

Original Research Article

Intersexuality: What Primary and Specialized Healthcare Providers Should Know and Do to End Cosmetic and Harmful Medical Practices on Infants and Children Born with Intersex Variations in Tanzania

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Abstract: The Public Statement by the African Intersex Movement, 2017 extends demands to end discrimination against persons born with intersex variations in Africa through legislative and other means. Cosmetic, irreversible and harmful medical and clinical procedures infants and children born with intersex variations have been subject to include unconsented and medically unnecessary surgeries, mutilation and sterilization that cause irreversible physical and psychological harm. I demonstrate, Tanzania a signatory to The Human Rights Charter is mandated to follow the same route to ensure persons born with intersex variations live and enjoy the right to quality and equitable health and healthcare available without discrimination. To date, however, it is unclear what measures Tanzanian government has taken to prohibit medically unnecessary surgeries and procedures on infants and children born with intersex variations. Similarly, no enacted law banning harmful medical and clinical variations on infants and children born with intersex variations in this country; suggesting violation of intersex rights is ongoing. Data presented in this paper come from desk research I conducted on intersexuality in Tanzania and beyond. I conclude awareness of intersex conditions is increasing among researchers, persons born with intersex variations, parents/guardians, activists and the media. This increase would come with increasing horror, which may stimulate legal reform. I recommend primary and specialized care providers, and the Tanzania government in particular, ought not to wait for this dishonor to surface — rather should act now to end cosmetic and harmful surgeries and protect vulnerable infants and children born with intersex variations in this country.

Keywords: Intersexuality, intersex rights, intersex variations, persons born with intersex variations, medical and clinical intersexuality research, desk research, Tanzania.

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INTRODUCTION

The First Ever African Intersex Meeting took place at the Centre for Human Rights at the University of Pretoria, in Johannesburg, South Africa from the 24th to 26th November 2017. The Participants (22 intersex people representing intersex organizations from 7 African countries) drafted a Public Statement to extend demands aiming to end discrimination against persons born with intersex variations (PBWIVs) in Africa, and to ensure the right of bodily integrity, physical autonomy and self-determination. The Public Statement by the African Intersex Movement, in part, states,

“We affirm that intersex people are real, and we exist in all countries of Africa. As intersex people in Africa, we live in a society that perpetuates violence and killings of intersex people by cultural, religious, traditional and medical beliefs and practices [my emphasis]. Therefore, we must be supported to be the drivers of social, political and legislative changes that concern us ...”

From the biomedical perspective, The Public Statement extends demands including: 1) “To put an end to mutilating and ‘normalizing’ practices such as genital surgeries, psychological and other medical treatments

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through legislative and other means (such as education, policy and treatment protocol change) ... Intersex people must be empowered to make their own decisions affecting their own bodily integrity, physical autonomy and self-determination”; 2) “To include intersex education in antenatal counseling and support; 3) “To put an end to non-consensual sterilization of intersex people”; 4) “To depathologise variations in sex characteristics in medical practices, guidelines, protocols and classifications, such as the World Health Organization’s International Classification of Diseases”; 5) “To ensure that sex or gender classifications are amendable through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), intersex or multiple options. In the future, sex or gender should not be a category on birth certificates or identification documents for anybody”; 6) “To ensure that intersex people have the right to full information and access to their own medical records and history”; 7) “To ensure that all professionals and healthcare providers that have a specific role to play in intersex people’s well-being are adequately trained to provide quality services”; and 8) “To acknowledge the suffering and injustice caused to intersex people”.

In this paper, I demonstrate that Tanzania is not different from the seven African countries represented at The First African Intersex Meeting in South Africa that drafted The Public Statement to extend demands and calls aiming, among others, to end forced, non-consensual, irreversible and scientifically unjustified ‘normalization’ and sterilization medical and clinical procedures against PBWIVs in Africa through legislative and policy. Certainly, Tanzania, a signatory to The Human Rights Charter would wish to follow the same route to ensure PBWIVs live and enjoy constitutional and human rights — including the right to quality and equitable health and healthcare available — without discrimination geared at ending medical injustice persons born with intersex variations undergo throughout their life courses. Inopportunistly, Tanzania lacks evidence on consequences of non-consensual medical and clinical procedures infants and children born with intersex variations are subjected to, a bottleneck that would hamper fulfilling this African and global mission to ensure the right of bodily integrity, physical autonomy and self-determination among PBWIVs in the country.

Importantly, perhaps, is that Tanzania lacks intersex-specific healthcare provision guidelines and strategies to empower PBWIVs to make their own decisions affecting their own bodily integrity, physical autonomy and self-determination as per The Public Statement by the African Intersex Movement, 2017. Furthermore, Tanzania lacks data on types of harmful medical and clinical procedures to which (primary and specialized) care providers forcefully and coercively subject infants and children born with intersex variations and harm caused to the victims and their families. To

generate data presented in this paper, I collected and reviewed (desk review) different documents on intersexuality including: published and unpublished research reports in Tanzania, the region and globally; media information; magazines; newspapers; formal and informal reports; published papers; grey literature and conducted formal and informal discussions with interested parties — members of intersex organizations and activists, researchers and medical doctors — in Tanzania.

WHY WORRY ABOUT INTERSEXUALITY IN TANZANIA NOW THAN BEFORE — A MEDICAL/CLINICAL LENS

On November 10, 2016, The United Nations (UN) issued a statement signed by UN Treaty bodies, including The African Commission on Human and Peoples’ Rights, urging governments to prohibit harmful medical and clinical practices on infants and children born with intersex variations, including unnecessary, forced and coercive medical and clinical procedures [surgery, sterilization, intersex genital mutilating (IGM), and treatment] without their full informed consent. The Statement underlines, “States must, as a matter of urgency, prohibit medically unnecessary surgery and procedures on intersex children. Intersex children should be the only ones who decide whether they wish to modify the appearance of their own bodies”. In addition, beginning in 1980s and 1990s, PBWIVs and activists have criticized the traditional intersex management model — the 1950-developed medical intersex management model — lobbying and advocating for a new intersex-centered approach as outlined in the Clinical Guidelines for the Management of Disorders of Sex Development (CMDSD 2006).

Furthermore, many countries have signed up the Vienna Declaration and Programme of Action, 1993 taking stern measures including legislative and policy establishment and or amendment outlawing surgical procedures on infants and children born with intersex variations. Moreover, the UN, PBWIVs and activists demand compensation and psychosocial support to PBWIVs subjected to cosmetic ‘normalizing’ surgeries.

At the time of writing this paper it was unclear what measures has the Tanzanian government taken to prohibit medically unnecessary surgeries and procedures on infants and children born with intersex variations as per the UN 2016 Statement and The Public Statement by the African Intersex Movement, 2017. Similarly, it was unclear if Tanzania has ratified the Vienna Declaration and Programme of Action, 1993 as there is no enacted law banning harmful medical and clinical procedures on infants and children born with intersex variations in this country. Intersex activism and movement are in the embryo stage in Tanzania; hence, there is no evidence of individuals, groups or intersex organizations that have openly criticized and pressured the government to mandate healthcare providers to employ the model for

medical intersex management supported by many intersex and activists outlined in the Clinical Guidelines for the Management of Disorders of Sex Development (CMDSD 2006).

In the absence of evidence on what strategies the Tanzania government has put in place and achieved in this direction, I use scanty information available and experiences from other countries to demonstrate what primary and specialized healthcare providers in Tanzania should know and do to end cosmetic and harmful practices on infants and children born with intersex variations and to ensure PBWIVs have access to quality and equitable health and healthcare services available in this country.

1. Medical management of intersex variations — A critique to the medical model

The traditional medical management of intersex is largely based on the theory and practice developed at Johns Hopkins University (JHU) in the 1950s by Dr. John Money and colleagues (Cohen, 2021; Pereira, 2022). ‘The medical intersex management model/theory’, ‘the Hopkins model’ or ‘the optimum gender of rearing’ model (ISNA, n.d. a) conceptualizes gender identity as workable and early surgery as necessary. Although in some cases, genital ambiguity is a sign of an underlying medical condition (such as the salt-wasting form of CAH), in most cases, medical treatment of intersex is socially ‘normalizing’ (rather than medically necessary) (ISNA, n.d. a). The medical model for managing intersex variations asserts there are ‘universally accepted sizes, shapes and standards of vagina and penis (Pereira, 2022).

That is, on the one hand, males must have a ‘standard’ penis, generally defined as “capable of vaginal penetration and urination while standing” (InterAct, n.d.a; Cara, 2002; ISNA, 2008; Pereira, 2022). Consequently, most infants with ambiguous genitalia are assigned as females (excluding XY infants with hypospadias, who often undergo surgeries to move their urethras to the tips of their penises). On the other hand, an infant with a large clitoris who is assigned as female will often undergo socially ‘normalizing’ surgery to reduce her clitoris (Pereira, 2022). An infant assigned as female with a small or absent vagina may have a vaginoplasty performed (InterAct, n.d. a; Pereira, 2022). An ‘adequate’ vagina, therefore, “is defined as one that is large enough for penetration by a [standard] penis” (Cara, 2002; Pereira, 2022). These standards for acceptable genitalia have been critiqued as mere social constructs and both heterosexist and phallogocentric (Cohen, 2021; Pereira, 2022).

Intersex activists and scholars critique the JHU medical model for several reasons. First, the model supports and encourages doctors to perform medically unnecessary, unscientifically grounded, costly, harmful and stigmatizing surgeries to infants and children born

with intersex variations. Second, doctors conduct ‘normalization’ procedures to infants and children born with intersex variations without their consent (Cohen, 2021). Whenever doctors seek consent, they often pressure desperate, heartbroken and ill-informed (on short- and long- term impacts of such procedures) parents and guardians to consent to surgery. In fact, the doctors make the decisions for patients (ISNA, n.d. a). Three, in most cases, ‘normalization’ procedures are criticized as being unscientific, rarely medically necessary, potentially harmful and contributing to stigma and discrimination. In fact, medical professionals were (and still are) unable to produce an intersex patient satisfied with his/her childhood treatment (ISNA, n.d. a).

The surgeries can cause new physical problems as a result of surgery and hormone treatments including reducing sexual functioning, stigma, scarring, low self-esteem, pain, (urinary) incontinence, urinary tract infections (UTIs), lifelong depression and causing irreversible physical psychological damage and mental health as a result of medical practices (Cleveland Clinic, n.d.; Creighton, *et al.*, 2001; Davis, 2013; Nelson, 2018; Clifton, 2020; Richmond, 2021; Cohen, 2021; Haug, 2021; Middleton, 2023). Finally, the model promotes secrecy and failure to be transparent and honest with intersex ‘patients’ about their health conditions and management plans (Cleveland Clinic, n.d.; Davis, 2013; Pereira, 2022). Intersex ‘patients’ have habitually been denied access to their treatment records, which subjects them to repeated counseling and diagnosis and denies them peer support and accessing consented medical treatments (Creighton, 2001; Nelson, 2018).

The model for the medical management of intersex supported by many PBWIVs and activists is outlined in the Clinical Guidelines for the Management of Disorders of Sex Development (CMDSD 2006) (ISNA, 2006). It suffices mentioning here that the key components of the procedure include: (1) using a patient-centered multidisciplinary team comprised of at least one patient and multiple health professionals from several different disciplines including: pediatric gynecology, neonatology, nursing, genetics, pediatric urology, endocrinology, psychology, counselling, mental health, medical ethics, and a social work (New York City, n.d.); (2) assigning the infant a sex based on all available information (not just the appearance of the genitals); (3) delaying unnecessary medical treatment so that the ‘patient’ can decide when/if to have ‘normalizing’ genital surgery or hormone treatments; (4) promoting honesty and openness with the family in order to reduce shame and stigma; and (5) providing the necessary psychosocial support.

Specifically, the Patient-Centered Model recommends (ISNA, n.d. a):

- Children with intersex, parents of those children, and adults with intersex should be treated in an open, shame-free, supportive, and

honest way. They should consistently be told the truth (this includes providers being honest about uncertainty), and should be given copies of medical records as soon and as often as they ask for them.

- Children and adults with intersex, and their family members, should be provided with access to trained psychologists and social workers, especially when they are in distress (as some parents of newborns with intersex are). Parental distress should not be treated with “normalizing” surgery on children, nor should surgeons, endocrinologists, and other non-psycho-social specialists attempt to cover family’s counseling needs.
- Care providers should also attempt to connect children and adults with intersex and parents of children with intersex so that they can give each other peer support outside of the clinical setting. This helps validate their feelings and experiences. Peer support saves families and lives.
- Following diagnostic work-up, newborns with intersex should be given a gender assignment as boy or girl, depending on which of those genders the child is more likely to feel as she or he grows up. Note that gender assignment does not involve surgery; it involves assigning a label as boy or girl to a child. (Genital “normalizing” surgery does not create or cement a gender identity; it just takes tissue away that they patient may want later).
- Medical procedures necessary to sustain the physical health of a child should be performed. Examples of these would be endocrinological treatment of a child with salt-wasting congenital hyperplasia, or surgery to provide a urinary drainage opening when a child is born without one; and,
- Surgeries done to make the genitals look “more normal” should not be performed until a child is mature enough to make an informed decision for herself or himself. Before the patient makes a decision, she or he should be introduced to patients who have and have not had the surgery. Once she or he is fully informed, she or he should be provided access to a patient-centered surgeon.

Currently, there is no law in Tanzania prohibiting the imposition of surgery on infants and children born with intersex variations, which has the sole purpose of altering external genitalia to match societal norms. This legal silence is not at all neutral; but actually, facilitates harmful practices to happen uncontrolled. This observation suggests primary and specialized care providers in this country are continuously subjecting infants and children born with intersex variations to harmful ‘normalization’ surgeries and treatment (See CHESO, 2019). However, primary and specialized care

providers in this country ought to know that ‘normalizing’ surgeries forced on infants and children born with intersex variations are medically unnecessary, medically unethical, harmful and have lifelong implications to the health and wellbeing of this group. ‘Normalizing’ surgeries, therefore, face strong and widespread condemnation from international human rights bodies including The Universal Declaration of Human Rights.

Similarly, primary and specialized care providers in this country ought to know that despite the good intentions they may have to conduct ‘normalizing’ surgeries on infants and children born with intersex variations, the practices violate this group’s human and citizenship rights. If at all necessary, primary and specialized care providers in this country should and are mandated to follow the Patient-Centered Model to provide honest and transparent care to PBWIVs in this country. Primary and specialized care providers ought to know that PBWIVs, like the endosex patients, have the right to be informed of their treatment options and associated risks, to determine their own course of treatment, and to be protected from harmful and unnecessary procedures. Performing unnecessary surgeries on infants and children born with intersex variations fails to live up to medical ethics and violates the bodily autonomy of this population group.

In the author’s view, awareness of intersex conditions is (slowly) increasing among researchers, PBWIVs, parents/ guardians, activists and the media in this country. This increase of awareness is likely to come with increasing horror, which may provide the stimulus for legal reform. Primary and specialized care providers, the Medical Association of Tanzania (MAT) and the Tanzania government in particular, ought not to wait for this dishonor to surface — rather should act now to end cosmetic and harmful surgeries and protect vulnerable infants and children born with intersex variations in this country as per (just to name a few) The UN Declarations, The Vienna Declaration and Programme of Action 1993; The Malta Declaration, 2013, The African Intersex Movement, 2017 and The African Commission on Human & Peoples’ Rights, 2022.

2. Interdiction of surgical procedures on infants and children born with intersex variations – A global trend

Following the Malta Declaration, 2013, Malta was the first country to ban unnecessary surgeries on infants and children born with sex variations in 2015 (Richmond, 2021; Pepy, 2022) and following the The UN Statement, 2021 calling for concrete measures to protect intersex people from discrimination and abuse, including medical surgeries, more than 50 countries (Factora, 2021; Middleton, 2023) signed it including: Germany (2021), Greece, Iceland (2021), Spain, India, Mexico, Ukraine, United States (US) and Portugal (2019). Other countries such as Austria, Cyprus and France have also tabled proposals for bans (Middleton,

2023). In Africa, Ghana, Kenya, Nigeria, South Africa, Namibia and Uganda, for instance, have outlawed surgical procedures on infants and children born with intersex variations.

Tanzania faces legal silence on harmful, coercive, cosmetic and unnecessary ‘normalizing’ medical and clinical procedures and treatment forced on infants and children born with intersex variations, which could be enabling these practices to continue unnoticed and uncontrolled thus causing more harm to this group in the country. Comprehensive public health and medical and clinical intersexuality research to be conducted in this country should generate evidence to inform policymakers on the negative effects of legal silence on the health and wellbeing of PBWIVs and their families in Tanzania and the urgency of introducing bills to prohibit intersex surgery.

3. Intersex defined: clinical nomenclature and group construction

Historically, someone who has some or all of the primary sex characteristics of both genders was referred to as ‘sex reversal’, ‘pseudohermaphrodite’, ‘eunuchs’ or ‘hermaphrodite’ (RHO, 2011; GenderGP, 2020; Hartney, 2023) terms used till the beginning of the 20th Century (UNDP, 2018). The term for intersex condition, therefore, was ‘hermaphroditism’, which came from joining the names of a Greek god and goddess, Hermes and Aphrodite (MIU, n.d.). Hermes was a god of male sexuality (among other things) and Aphrodite a goddess of female sexuality, love, and beauty. Hence, hermaphrodite means “a person or animal having both male and female sex organs.”

In science (biology), however, the term is used to describe organisms (mainly plants than animals) that have both female and male sex organs (Hartney, 2023). The term, therefore, classifies intersex persons as either ‘female’ or ‘male’ depending on predominant characteristics (Carpenter, 2018a; 2018b). Currently, however, PBWIVs, parents/ guardians and activists perceive the term hermaphrodite mythological, pathologizing, dehumanizing, misleading, confusing, insensitive, discriminatory, slur, derisory, derogatory, offensive, pejorative, and stigmatizing (MIU, n.d.; Cleveland Clinic, 2001; Lundberg, *et al.*, 2018; Carpenter, 2019a; GenderGP, 2020; Weiss, 2023; Hartney, 2023). However, some PBWIVs may choose to reclaim the word (Leonard, 2012) but should never be used to describe others (Klein, 2021).

Technically, intersex is defined as “congenital anomaly of the reproductive and sexual system” (Wilson, 2012). There is no single ‘intersex body’; it encompasses a wide variety of conditions that do not have anything in common except that they are deemed ‘abnormal’ by the society. It should be noted, however, that “Being transgender or gender diverse is different from having intersex variations (although a small number of children

are both) ... Intersex refers specifically to being born with variations in chromosomes, genitals, and or reproductive organs, and not to a person’s gender” (APA, n.d). Intersex situations are a variety of conditions that lead to atypical development of physical sex characteristics collectively referred to by contested terms though (Carpenter, 2019) as ‘Disorders of Sex Development (DSDs)’, ‘Variations in Sex Characteristics (VSC)’ or ‘Diverse Sex Development’; ‘Disorders or Differences of Sex Development’, ‘innate variations of sex characteristics’ or ‘conditions associated with reproductive development’ (Amnesty International, 2018a; 2018b; Victoria; 2019a, 2019b; GenderGP, 2020; Carpenter, 2021). These conditions can involve abnormalities of the external genitals, internal reproductive organs, sex chromosomes, or sex-related hormones (Victoria, 2019).

In the view of some intersex activists like Carpenter (2019), these medical terminologies are “offensive and contested”. For example, the use of the concept ‘disorder’ informs ‘something is wrong’ and should be ‘medically fixed or normalized’ (Richmond, 2021). This understanding, unfortunately, has for a long time informed unconsented and unnecessary surgery performed on infants, children and even adults born with intersex variations. According to the APA (2006), such conditions include: external genitals that cannot be easily classified as ‘male’ or ‘female’; incomplete or unusual development of the internal reproductive organs; inconsistency between the external genitals and the internal reproductive organs; abnormalities of the sex chromosomes; abnormal development of the testes or ovaries; over- or underproduction of sex-related hormones and inability of the body to respond normally to sex-related hormones.

A detailed diagnosis or diagnostic grouping of PBWIVs is presented in other works like: Amnesty International. n.d.; InterACT. n.d. c; MIU, n.d.; Gold, 2001; Rich, *et al.*, 2016; Amnesty International, 2018b; UNDP, 2018; GenderGP, 2020; Carpenter, 2021; Bashforth, 2022 and Weiss, 2023 and beyond the scope of this paper. It suffices noting that there are many contested sex chromosome variations. The Victoria State Government, for example, noted “There are more than 30 intersex variations that can affect people in different ways [and] can result from chromosomal, hormonal and/or anatomical differences” (Victoria, 2019b). TransFaith InterSections (n.d.) and Richmond (2021) observed there are as many as 40 or more conditions that fit the intersex classification. The Organization Intersex Human Rights Australia states that there are at least 40 known intersex variations (APA, n.d.; Leonard, 2012; Kuehnle, 2021) with diverse characteristics, including genetic, anatomic and chromosomal variations (Carpenter, 2019c). The Kenya National Commission on Human Rights (KNCHR, n.d.) reported “There are as many as 46 of physiological sex characteristics that are intersex”. GenderGP (2020) observed there are 40+

conditions that meet the intersex classification in the United Kingdom (UK).

Relevant diagnoses include: androgen insensitivity, congenital adrenal hyperplasia (CAH) with XX or mosaic sex chromosomes, 5 α reductase deficiency, 17 β hydroxysteroid dehydrogenase 3 deficiency, gonadal dysgenesis, micropenis, Klinefelter syndrome, Kallmann syndrome, Mayer-Rokitansky-Küster syndrome (MRKH, müllerian agenesis, vaginal agenesis), Swyer syndrome, mosaicism involving sex chromosomes, müllerian (duct) aplasia, ovo-testes, progestin induced virilisation, Turner's syndrome/X0 (TS), Triple-X syndrome (XXX) and XY gonadal dysgenesis (MIU, n.d.; Gold, 2001; IHRA, 2013; IHRA, 2016; Carpenter, 2021; Kuehnle, 2021; interactadvocates.org. 2021).

What is disturbing, perhaps, is that doctors do not agree on what should count as 'intersex'. According to InterAct (n.d. a),

Some [doctors] think you [intersex] have to have 'ambiguous genitalia' to count as intersex, even if your inside is mostly of one sex and your outside is mostly of another ... Some think your brain has to be exposed to an unusual mix of hormones prenatally to count as intersex—so that even if you're born with atypical genitalia, you're not intersex unless your brain experienced atypical development ... And some think you [intersex] have to have both ovarian and testicular tissue to count as intersex.

Comprehensive medical and clinical intersexuality research to be conducted in Tanzania should, among other objectives, establish how the naming of different intersex variations by primary and specialized care providers in this country has affected the health and wellbeing of PBWIVs and their families. In addition, these studies should uncover how PBWIVs' experience with the healthcare system influences their current health seeking behaviors for their intersex variations and other health problems they and their families face.

4. How common is intersex?

According to experts, between 0.05 and 1.7 percent of the population is born with intersex variations (FREE & EQUAL, 2017; UNDP, 2018; GenderGP, 2020; Kuehnle, 2021). InterACT (n.d. b) estimated intersex characteristics occur in 1 of every 1500 to 1 of every 2000 births (See also APA, 2006; RHO, 2011). Blackless, *et al.*, (2000) estimated that as many as 1 in 100 people may have hormonal, anatomical, or chromosomal variations that fall outside of what is typically understood as typically 'female' or 'male' (See also Gold, 2001; Klein, 2021). The Cleveland Clinic (2022) reported around 2 percent of people worldwide have intersex variations (See also Victoria, 2019c; Hartney, 2023; nyc.gov. 2023). The Amnesty International (2018a) reported "There are millions of

people around the world who have sexual characteristics that do not fit typical binary notions of male or female bodies. Many, though not all, of these people identify as intersex" (see also Victoria, 2019c).

Blackless, *et al.*, (2000) surveyed the medical literature from 1955 to 2000 for studies of the frequency of deviation from the ideal 'male' or 'female' concluded, "this frequency may be as high as 2 percent of live births". The frequency of individuals receiving 'corrective' genital surgery, however, probably runs between 1 and 2 per 1,000 live births. In Australia and New Zealand, the estimates range from one in 2000 births to four per cent of the population or a mid-range figure of 1.7 percent of all births (DiProperzio, 2014; AHRC, 2014; O'Callaghan, 2016; Human Rights Commission. 2017; Richmond, 2021). The APA (2006) estimated that "as many as 1 in every 1500 babies is born with genitals that cannot easily be classified as male or female." Sources estimate that about 1 to 2 in 100 people born in the US are intersex (APA, 2006). Wilson (2012) noted, "Registers of birth 'defects' held by [the US] state health departments reveal that somewhere between 13 and 20 children per one thousand births are children with visible intersex differences". Richmond (2021) noted, approximately 1.7 percent of the global population is intersex, and up to 1.1 million people in the UK alone, adding "Being intersex is as common as being a twin".

Unfortunately, there are no statistics on PBWIVs in Tanzania. However, existing connotative terms or euphemisms of 'intersex person' or 'intersex variations' in Kiswahili, the National Language and first languages of some societies in Tanzania, qualitatively confirms that children and adults born with intersex variations exist in this country (Kamazima, 2023a; 2023b).. Meijer and Groeneveld (2007)'s study: "*Intersex: Four cases in one family*" conducted in Northern Tanzania and a qualitative study by Thomas (2016) titled, "*A Third Sex Identity: Assessing Cultural and Structural Violence Against Intersex People in Tanzania*" conducted in the then three districts of Dar-es-Salaam (administrative) Region — Ilala, Kinondoni, and Temeke — between October 26, 2015 and April 2, 2016, prove beyond reasonable doubts that persons born with intersex variations exist in this country.

Similarly, the fact that there are registered organizations — The Children Education Society (CHESO, 2006) and The Tanzania Voice of Humanity (2020) — striving to improve the welfare of persons born with intersex variations in the country further attests this population group is real and exists (no matter how many they are) in Tanzania. Furthermore, informal conversations with medical doctors — pediatrics obstetric and gynecologists — in Mwanza, Kagera, Morogoro, Dodoma, Mbeya and Dar-es-Salaam confirmed encountering cases of children born with intersex variations.

5. *Paucity of medical and clinical intersexuality research in Tanzania*

Indeed, as is the case in many other (African) countries, there is limited medical and clinical intersexuality-related research in Tanzania. The literature review I conducted, I did not find any published or unpublished medical or clinical study on intersex in Tanzania. This finding suggests that comprehensive medical and clinical intersexuality research are mandatory in this country now than before to increase PBWIVs' understanding, respect, inclusion and visibility. In addition, research data would inform governments' interventions targeting PBWIVs and thus adhering to the principles of The Malta Declaration (2013) and meeting demands and calls made in The Public Statement by The African Intersex Movement, 2017. Comprehensive medical and clinical intersexuality research to be conducted in this country, therefore, should, among other objectives, find out what has happened to former intersex 'patients', and how the healthcare system or the government could be held accountable for the (sometimes) poor effects of good intentions. In addition, medical and clinical intersexuality research should generate evidence to inform intersex-specific healthcare provision guidelines and strategies and PBWIVs-friendly laws and policies.

DISCUSSION

There are many types of surgeries (Felton, 2022) infants and children born with intersex variations are subjected to including: *Clitoroplasty* (clitoral reduction or recession, is aimed at reducing or repositioning the clitoris); *Vaginoplasty* (aimed at creating or altering the appearance of the vagina); *Hypospadias repair* (repositioning of an already working urethra); and *Gonadectomy* (the removal of sex hormone organs). In addition, surgery-surviving PBWIVs undergo frequent, unconsented and costly surgeries; prolonged costly hormonal therapy; frequent and costly counselling sessions; and have traumatic patient experiences. These interventions often start at a very young age (before the child reaches 12 months old) and can continue throughout PBWIVs' life (Richmond, 2021). A Uganda-born intersex put it clear that "You're taught growing up as intersex that your body is no longer your own — it is to be abused, examined and tested against your will" (Kaggwa, 2016a). In some cases, intersex have reported mental illnesses and demonstrate low self-esteem (headtohealth, n.d.; Kaggwa, 2016a, 2016b; Lindahl, 2019).

It is estimated that 30-80 percent of PBWIVs endure more than one surgery and some undergo five or more surgeries (RHO, 2011). Recently, the practice of surgically altering the genitals of infants and children born with intersex variations to conform to assumptions about absolute dimorphism has been questioned (Dreger, 2017; Chappell, 2017; Marven, 2018; Loeffler, 2018; Hill, 2019). The argument against the practices is that surgeries do more harm to the PBWIVs some of which

are lifelong lasting. Evidence shows that in most cases adult PBWIVs later reject 'corrected' sex or gender assigned at birth — a potentially traumatic situation (RHO, 2011; Kakande, 2016; Thomas, 2016; Soko Directory Team, 2019). Julius Kaggwa, for instance, was born with intersex variation (with both male and female genitalia) in Uganda 53 years ago and raised as a girl called Juliette. At the age of 17, her period had not started, her voice had deepened and she had started growing facial hair. She later underwent surgery to close the vagina. He now lives in a happy heterosexual marriage (Kaggwa, 2016b).

More disturbing, perhaps, is that doctors and parents do not disclose medical history or lie to PBWIVs, which denies them peer support and accessing consented medical treatments (Creighton, 2001; Kirkland, 2017). In addition, the secrecy surrounding an intersex diagnosis can increase feelings of social stigma and damage a child's trust in their parents (Lee, *et al.*, 2006; Kleeman, 2016). It is reported that PBWIVs have often been used for clinical research without their informed consent, and photos of their bodies have been used without their knowledge. Creighton, *et al.*, (2002) reported that "former patients discovered naked photos of themselves as children in textbooks while researching their condition." Where consent is sought from parents, doctors and researchers provide them limited and unreliable information. In some cases, PBWIVs have been referred to with dehumanizing pronouns like 'it' (Koyama, 2008) versus gendered pronouns 'she' and 'he'. According to the Intersex Society of North America (ISNA, 2008), "As a result of treatment received as children, intersex people may be hesitant to seek out medical treatment for health problems" and "Patients who were lied to figured that much out, and often stopped getting medical care they needed to stay healthy" (Inter Act. n.d.).

Certainly, PBWIVs could experience health-related issues that stem from having atypical genitalia (Cleveland Clinic, n.d.; Weiss, 2023). For example, someone having a uterus without a uterine or vaginal opening may cause a need for medication or surgery, as menstrual blood has no way of leaving the body. Similarly, somebody with female genitalia but no uterus may experience trouble with fertility. However, surgeries, such as the removal of testes or ovaries, have irreversible effects on the fertility of PBWIVs. Such procedures should be conducted only with the fully informed consent of the individual (Mulaikal, 1987). Surgery on the genitals of PBWIVs often removes sexual nerve tissue, impairing their ability to enjoy a healthy sex life (Creighton, *et al.*, 2001). Traditionally, surgeons prioritized the fertility of women born with intersex variations and the appearance of their genitalia over their ability to experience sexual pleasure. Boys with small penises were often surgically altered to feminize them and then raised as girls, since it was assumed that men with small penises could not have satisfying sexual lives as adults (ISNA, 2008).

Many women born with intersex variations are not sexually active and report difficulties with penetrative sex and or a lack of sexual pleasure, which may be the result of surgical variations when they were children. A study conducted in the UK showed “only 22 percent of women with intersex variations were sexually active, and half reported a lack of sexual pleasure as a result of surgery” (Morgan, *et al.*, 2005). A study conducted in London “found that a third of intersex women had never been sexually active, and had difficulty achieving orgasm” (Minto, *et al.*, 2001). Other studies in America and the UK suggest that “35-90 percent of intersex women may have difficulties with intercourse” (Mulaikal, *et al.*, 1987; Minto & Creighton, 2003).

PBWIVs with “Frasier Syndrome (which affects skin development) may have a cancer risk as high as 60 percent” (Cools, *et al.*, 2006). “Men with Klinefelter Syndrome (an extra X chromosome) may have a 40 percent chance of developing osteoporosis” (Ferlin, *et al.*, 2010) and “a risk of breast cancer fifty times that of other men” (Hurtborn, *et al.*, 1997). “People with CAH (which affects enzyme-production) may have low levels of cortisone, the hormone that helps dealing with stress, or may have problems maintaining their salt levels” (ISNA, 2008). Other “intersex conditions put people at risk for scoliosis, diabetes, lupus, or for kidney, cardiovascular, or thyroid problems” (TransFaith InterSections, n.d). Unfortunately, research is unclear whether PBWIVs are at increased mental health risk. Some studies have found that “women with intersex variations are psychologically and socially well adjusted (Morgan, *et al.*, 2005), while other research suggests that “people with intersex variations may be at high risk for mental illness (Silijper *et al.*, 1998).

The National LGBTI Health Alliance, Australia (2016) showed that PBWIVs in that country, 60 percent of the group reported they had experienced a medical treatment variations related to their intersex variation, with over half being before they were aged 18 years; 19 percent aged 16 and over had attempted suicide on the basis of issues related to having a congenital sex variation; 60 percent aged 16 and over had thought about suicide on the basis of issues related to having a congenital sex variation; 42 percent aged 16 and over had thought about self-harm, and 26 percent had engaged in self-harm on the basis of issues related to having a congenital sex variation.

Similarly, 41percent of PBWIVs aged 16 and over describe their mental health as fair or poor; 21.3 percent aged 16 and over have been diagnosed with depression; 12.9 percent aged 16 and over have been diagnosed with anxiety; and 7.7 percent had been diagnosed with Post-Traumatic Stress Disorder. Some PBWIVs who were assigned a sex at birth that does not represent their bodies or identities later in life reported experiencing dysphoria as puberty express a different

biological sex than expected for that person. Some of the health risks, therefore, can be controlled with surgery and hormones — for example, creating a vaginal opening for blood to leave the body during menstruation.

More important, perhaps, is that repeated and unnecessary consultations and counseling recommended by doctors are costly and intersex variations services (surgeries) are unavailable in many (African) countries. In Uganda, for example, a consultant obstetrician and gynecologist in Kampala told the intersex child’s parents they would need around \$50,000 to pay for the surgery in Britain as Uganda lacks the facilities to safely undertake such complex surgeries (Kakande, 2016). Karyotyping (a process that is carried out to determine the real sex of a child) is unavailable in Kenya. So, parents are continuously advised to seek this service in Germany or South Africa. A couple interviewed in Nairobi, for instance, reported spending nearly KSh. 4 million (appr. \$40,000) treating their eight years old intersex child (Agade, 2019). In Ghana, surgeries on PBWIVs are expensive as high as about GH¢70,000.00 (appr. \$5,926) at different stages and could be conducted at any stage of life (Aryeetey, 2021).

However, some African countries — Ghana, Kenya, Nigeria, South Africa, and Uganda, for instance — have outlawed surgical variations for intersex toddlers. In 2015, the Ugandan Parliament issued guidelines to the Ministry of Health recommending against such violations on intersex newborns. Among other things, “The guidelines stress counselling for the parents, and there are counsellors trained to do that ... Surgery can only be done when the child is old enough and has shown more features of either sex or the child can decide for him/herself” (Kakande, 2016; Papisova & Kheraji, 2017; GenderGP. 2020). In Ghana, intersex babies are now allowed to grow to adolescence to decide which sex they want to maintain (Aryeetey, 2021). Tanzania is mandated to follow suit to prohibit harmful medical practices on infants and children born with intersex variations in this country.

CONCLUSION AND RECOMMENDATIONS

Incontestably, primary and specialized healthcare providers are celebrated for marvelous work they do caring for the citizenry’s health and wellbeing in this country. However, I recommend primary and specialized care providers in Tanzania should know that intersex variations are not diseases that require treatment; are not disorders that necessitate karyotyping or immediate afterbirth emergency corrections. In fact, there is no scientific evidence that cosmetic or elective variations help children born with intersex variations. Evidence shows that in most cases adult intersex later reject ‘corrected’ sex or gender assigned at birth. Healthcare providers — primary and specialized alike — should be knowledgeable about intersex variations and their common (health) experiences and be able to make unavoidable referrals when needed. Healthcare providers

are mandated to provide ethical medical support and conduct ethical intersex medical or clinical research that addresses stigma and discrimination affecting PBWIVs (infants, young and adults) and their families. It is the provider's responsibility to deliver care that is honest, respectful, confidential, transparent and non-intersex discriminatory to PBWIVs, parents or guardians and their (extended) families. This is in line with provisions in The Vienna Declaration and Programme of Action 1993; The Malta Declaration, 2013, The African Intersex Movement, 2017; The Universal Declaration of Human Rights and WHO Surveillance, 2017; and The African Commission on Human and Peoples' Rights, 2022.

Whenever necessary, the intersex 'patients' should have access to their treatment records to avoid unnecessary repeated, costly and (often) abusive counseling, diagnoses and interventions. Most important, perhaps, is that medicalization of intersex variations should stop and medical training curricula should orient and develop positive medical doctors' beliefs, perceptions, attitudes and practices towards PBWIVs in this country and beyond. Networking with intersex-led organizations in the country — The Children Education Society (CHESO, 2006) and The Tanzania Voice of Humanity (2020), for instance, and the medical personnel and associations in countries where this goal has been achieved or ongoing — Australia, Kenya, Uganda, Malaysia, Nepal, New Zealand and South Africa, for example — would be an efficacious strategy towards attaining this accomplishment.

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REFERENCES

- Agade, H. (2019). The challenge of having an intersex child. Available at: <https://africa.cgtn.com/2019/09/04/the-challenge-of-having-an-intersex-child/> Accessed March 12, 2023.
- The Arts and Humanities Research Council (AHRC). (2014). AHRC annual report and accounts 2013 to 2014. Available at: <https://www.gov.uk/government/publications/ahrc-annual-report-and-accounts-2013-to-2014> Accessed June 3, 2023.
- American Psychological Association (APA). (2006). Answers to your questions on Individuals With intersex Conditions. Available at: <https://www.apa.org/topics/lgbtq/intersex.pdf> Accessed February 17, 2023.
- Amnesty International. (2018a). Differences in sex development. Available at: <https://www.nhs.uk/conditions/differences-in-sex-development/> Accessed February 17, 2023.
- Aryeetey, L. N. D. (2021). Intersex persons have equal rights. Available at: <https://www.ghanabusinessnews.com/2021/06/12/intersex-persons-have-equal-rights/> Accessed on March 17, 2023.
- Bashforth, E. (2022). What it means to be intersex? Available at: <https://patient.info/news-and-features/what-does-it-mean-to-be-intersex> Accessed February 17, 2023.
- Blackless, M., Charuvastra, A., Derryc, A., Fausto-sterling, A., Lauzanne, K., & Lee, E. (2000). How Sexually Dimorphic Are We? Review and Synthesis. *American Journal of Human Biology*, 12, 151–166. Available at: <https://onlinelibrary.wiley.com/doi/epdf/10.1002/%28SICI%291520-6300%28200003%2F04%2912%3A%3C151%3A%3AAID-AJHB1%3E3.0.CO%3B2-F> Accessed May 27, 2023.
- Cara, J. F. (2002). Approach to the Management of Intersex: Past and Present Concepts. Available at: <https://www.medscape.org/viewarticle/446418> Accessed June 5, 2023.
- Cleveland Clinic. n.d. Intersex. Available at: <https://my.clevelandclinic.org/health/articles/16324-intersex> Accessed June 5, 2023.
- Carpenter, M. (2018a). 'The "Normalization" of Intersex Bodies and "Othering" of Intersex Identities in Australia'. *Journal of Bioethical Inquiry*, May, 1–9. Available at: <https://link.springer.com/article/10.1007/s11673-018-9855-8> Accessed May 28, 2023.
- Carpenter, M. (2018b). 'The "Normalisation" of Intersex Bodies and "Othering" of Intersex Identities'. In *The Legal Status of Intersex Persons*, edited by Jens Scherpe, Anatol Dutta, and Tobias Helms, 445–514. Cambridge, England: Intersentia. Available at: <file:///C:/Users/Dell/Downloads/Carpenter2020normalisationothering.pdf> Accessed June 10, 2023.
- Carpenter, M. (2019). Identification documents. Intersex Australia. Available at: <https://ihra.org.au/identities/> Accessed February 17, 2023.
- Carpenter, M. (2021). Health and wellbeing. Intersex Australia. Available at: <https://ihra.org.au/health/> Accessed February 17, 2023.
- Chappell, B. (2017). 'I'm Intersex,' A Supermodel Says, Hoping To End Stigma. *National Public Radio_The Two Way Radio*. Available at: <https://www.npr.org/sections/thetwo-way/2017/01/24/511385718/im-intersex-a->

- supermodel-says-hoping-to-end-stigma Accessed May 27, 2023.
- Children Education Society (CHESO). (2019). Challenges and best practices to end violence against intersex children and their mothers in Tanzania. A position paper presented at the National Conference on Ending Violence Against Women and Children in Tanzania. Dar-es-Salaam University College of Education. Dar-es-Salaam, Tanzania. March 21 & 22.
 - Cleveland Clinic. (2022). Intersex. Intersex Australia. Available at: <https://my.clevelandclinic.org/health/articles/16324-intersex> Accessed February 17, 2023.
 - Clifton, D. (2020). New York City Proposes Bill to End Nonconsensual Surgeries on Intersex Youth. Available at: <https://www.them.us/story/new-york-city-bill-to-end-nonconsensual-intersex-surgeries> Accessed June 4, 2023.
 - Cohen, C. (2021). Surgeries on Intersex Infants are Bad Medicine. Available at: <https://healthlaw.org/surgeries-on-intersex-infants-are-bad-medicine/#:~:text=Rather%2C%20intersex%20surgeries%20%E2%80%94%20most%20of,inaccurate%20gender%20assignment%2C%20and%20trauma> Accessed June 6, 2023.
 - Cools, M., Drop, S. L. S., Wolffenbuttel, K. P., Oosterhuis, J. W., & Looijenga, L. H. J. (2006). Germ Cell Tumors in the Intersex Gonad: Old Paths, New Directions, Moving Frontiers. *Endocrine Reviews*, 27(5), 468-484. Available at: <https://academic.oup.com/edrv/article/27/5/468/2355191> Accessed May 25, 2023.
 - Creighton, S., Alderson, J., Brown, S., & Minto, C. L. (2002). Medical photography: Ethics, consent, and the intersex patient. *British Journal of Urology*, 89(1), 67-71. Available at: <https://onlinelibrary.wiley.com/doi/full/10.1046/j.1464-410X.2002.02558.x> Accessed April 25, 2023.
 - Davis, G. (2013). UN Condemns “Normalization” Surgery for Intersexuality. Available at: <https://msmagazine.com/2013/02/07/un-condemns-normalization-surgery-for-intersexuality/> Accessed June 6, 2023.
 - DiProperzio, L. (2014). What to Do if You Have an Intersex Child. Available at: <https://www.parents.com/parenting/what-to-do-if-you-have-an-intersex-child/> Accessed February 17, 2023.
 - Dreger, A. D., & Herndon, A. M. (2009). Progress and Politics in the Intersex Rights Movement Feminist Theory in Action. *GLQ: A Journal of Lesbian and Gay Studies*, 15(2), 199–224. <https://doi.org/10.1215/10642684-2008-134> Available at: <https://aeon.co/essays/people-born-intersex-have-a-right-to-genital-integrity>. Accessed March 6, 2023.
 - Factora, J. (2021). Over 50 Nations Sign Global Statement Calling for Intersex Rights. Available at: <https://www.them.us/story/countries-call-united-nations-end-intersex-surgeries> Accessed June 4, 2023.
 - Felton, A. (2022). What is Intersex? Available at: <https://www.webmd.com/sex/what-is-intersex> Accessed February 17, 2023.
 - Ferlin, A., Schipilliti, M., Di Mambro, A., Vinanzi, C., & Foresta, C. (2010). Osteoporosis in Klinefelter's syndrome. *Molecular Human Reproduction*, 16(6), 402-410. Available at: https://watermark.silverchair.com/gap026.pdf?token=AQECAHi208BE49Ooan9khhW_ercy7Dm3ZL.. Accessed March 25, 2023.
 - FREE & EQUAL. United Nations Rights for LGBT Equality. (2017). Factsheet. Available at: <https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf> Accessed March 5, 2023.
 - GenderGP. (2020). An Intersex Person's Account of Realizing Their True Gender. Available at: <https://www.gendergp.com/growing-up-intersex/> Accessed February 17, 2023.
 - Gold, C. (2001). The Intersex Spectrum. Available at: <https://www.pbs.org/wgbh/nova/article/intersex-spectrum/> Accessed February 17, 2023.
 - Hartney, E. (2023). What Is Intersex? Available at: <https://www.verywellhealth.com/what-is-intersex-21881> Accessed February 17, 2023.
 - Haug, O. (2021). Germany Just Banned on Surgeries on Intersex Infants. Advocates Say It Doesn't Go Far Enough. Available at: <https://www.them.us/story/germany-banned-intersex-surgeries-on-infants> Accessed June 4, 2023.
 - Head to Health. n.d. Intersex People. Available at: <https://www.headtohealth.gov.au/supporting-yourself/support-for/intersex> Accessed February 17, 2023.
 - Hill, L. (2019). Pressure mounts to curtail surgery on intersex children. *Chicago Tribune*. Available at: <https://www.chicagotribune.com/lifestyles/health/ct-surgery-intersex-children-20170725-story.html> Accessed May 27, 2023.
 - Human Rights Commission. (2017). What's it like to be intersex? New Zealand. Available at: <https://www.hrc.co.nz/news/whats-it-be-intersex/> Accessed May 27, 2023.
 - Hultborn, R., Hanson, C., Kopf, I., Verbiene, I., Warnhammar, E., & Weimarck, A. (1997). Prevalence of Klinefelter syndrome in male breast cancer patients. *Anticancer Research*, 17 (6D), 4293–4297. Available at: <https://europepmc.org/abstract/med/9494523> Accessed March 25, 2023.
 - InterAct. n.d. a. What's wrong with the way intersex has traditionally been treated? Available at: <https://isna.org/faq/concealment/> Accessed February 27, 2023.

- InterAct. n.d. b. What is intersex? Available at: https://isna.org/faq/what_is_intersex/ Accessed February 27, 2023.
- interactadvocates.org. (2021). Intersex Definitions. Available at: <https://interactadvocates.org/intersex-definitions/> Accessed May 4, 2023.
- Intersex Human Rights Australia (IHRA). (2013). What is intersex? Available at: <https://ihra.org.au/18106/what-is-intersex/> Accessed March 18, 2023.
- Intersex Society of North America (ISNA). (2006). Clinical Guidelines for the Management of Disorders of Sex Development in Childhood (CMDSD 2006). Available at: <http://www.accordalliance.org/dsdguidelines/clinical.pdf> Accessed June 5, 2023.
- Intersex Society of North America (ISNA). 2008. What's wrong with the way intersex has traditionally been treated? Available at: <http://www.isna.org/faq/concealment> Accessed May 29, 2023.
- Kaggwa, J. (2016a). Understanding intersex stigma in Uganda. Available at: <http://intersexday.org/en/understanding-stigma-uganda/> Accessed March 16, 2023.
- Kaggwa, J. (2016b). I'm an intersex Ugandan – life has never felt more dangerous. Available at: <https://www.theguardian.com/world/2016/sep/16/intersex-ugandan-lgbt-gay-rights-life-never-felt-more-dangerous> Accessed March 16, 2023.
- Kakande, Y. (2016). In Uganda, parents seek controversial genital surgery for 'intersex' babies. Thomson Reuters Foundation. Available at: <https://news.trust.org/item/20161218060443-tqfr4/> Accessed March 16, 2023.
- Kamazima, S. R. 2023a. Intersexuality: The Role of Political Elite in Recognizing, Respecting, Protecting and Affirming Persons Born with Intersex Variations' Human and Citizenship Rights in Tanzania. *EAS J Humanit Cult Stud*, 5(5), 250-264.
- Kamazima, S. R. 2023b. Intersexuality: what public health personnel should know and do to protect and preserve persons born with intersex variations' human rights and citizenship rights in Tanzania. *EAS J Psychol Behav Sci*, 5(5), 135-144.
- Kenya National Commission on Human Rights (KNCHR). n.d. Intersex Persons in Kenya. Available at: <https://www.knchr.org/Our-Work/Special-Interest-Groups/Intersex-Persons-in-Kenya> Accessed March 5, 2023.
- Kirkland, F. (2017). Intersex patients 'routinely lied to by doctors.' Available at: <https://www.bbc.com/news/health-39979186> Accessed June 11, 2023.
- Klein, E. A. (2021). Am I Intersex? Available at: <https://www.o.school/article/am-i-intersex> Accessed February 17, 2023.
- Kleeman, J. (2016). 'We don't know if your baby's a boy or a girl': growing up intersex. *The Guardian*. <https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex> Accessed May 27, 2023.
- Koyama, E. (2008). Adding the "I": Does Intersex Belong in the LGBT Movement? 2008; Available at: 2023. <http://www.intersexinitiative.org/articles/lgbti.html> Accessed May 3, 2023.
- Kuehnle, F. (2021). What does it mean to be intersex? Available at: <https://www.medicalnewstoday.com/articles/intersex> Accessed February 27, 2023.
- Lee, P. A., Houk, C. P., Ahmed, S. F., & Hughes, I. A. (2006). Consensus statement on management of intersex disorders. *Pediatrics*, 118(2), 488-500. Available at: <https://pediatrics.aappublications.org/content/118/2/e488.short> Accessed April 4, 2023.
- Löeffler, J. (2018). These Children Aren't Sick — But They Are Still Having Operations. *BuzzFeed News*. Available at: <https://www.buzzfeednews.com/article/julianoeloeffler/intersex-operations-children-germany-netflix#news-content> Accessed May 27, 2023.
- Leonard, J. (2012). What does it mean to be intersex? Available at: <https://www.medicalnewstoday.com/articles/intersex> Accessed February 17, 2023.
- Lindahl, H. (2019). 9 Young People on How They Found Out They Are Intersex. Available at: <https://www.teenvogue.com/gallery/young-people-on-how-they-found-out-they-are-intersex> Accessed February 17, 2023.
- Lundberg, T., Hegarty, P., & Roen, K. (2018). Making sense of 'Intersex' and 'DSD': how laypeople understand and use terminology. *Psychology & Sexuality*, 9(2), 161-173. <https://doi.org/10.1080/19419899.2018.1453862> Available at: <https://www.tandfonline.com/doi/pdf/10.1080/19419899.2018.1453862> Accessed March 5, 2023.
- Malta Declaration. (2013). (29 Nov – 1 Dec.) Available at: <https://www.oieurope.org/malta-declaration/> Accessed February 17, 2023.
- Marven, L. (2018). What are some of the experiences and needs of intersex people in my community? *VAWnet*. Available at: <https://vawnet.org/news/what-are-some-experiences-and-needs-intersex-people-my-community> Accessed May 27, 2023.
- Meijer, R. P., & Groeneveld, A. E. (2007). Intersex: Four cases in one family. *Journal of Pediatric Urology Company*, 3(2), 137-141. DOI: <https://doi.org/10.116/j.jpuro.2006.03.009> Available at [https://www.jpuro.com/article/S1477-5131\(06\)00062-3/fulltext](https://www.jpuro.com/article/S1477-5131(06)00062-3/fulltext) Accessed April 18, 2023.

- Michigan Institute of Urology (MIU). n.d. Intersex. Available at: <https://www.michiganurology.com/specialty/intersex/> Accessed February 17, 2023.
- Middleton, L. (2023). EXPLAINER: What is intersex surgery and where is it banned? Available at: <https://www.openlynews.com/i/?id=d24d7290-e353-4c47-b412-03ccad0ee34c> Accessed June 6, 2023.
- Migeon, C. J., Wisniewski, A. B., Gearhart, J. P., Meyer-Bahlburg, H. L., Rock, J. A., Brown, T. R., Casella, S. J. Maret, A. Ngai, K. M., Money, J., & Berkovitz, G. D. (2002). Ambiguous genitalia with perineoscrotal hypospadias in 46, XY individuals: long-term medical, surgical, and psychosexual outcome. *Pediatrics*, 110(3), e31. Available at: <https://pediatrics.aappublications.org/content/pediatric/110/3/e31.full.pdf> Accessed April 25, 2023.
- Minto, C., Creighton, S., & Woodhouse, C. (2001). Long Term Sexual Function in Intersex Conditions with Ambiguous Genitalia. *Journal of Pediatric & Adolescent Gynecology*. 14(3):141-142. Available at: [https://www.jpagonline.org/article/S1083-3188\(01\)00111-5/abstract](https://www.jpagonline.org/article/S1083-3188(01)00111-5/abstract) Accessed May 25, 2023.
- Minto, C., & Creighton, S. (2003). Sexual Function in Adult Women with Complete Androgen Insensitivity Syndrome. *Fertility & Sterility*, 80(1), 157-164. Available at: [https://www.jpagonline.org/article/S1083-3188\(01\)00117-5/abstract](https://www.jpagonline.org/article/S1083-3188(01)00117-5/abstract) Accessed May 25, 2023.
- Morgan, J. F., Murphy, H., Lacey, J. H., & Conway, G. (2005). Long term psychological outcome for women with congenital adrenal hyperplasia: cross sectional survey. *British medical Journal*. 330:340-341. Available at: <https://www.bmj.com/content/bmj/330/7487/340.full.pdf> Accessed May 25, 2023.
- Mulaikal, R. M., Migeon, C. J., & Rock, J. A. (1987). Fertility rates in female patients with congenital adrenal hyperplasia due to 21hydroxylase deficiency. *New England Journal of Medicine*, 316, 178-182. Available at: <https://doi.org/10.1056/NEJM198701223160402> Accessed May 15, 2023.
- National LGBTI Health Alliance. (2016). The Statistics At a Glance: The Mental Health of Lesbian, Gay, Bisexual, Transgender and Intersex People in Australia. Available at: <https://lgbtihealth.org.au/statistics/> Accessed May 27, 2023.
- Nelson, A. (2018). Genital normalising surgeries on intersex infants: A scandal in waiting? Available at: <https://blog.policy.manchester.ac.uk/posts/2018/05/genital-normalising-surgeries-on-intersex-infants-a-scandal-in-waiting/> Accessed June 6, 2023.
- New York City. (2023). Intersex Health. Cit of New York. Available at: <https://www.nyc.gov/site/doh/health/health-topics/intersex-health.page> Accessed February 27, 2023.
- O'Callaghan, H. (2016). What happens when a child is born intersex in Ireland. *Irish Examiner Ltd*. Available at: <https://www.irishexaminer.com/lifestyle/healthandlife/what-happens-when-a-child-is-born-intersex-in-ireland-428823.html> Accessed May 27, 2023.
- Papisova, V., & Kheraj, E. (2017). Why Intersex Genital Mutilation Needs to Stop. Available at: <https://www.teenvogue.com/story/intersex-genital-mutilation> Accessed February 17, 2023.
- Pepy, L. (2022). Malta's pioneering law on intersex children. Available at: https://www.lemonde.fr/en/science/article/2022/06/12/malta-s-pioneering-law-on-intersex-children_5986507_10.html Accessed June 3, 2023.
- Pereira, L. W. (2022). Intersex Legal Activism. United Nations on The Human Rights of Intersex People. Available at: <https://fra.europa.eu/sites/default/files/fra-2015-focus-04-intersex.pdf> Accessed June 7, 2023.
- Rainbow Health Ontario (RHO). (2011). RHO FACT SHEET: INTERSEX HEALTH. Available at: https://rainbowhealth.wpenginepowered.com/wp-content/uploads/2011/08/RHO_FactSheet_INTERSEXHEALTH_E.pdf Accessed March 4, 2023.
- Rich, A. L., Phipps, L. M., Tiwari, S., Rudraraju, H., & Dokesi, P. O. (2016). The Increasing Prevalence in Intersex Variation from Toxicological Dysregulation in Fetal Reproductive Tissue Differentiation and Development by Endocrine-Disrupting Chemicals. *Environmental Health Insights*, 10, 163–171. doi:10.4137/EHI.S39825. Available at: file:///C:/Users/Dell/Downloads/f_5890-EHI-The-Increasing-Prevalence-in-Intersex-Variation-from-Toxicological-Dys.pdf_7827.pdf Accessed March 6, 2023.
- Richmond, E. (2021). The rights of intersex children - Meet the Manchester academic and the activist hoping to help intersex children get a better start. *The University of Manchester Magazine*. Available at: <https://www.manchester.ac.uk/discover/magazine/features/rights-of-intersex-children/> Accessed March 5, 2023.
- Slijper, F. M. E., Drop, S. L., Molenaar, J. C., & de Muinck, K. (1998). Long term psychological evaluation of intersex children. *Archives of Sexual Behavior*, 27, 125-145. Available at: <https://link.springer.com/article/10.1023/A:1018670129611> Accessed April 17, 2023.
- Soko Directory Team. (2019). Kenya Has About 1,524 Intersex Citizens - KNBS. Available at: <https://sokodirectory.com/2019/11/kenya-has-about-1524-intersex-citizens-knbs/> Accessed March 13, 2023.
- The Intersex Society of North America (ISNA). n.d. a What's the history behind the intersex rights movement? Available at:

- <https://isna.org/faq/history/> Accessed February 27, 2023.
- The Intersex Society of North America (ISNA). n.d. b. What does ISNA recommend for children with intersex? Available at: <https://isna.org/faq/patient-centered/> Accessed June 9, 2023.
 - Thomas, G. (2016). A Third Sex Identity: Assessing Cultural and Structural Violence Against Intersex People in Tanzania. Master Degree in Women's Law, Southern and Eastern African Regional Centre for Women's Law, University of Zimbabwe.
 - TransFaith InterSections. n.d. Types of Intersex Conditions. Available at: <http://www.transfaithonline.org/intersections/intersex/types/> Accessed March 4, 2023.
 - United Nations Development Program (UNDP). 2018. INTERSEX RESEARCH STUDY ALBANIA, BOSNIA AND HERZEGOVINA, THE FORMER YUGOSLAV REPUBLIC OF MACEDONIA AND SERBIA 2017. Available at: <https://www.lgbti-era.org/sites/default/files/pdfdocs/Intersex%20Research%20Study-ENG.pdf> Accessed March 5, 2023.
 - Victoria. (2019a). Health of people with intersex variations. Available at: <https://www.health.vic.gov.au/populations/health-of-people-with-intersex-variations> Accessed February 27, 2023.
 - Victoria. (2019b). Sex characteristics variations in babies and children: information for families. Department of Health and Human Services. Available at: <https://www2.health.vic.gov.au/about/populations/lgbti-health/health-of-people-with-intersex-variations> Accessed March 5, 2023.
 - Victoria. (2019c). Sex characteristics variations in babies and children: information for families. Department of Health and Human Services. Available at: <https://www2.health.vic.gov.au/about/populations/lgbti-health/health-of-people-with-intersex-variations> Accessed March 5, 2023.
 - Weiss, K. (2023). What to Know About Having a Baby Who Is Intersex. Available at: <https://www.healthline.com/health/baby/what-does-intersex-look-like> Accessed February 17, 2023.
 - Wilson, G. (2012). Intersex Genital Mutilation – IGM: The Fourteen Days of Intersex. Available at: <https://oiiinternational.com/2574/intersex-genital-mutilation-igm-fourteen-days-intersex/> Accessed February 23, 2023.

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