting: A New Paradigm’. Euromind. April 6. <http://euromind.global/en/brian-d-earp-and-rebecca-steinfeld/>.

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