

Review Article

Intersexuality: What Parents, Guardians and Communities Should Know and Do to Care and Protect Infants and Children Born with Intersex Variations' Rights in Tanzania

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Abstract: Tanzania lags behind in the course of ending stigma and discrimination against persons born with intersex variations. To date, the Tanzania Government has not enacted any law outlawing cosmetic surgeries, stigma and discrimination against persons born with intersex variations as per demands and calls from, among others, The First African Intersex Meeting, 2017 and The African Commission on Human and Peoples' Rights, 2023. Undoubtedly, this legal/policy silence is not at all unprejudiced. It facilitates harmful practices to take place unnoticed and uncontrolled. Primary and specialized healthcare providers, parents, traditional and religious leaders, therefore, continue performing harmful normalization surgeries and treatment, tradition-led mutilations and killings of infants and children born with intersex variations. In this context, I use scanty evidence available in the country and experience from other parts of the globe to highlight on what parents, guardians and communities should know and do to care and protect infants and children born with intersex variations' human and citizenship rights in Tanzania. I recommend parents, guardians and community members to better understand who infants and children born with intersex variations are and their (health) needs. Intersex variations are not disorders requiring immediate or emergency (medical) interventions. 'Normalization' surgeries should wait until the children are mature enough to make informed consent to alter their physical appearances. Whenever possible, parents and guardians should seek, share support and correct intersex information from parents/guardians with similar experiences and adult persons born with intersex variations, media, internet and intersex-led groups and organizations and institutions within and outside Tanzania. Importantly, parents, guardians, persons born with intersex variations, intersex movements, activists and persons born with intersex variations-led organizations should lobby, openly criticize and pressurize the government to enact persons born with intersex variations-friendly policies, laws, and (treatment) guidelines aiming at ending harmful practices that persistently violate their human and citizenship rights. In turn, this commitment would enable infants and children born with intersex variations to grow up and live free from body shaming, stigma, harm and pain in a country/world where their human and citizenship rights are cherished.

Keywords: Intersex, intersexuality, infants and children born with intersex variations, intersex discrimination, intersex activism, intersex rights, desk research, Tanzania.

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INTRODUCTION

The First 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 members made 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 states,

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“We recall the principles of the Public Statement by the Third International Intersex Forum (known as the Malta Declaration) and extend the demands aiming to end discrimination against intersex people in Africa, to ensure the right of bodily integrity, physical autonomy and self-determination.

“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. Therefore, we must be supported to be the drivers of social, political and legislative changes that concern us ...”

In addition, The African Intersex Movement makes six calls including: 1) “National governments to address the concerns raised by the African Intersex Movement and draw adequate solutions in direct collaboration with intersex representatives and organizations”; 2) “Traditional and religious leaders to stop harmful cultural practices, such as tradition-led mutilations and killings of intersex people”; and 3) “Community leaders to engage in intersex education to dispel misconceptions and stigma around intersex people”.

At the time of writing this paper, there was no evidence of any effort or strategies taken by the Tanzania Government to fulfil demands and calls made by The African Intersex Movement in 2017 to end negative norms and harmful (traditional and biomedical) practices on infants and children born with intersex variations. I argue and present that Tanzania lags behind towards ending stigma discrimination against PBWIVs in Africa, and to ensure the PBWIVs’ right of bodily integrity, physical autonomy and self-determination.

Similarly, I establish that in this respective, Tanzania demonstrates no stern measures to ensure constitutional and human rights to the citizenry without discrimination geared at ending stigma and secrecy around intersex variations and PBWIVs in the country and beyond. In addition, I urge parents, guardians and community members — the political and medical elite alike — to engage in intersex education to dispel misconceptions and stigma around PBWIVs as stipulated in, among others, The African Intersex Movement Public Statement, 2017 and The African Commission on Human and Peoples’ Rights Resolution, 2023.

Furthermore, in collaboration with PBWIVs-led organizations, intersex activists and movements in the country and abroad, parents, guardians and community members should initiate dialogue to pressurize the government to establish PBWIVs-friendly laws and policies aiming at ending stigma and discrimination against this vulnerable group. The government should, by law, mandate healthcare

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

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.

In the absence of evidence on what strategies the Tanzania government has put in place and achieved to end stigma and discrimination against PBWIVs, I use scanty information available and experiences from other countries to highlight on what parents, guardians and communities should know and do to care and protect infants and children born with intersex variations’ rights in Tanzania.

TRADITIONAL AND MODERN INTERSEX VARIATIONS MANAGEMENT APPROACHES — A PROBLEM

PBWIVs have inborn (not acquired) sex characteristics atypical from social and medical nomenclatures of ‘male’ or ‘female’ bodies that trigger risks or experiences of killings, abandonment, hatred, discrimination, stigma, harm, pain, and homophobia [when perceived as part of the homosexual (LGBTQ+) activism]. PBWIVs’ rights are consistently, erroneously, intentionally or unintentionally violated. Habitually, in many humanities on the globe, infants and children born with intersex variations were (and still are) killed, mystified ‘semi-gods’ or ‘half-humans’, mothers accused of witchcraft or sorcery and bringing misfortunes to the family and the clan (Wilson, 2012; Segawa, 2020). As a result, some mothers abandon infants born with intersex variations in latrines/toilets, rubbish heaps, forests or on the streets (Kakande, 2016; Kaggwa, 2016b; BBC, 2017). Others with either medicine practitioners, traditional healers (THs)/traditional birth attendants (TBAs) or some other allies confederate to exterminate the ‘abnormal’ child (Kaggwa, 2016a).

In some societies in Africa, infants and children born with intersex variations were (and still are) taken to THs or traditional therapists for cure (Kakande, 2016; Kaggwa, 2016a; 2016b; BBC, 2017; Ausserer, 2021) including traditional genital mutilation. A TH in Uganda, for example, observed, “Not fulfilling family obligations and angering one’s ancestors could be a reason one gets an intersex child ... This can be rectified if a traditional healer speaks to the ancestral spirits, identifies their demands, and has them fulfilled” (Kakande, 2016). Yet,

some parents and family members take PBWIVs to Churches for prayers to remove the curse associated with intersexuality (Kakande, 2016).

PBWIVs in Africa are double disadvantaged facing stigma and poverty. PBWIVs living in Northern Uganda, for example, “live in extremely harsh and impoverished living conditions, and having to go hungry for weeks and extremely ration their food” (Kaggwa, 2016a). This situation — poor socio-economic status — “forces some parents to send intersex children perceived a burden to rebel camps or abandoning them in run-down mud huts, explaining, in part, the violations and abuse they face on the daily basis” (Kaggwa, 2016a).

Influenced by heteronormality and advancing technology, beginning in the late 1950s, doctors and parents subject infants and children born with intersex variations to unnecessary, harmful, uninformed, expensive, coerced counseling, irreversible ‘normalizing’ surgeries and forced intersex genital mutilation (IGM) aimed at changing the sexual and reproductive anatomy to align ‘male’ and ‘female’ social classifications. Undeniably, doctors perform surgeries without the infants’ and children’s informed consent and assign sex or gender not of their choice (ERT, 2013; Kaggwa, 2016a). Regrettably, the surgeries are irreversible resulting in physical harm, self-esteem demolition, emotional trauma, permanent pain, permanent infertility, incontinence, loss of clitoral or sexual sensation, depression and life-long mental suffering (Kakande 2016; Kaggwa, 2016a).

Currently, with support of advanced technology, some intersex variations could be detected during pregnancy, which increases the unborn intersex’s risks including: being aborted; exposure to hormonal therapy; hormonal therapy risks to fetus’ growth; and chances of developing intersex-related medical problems (RoK, 2018). With increased access to this technology, parents are likely to insistently seek such services within their countries and abroad. Certainly, abortion and medical interventions jeopardize the fetus’ (human) rights. More important, perhaps, the recently rekindled (from March, 2023) revulsion and enduring anti-homosexuality movements in Africa, could adversely impact PBWIVs’ human rights, citizenship rights and wellbeing if they remain visible through the LGBTQ+ lens in countries like Tanzania (Kamazima, *et al.*, 2021a; 2021b; 2021c; Kamazima, 2023a; Kamazima, 2023b) where homosexuality is illegal, criminalized and penalized to life imprisonment. Undoubtedly, intersex being politically pigeonholed LGBTQ+ and part of the homosexuals’ rights lobbying and advocacy negotiations could adversely impact intersex conditions and life struggles.

INFANTS AND CHILDREN BORN WITH INTERSEX VARIATIONS WILL NOT GROW TO BECOME HOMOSEXUALS — A DEEP ROOTED MYTH

Many people — the lay and elite alike — confuse ‘homosexual’, ‘transgender’ and ‘transsexual’ individuals with PBWIVs because of phony similarities that blur the two groups (Fair Planet, 2014; Thomas, 2016; Wasike & Mwadzaya, 2019; Victoria, 2019c; Koigi, 2019; Hegarty & Smith, 2023). By and large, the two groups face akin but diverse levels of secrecy, exclusion, discrimination, stigma and body shaming (Kakande, 2016; Segawa, 2020) and would require to decide on their own gender identity that could necessitate hormonal treatments and or surgery (Hegarty & Smith, 2023). Albeit rare, some PBWIVs also decide to change genders at some point in their life (Kakande, 2016; Thomas, 2016; Soko Directory Team, 2019; Kaggwa, 2016a) and might also identify ‘transgender’ or ‘transsexual’ (Klein, 2021). Normally, majority of PBWIVs identify ‘male’, ‘female’ and ‘heterosexual’ (Amnesty International, 2018a; Victoria, 2019c).

Certainly, PBWIVs share some characteristics with LGBTQ+. Nevertheless, LGBTQ+ are not born with atypical sexual and reproductive systems and do not have the same history of surgical interventions during their childhood as PBWIVs (Koyama, 2008; Marven, 2018). Actually, while PBWIVs struggle against surgeries and medical treatments they are forcefully subjected to, the homosexuals, transgender and transsexual brawl to access these harmful and irreversible medical procedures (Kamazima, 2023c). It suggests, therefore, that being born with intersex variation has nothing to do with being ‘homosexual’, ‘transgender’ or ‘transsexual’ (Amnesty International. n.d.; Thomas, 2016; Amnesty International, 2018a; ERT, 2013; Kamazima, 2023b, 2023c). Intersex is, rather, a biological factor and a naturally occurring characteristic — NOT a sexual desire. Intersex variation is atypical from gender identity (the inner sense of feeling ‘male’ or ‘female’) and sexual orientation (physical and or sexual attraction). Therefore, PBWIVs have anatomy that is not considered typically ‘male’ or ‘female’ (Amnesty International, 2018a). In contrast, persons who are transgendered have an internal experience of gender identity that is different from most people.

More important, perhaps, is that “Some policies designed for [LGBTQ+] may apply to intersex, while others may not ... Simply adding the letter ‘I’ or the word intersex to an [LGBTQ+] policy does not make any policy intersex inclusive” (Carpenter, 2014). In fact, some PBWIVs do not want to be included in the acronym (InterAct, n.d). Reporting on his experience working with LGBTQ+ organizations, a Ugandan intersex and activist stated,

For intersex individuals in Uganda, there is no real safe place ... The conservative, elusive, and vehemently

repressive society considers us [PBWIVs] to be bisexual or gay, while the gay community considers us to be aliens and objects of curiosity who must explain our association to their cause! We must prove our 'maleness' or 'femaleness' to them, because the intersex body is still a source of great discomfort even among the LGBTI community (Kaggwa, 2016a).

Likewise, intersex activists in Kenya demand to be separated from the LGBTQ+ community as their variations are congenital conditions, not sexual orientations (Wasike & Mwadzaya, 2019). Therefore, parents, guardians and community members should understand that infants and children born with intersex variations will never grow to become homosexuals; they could lead better and health lives with the variations they were born with without normalization surgeries (InterAct. n.d.; Kamazima, 2023b).

HOW COMMON IS INTERSEX GLOBALLY AND IN TANZANIA?

The number of PBWIVs is enigmatic and contested. What is for sure, however, is that they exist in all regions and all countries around the world (Malta Declaration, 2013; Kheraj & Papisova, 2017a; Posch, 2019). On the one hand, some studies estimated that intersex conditions affect one in 2,000 children (ISNA, 2008; DiProperzio, 2014; Greenfield, 2014). Fausto-Sterling (1993) estimated that 1.7 to 4 percent of people actually have intersex variations (Victoria, 2019a; Amnesty International, n.d.; Fausto-Sterling, 1993; Amnesty International, 2018; GenderGP, 2020). On the other hand, it is observed that the 1.7 percent estimate by Anne Fausto-Sterling (1993) “includes conditions which most clinicians do not recognize as intersex, such as Klinefelter syndrome, Turner syndrome, and late onset adrenal hyperplasia” (See also Bashforth, 2022). Sax (2002) adds, “If the term *intersex* is to retain any meaning, the term should be restricted to those conditions in which chromosomal sex is inconsistent with phenotypic sex, or in which the phenotype is not classifiable as either male or female ... Applying this more precise definition, the true prevalence of intersex is seen to be about 0.018 percent, almost 100 times lower than Fausto-Sterling’s estimate of 1.7 percent”.

Unfortunately, there are no data on PBWIVs in Tanzania. However, scanty information available from unwavering sources proves PBWIVs (no matter how many they are) exist in this country. Meijer and Groeneveld (2007), for example, reported on four intersex cases in one family in Northern Tanzania aged 23, 15, 13 and 4 years. The four cases were determined as 46XY classified as dysgenetic male pseudohermaphrodites. “In agreement with the patients and parents, they [patients] were assigned the male gender and surgery was performed accordingly” (Meijer and Groeneveld, 2007).

On Tuesday, August 28, 2018, the Rubya Hospital Medical Officer In-Charge, George Kasibante, reported “Of the birth of an intersex — hermaphrodite — baby at the hospital [Muleba Designated District Hospital] in Muleba District, Kagera Region” (The Citizen, 2018). On October 3rd & 4th, 2023, the media covered a ‘celebrated surgery’ conducted at Temeke Regional Referral Hospital (TRRH) in Dar-es-Salaam that “successfully normalized an intersex aged 22 a ‘male’” (Mtanzania Digital, 2023; Mwananchi Newspaper, 2023). However, the context within which the surgery took place needs further follow up to conclude if the procedure was consented or a human right violation.

The CHESO Intersex Child Rights Monitors have reported on intersex newborns in different parts of the country including Mara, Tanga and Dar-es-Salaam regions (CHESO, 2019). In addition, Tanzania Voice of Humanity (2020), a Dar-es-Salaam-based Non-Governmental Organization working with and for PBWIVs confirms, “Though least understood and under researched, intersex exist in this country [Tanzania] ... This kind of disability is not well known even [among] the medical personnel ... Communities are unaware of the existence of this group and perceive it [intersex] as curse” (namati.org, n.d.).

Similarly, 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. ‘*Jinsi tata*’, ‘*Jinsia tofauti*’, ‘*Jinsi mbili*’ or ‘*Huntha*’ [Arabic, Kenya] are terms in Kiswahili literally meaning ‘intersex’ or ‘two-sexed’ person(s). Connotative terms or euphemisms in first languages include: ‘*Sorari*’ or ‘*Puqli*’ (Kiiraqw, Arusha Region), ‘*Ekibugilane*’, ‘*ekikube*’, ‘*ekimbulimbuli*’ and ‘*ekikulekule*’ (Oluhaya/Oluganda, Kagera Region); ‘*Kisaya*’ (Kimeru, Arusha Region) ‘*Ndebile*’ (Kisukuma, Mwanza Region) and *Kisuuku* (Kikiboshu, Kilimanjaro Region).

Furthermore, informal conversations with medical doctors — pediatrics obstetric and gynecologists — in Dar-es-Salaam, Dodoma, Kagera, Mbeya, Morogoro and Mwanza confirmed encountering cases of children born with intersex variations. In addition, Thomas’ (2016) qualitative study conducted in Dar-es-Salaam (administrative) Region proves beyond reasonable doubts that PBWIVs variations exist in Tanzania. Moreover, the fact that there are registered non-governmental organizations (NGOs) — The Children Education Society (CHESO, 2006) and The Tanzania Voice of Humanity (2020), for instance — striving to improve the welfare of PBWIVs in the country further attests this population group is real and exists in Tanzania.

INTERSEX FACE (SEVERE) LIFE-COURSE CHALLENGES AND HUMAN RIGHTS VIOLATIONS

PBWIVs' daily life is characterized by actions and reactions that violate their human and citizenship rights. A detailed analysis of PBWIVs' living experiences is presented by Kamazima (2023b). On the daily basis, children, adolescents and adults born with intersex variations face (life-long) stigma, body shaming and discrimination in all spheres of life — socialization, education, employment and sports; abuse, intersex secrecy impact; abandonment; poor socialization; exclusion; self-denial; withdrawn lifestyles; low self-esteem; suicide consideration or attempts; and develop and suffer from mental illness and psychosocial trauma. In addition, PBWIVs lack societal recognition and visibility in their communities and struggle with fear to disclose their status.

In short, PBWIVs live in conditions that persistently violate all aspects of their (human and citizenship) rights including the right to live and the right to quality and equitable health and healthcare. A Ugandan-born intersex, for example, recalled “I have suffered harassment throughout my life, including from my in-laws from my first marriage ... They became very abusive, both verbally and physically ... At one point my sister's husband tried to rape me — it's curious type of “cure” [correction rape] also inflicted on lesbians to “correct them” (Kaggwa, 2016b).

1. PBWIVs' health conditions: Being intersex can come with unique stressors that impact mental health. Due to stigma and lack of awareness, PBWIVs face unique health challenges (Kamazima, 2023c). This is especially true for infants and children born with intersex variations who often have less control over their medical care, more health disparities and sometimes receive medically unnecessary procedures. Such procedures include any action to change intersex variations. Living with biological differences in a stigmatizing society can create personal distress (Kaggwa, 2016a; 2016b; Thomas, 2016).

This condition, in turn, can lead to secrecy and shame relating to bodily appearance and function (Lee, *et al.*, 2006; Kleeman, 2016). The situation gets worse with lack of accurate information and limited opportunities for contact with peers that increase social isolation. Sometimes PBWIVs' conditions create other physical health issues that could then become their own source of stress. Historically, PBWIVs and their parents were not given full or accurate diagnostic facts, or information on their surgical and other medical histories (Creighton, *et al.*, 2001; Creighton, *et al.*, 2002; Kirkland, 2017). Unfortunately, medical professionals thought withholding this information helped PBWIVs to grow up conforming to conventional sex and gender norms — a practice that is no longer acceptable in the contemporary world (headtohealth.gov.au, n.d).

2. PBWIVs and education: PBWIVs lack or possess (sex and gender) conflicting documentation for school registration. PBWIVs, therefore, face difficult enrolling in schools. Those enrolled, encounter challenges adjusting to sexed school systems, facilities and possibility of mishandling (Carpenter, 2019b). Intersex pupils/students face harassment, stigma, discrimination, body shaming, and bullying by colleagues, support staff and even teachers (Kaggwa, 2016a). Often, pupils/students born with intersex variations demonstrate low cognitive abilities as they keep moving from school to school to hide their identifies; miss classes to attend (unnecessary) treatments or medical appointments and counseling (Carpenter, 2019b). Some pupils/students born with intersex variations drop out of school completely (Kaggwa, 2016a; Wasike & Mwadzaya, 2019), which unfavorably affects their mature lives. Some intersex school dropouts turn to substance use and abuse that pushes them into hostile poverty-ridden living conditions (Intersex Nigeria, n. d; Kaggwa, 2016b; Segawa, 2020).

3. PBWIVs and employment: intersex variations are quite different and each type would come with varied (workplace) experiences (Carpenter, 2014). PBWIVs lack legal identifications or hold identities informed by their body, physical characteristics or life experience. Potential PBWIVs workers, therefore, face difficulties applying for gendered careers. PBWIVs who apply for such jobs are forced to disclose their intersex status that furthers stigma and discrimination. Employed PBWIVs are likely to experience bullying, stigmatization and body shaming from employers, co-workers and clients or customers (Carpenter, 2014).

4. PBWIVs and sports: PBWIVs suffer exclusion and stigmatization in sports, mainly “body shaming and the idea that [their] bodies are too masculine or too feminine” (Carpenter, 2019c). Women born with intersex variations, for instance, are blacklisted from or not permitted to compete as women. Women athletes' sex testing involving examinations of women's genitals and other sex characteristics is performed to avoid mixed-sex and women's sport participation by men (Carpenter, 2019c). Women athletes suspected ‘too masculine’ are publicly humiliated or forced to undergo insensitive and unwanted tests often leading to their total withdrawal from competitive sports, other social spaces and activities (CHR UP, n.d. b; BBC, 2011; Carpenter, 2019c; Intersex Nigeria 2021).

YOUR (TANZANIA) GOVERNMENT IS MANDATED TO OUTLAW COSMETIC SURGERIES AND END STIGMA AND DISCRIMINATION AGAINST PBWIVs

The World Conference on Human Rights in Vienna adopted The Vienna Declaration and Programme of Action on June 25, 1993. The Declaration mandates states to take stern measures including policy establishment and legislative amendment outlawing

surgical interventions on infants and children born with intersex variations. Since then, many countries have signed up this Declaration and taken measures in this direction (OHCHR, 1993). Similarly, after The Malta Declaration, 2013, Malta was the first country to ban superfluous surgeries on infants and children born with sex variations in 2015 and over 50 countries have ratified this Declaration (Richmond, 2021; Pepy, 2022). The UN Statement, 2021, called for governments' concrete measures to safeguard PBWIVs from stigma, discrimination and abuse, including medical interventions.

In the same spirit, a series of Intersex Fora — 1st Brussels, Belgium in 2011; the 2nd Stockholm, Sweden in 2012; the 3rd Valletta, Malta 2013 and the 4th Amsterdam, The Netherlands in 2017 — echoed the demand to world governments “to end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination” and called “National governments to address the concerns raised by the Intersex Fora and draw adequate solutions in direct collaboration with intersex representatives and organizations”. The First Ever African Intersex Meeting that took place at the Centre for Human Rights at the University of Pretoria, in Johannesburg, South Africa from the 24th to 26th November 2017 extended demands aiming to end discrimination against PBWIVs in Africa, and to ensure the right of bodily integrity, physical autonomy and self-determination. In addition, The Meeting called African governments to “address the concerns raised by the African Intersex Movement and draw adequate solutions in direct collaboration with intersex representatives and organizations”.

The United Nations (UN) issued a Statement signed by UN Treaty bodies, including The African Commission on Human and Peoples' Rights, on November 10, 2016, urging governments to embargo harmful and irreversible medical and clinical practices on infants and children born with intersex variations, including unnecessary, forced and coercive medical and clinical interventions without their full informed consent. The Statement accentuates, “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, The African Commission on Human and Peoples' Rights (ACHPR) meeting at its 74th Ordinary Session (held from 21 February to 07 March 2023) passed a Resolution on the Promotion and Protection of the Rights of Intersex Persons in Africa [ACHPR/Res.552 (LXXIV) 2023]. According to ACHPR (2023) The Resolution calls upon States to,

Promote and protect the rights of intersex persons and stop non-consensual genital surgical, hormonal and/or sterilization practices, which violate their right to bodily

integrity, physical integrity and self-determination. It also calls for duty bearers to end all human rights violations against intersex persons, particularly the severe forms of infanticide and child abandonment, including prohibiting discrimination based on intersex traits, sexual characteristics and status in education, health, employment, competitive sports and access to public services, as well as ensuring decisions regarding intersex minors are taken in their strict and sole best interest. It further calls for educational, counselling, training and legal reform services for better protection of intersex rights and the environment in which their human rights defenders work.

At the time of writing this paper it was unclear what engagements the Tanzania government had taken to fulfil demands and calls from The UN Human Rights Declarations and Resolutions, The World Intersex Fora (that took place between 2011 and 2017), The African Intersex Movement 2017, and The African Commission on Human and Peoples' Rights [ACHPR/Res.552 (LXXIV) 2023] to end stigma and discrimination against PBWIVs and to ensure the right of bodily integrity, physical autonomy and self-determination of PBWIVs in Tanzania, Africa and globally. Nevertheless, it was evident that to date Tanzania has no legislated law prohibiting harmful medical and clinical interventions on infants and children born with intersex variations in the country. Indubitably, this legal quietness is not at all unprejudiced; it facilitates harmful practices to take place uncontrolled. It further suggests that primary and specialized care providers in this country continue to subject infants and children born with intersex variations to unnecessary, forced, coercive, harmful and irreversible normalization surgeries [including IGM and sterilization] and treatment (See CHESO, 2019). Furthermore, it suggests that parents, traditional and religious leaders in Tanzania continue performing harmful cultural practices, such as tradition-led mutilations and killings of infants and children born with intersex variations.

Tanzania lacks data on types of harmful and non-consensual medical and clinical procedures infants and children born with intersex variations are subjected to. This is a bottleneck that would hamper fulfilling the African and global mission to ensure the right of bodily integrity, physical autonomy and self-determination among PBWIVs in the country and beyond. Similarly, Tanzania lacks evidence on the consequences of forced and coercive medical and clinical procedures to which primary and specialized care providers subject infants and children born with intersex variations and harm caused to the victims' and their families' health and wellbeing. This information is crucial to raise PBWIVs' awareness and recognition among the general public — the lay and the elite, alike — for the affirmation of their human and citizenship rights in this country and beyond as per The UN Human Rights Declarations and Resolutions, The World Intersex Fora (that took place

between 2011 and 2017), The African Intersex Movement 2017, and The African Commission on Human and Peoples' Rights [ACHPR/Res.552 (LXXIV) 2023]

DISCUSSION

Certainly, giving birth to a child with intersex variation comes with grave shock, shame, denial, rejection, hostility and superstitions to parents and family members. Some parents, family members or influential persons in the community opt killing, abandoning or subjecting infants and children born with intersex variations to harmful traditional or modern 'normalization' procedures to streamline their genitalia (Kakande, 2016; BBC, 2017; Segawa, 2020; Ausserer, 2021; Kamazima, 2023a; 2023b; 2023c). Some desperate families decide to just let infants born with intersex variations die (BBC, 2011). That is, killing infants born with intersex variations was — and still is — considered to be the best and normal way to handle intersex nativities. Surviving intersex are raised in secrecy and isolation and usually cut off from the social life and space surrounding them.

In Ghana, for instance, "Intersex infant, child or adult is perceived a 'bad omen' and it is a taboo to live with such a [creature]" (Aryeetey, 2021). In Uganda, "Being intersex can be considered a curse, and something to get rid of" (BBC, 2017; Ausserer, 2021) and "Babies of ambiguous gender are generally treated with disdain by Ugandan society — and even their own family members, who often refuse to give the children a name ... Meaning the child is non-person, rejected and not belonging to the clan lineage [extended family]" (Segawa, 2020; see also Kaggwa, 2016b). Kenyan societies ostracize families with infants and children born with intersex variations or brand them evil omen.

As a result, parents either hide their children born with intersex variations or take them to (medical) doctors for surgery (Koigi, 2019) or to African practitioners for traditional IGM. Therefore, parents, face overwhelming pressure at all levels — family, community, spiritual, cultural, and political — to have a child with a body that conforms to the socially constructed 'male' or 'female' body. In most cases, "Parents will often kill their intersex babies or surrender them to harmful [traditional and modern] mutilations" (Kaggwa, 2016a).

Intersex is not about sexual orientation, gender identity or being gender sundry. PBWIVs have the same range of sexual orientations and gender identities as non-intersex persons or the *endosex*. Some PBWIVs identify with the sex they were raised and are heterosexual. Others identify with the sex they were raised and are attracted to people of the same sex or are bisexual. Some PBWIVs reject the sex they were assigned at birth and identify as the opposite sex, as gender diverse or as

neither 'male' nor 'female' (Thomas, 2016; Victoria, 2019b).

A message to PBWIVs' parents, guardians and members of the public is clear: anyone can be born with intersex variation and, in some cases, persons may even die never knowing they are intersex (InterAct. n.d.; Victoria, 2019c; Leonard, 2012; Carpenter, 2014; Thomas, 2016; Lindahl, 2019; GenderGP, 2020; Aryeetey, 2021; Weiss, 2023; Hartney, 2023; Kamazima, 2023c). Some persons may be born with more than one intersex variation (GenderGP, 2020) suggesting how complex intersex life could be. In rare occurrences, intersex are only diagnosed after they have passed away and are discovered through an autopsy (Felton, 2022). Furthermore, PBWIVs exist in all societies and countries around the globe. PBWIVs, therefore, are our partners, spouses, friends, relatives, neighbors, classmates, coworkers, employers, celebrities, politicians, respected persons in our communities (like THs, TBAs, religious and traditional leaders) and or those we associate with. Since PBWIVs appear like most of us, you may have unknowingly interrelated with one of them! PBWIVs are generally normal and healthy; they need to be recognized, respected and loved.

Being born with intersex variation is not a curse, neither is it a disease or a disorder that requires emergency 'medical normalization'. Rather, it is a variation in sex characteristics including genitals and chromosome patterns that do not fit the socially and medically constructed portrayals of 'boy' or 'girl' or 'male' or 'female' bodies. PBWIVs are not at all 'homosexuals', 'transgender' or 'transsexual'.

Surely, PBWIVs are not 'hermaphrodites' alleged to have male and female genital organs fully functioning at the same time and can make sex on themselves as most of the public think! Traditional and religious leaders and other influential people should know PBWIVs are real and deserve the right to live. Parents, guardians, community members and influential persons/leaders should be agents of change among societies to stop harmful cultural practices, such as tradition-led or religious-motivated IGM and killing infants born with intersex variations.

Infants and children born with intersex variations have the right to universally accepted children's rights like other children — the endosex

Parents, guardians and community members should know that like the endosex, children born with intersex variations have the right to the 8 Fundamental Rights of the Child as guided and determined by The Four (4) Guiding Principles of the Convention on the Rights to the Child: The Principle of Non-Discrimination; The "Best Interests of the Child" Principle; The Principle of life, Survival and Development and The Principle of Inclusion and

Participation. The 8 Fundamental Children's Rights are the right to: 1) life — each child must be able to live his or her own life, not to be killed and to survive and to grow up in proper conditions; 2) education — allows each child to receive instruction, to enjoy a social life, and to build his or her own future, which is essential for the child's economic, social and cultural development; 3) food — child's right to eat healthy and not to die of hunger or suffer from malnutrition; and 4) health — children must be protected against illness, allowed to grow and become healthy adults and members of their respective active societies.

Other rights are the right to: 5) water — children have the right to safe drinking water and proper sanitary conditions, which are essential for good health, survival and proper growth; 6) identity — the right to have a surname, first name and middle names, nationality/citizenship, know his or her parents and relatives, ensure child's existence and rights must be officially recognized); 7) freedom — the child's right to express him or herself, have opinions, have access to information, religious freedom and participate in decisions which affect his or her life, and 8) protection — to live in a secure and protective environment which preserves the child's well-being, and to be protected from all forms of mistreatment, stigma, discrimination, and exploitation.

Parents, guardians and community members in Tanzania, therefore, should leave no stone unturned to protect and affirm infant and children born with intersex variations' human and citizenship rights as per The UN Human Rights Declarations and Resolutions; The Vienna Declaration and Programme of Action, 1993; The Malta Declaration, 2013; The World Intersex Fora (that took place between 2011 and 2017); The African Intersex Movement, 2017 and The African Commission on Human and Peoples' Rights, 2023.

PBWIVs should be free from stigma, discrimination and (their) rights' violations

PBWIVs are often subjected to stigma, discrimination and abuse due to their atypical characteristics or when perceived not to conform to socially and medically fabricated gender norms. In many countries, including Tanzania, there are no anti-discrimination laws and policies banning discrimination against PBWIVs. As a result, infants and children born with intersex variations are persistently subjected to unnecessary, forced, coercive and irreversible medical and clinical interventions — surgery, sterilization, IGM, and treatment — without their full informed consent.

Indubitably, this legal silence is not at all impartial; it facilitates harmful practices to take place unnoticed and uncontrolled. That is, it leaves PBWIVs vulnerable to discriminatory practices in a range of settings, including poor or no visibility, access to health services, education, public services, employment and

sports (Kamazima, 2023b). Healthcare professionals in many countries lack appropriate training, knowledge and understanding of intersex variations to recognize and respect PBWIVs-specific health needs, provide appropriate and transparent healthcare, and respect the autonomy and PBWIVs' rights to physical integrity and health (Kamazima, 2023c). Some PBWIVs also face barriers and discrimination acquiring legal documents — birth certificates and travel documents — or if they wish to or need to amend sex markers on birth certificates and official documents (Carpenter 2019a; Koigi, 2019; Kamazima, 2023b; 2023c).

Hyper-androgenic female intersex athletes (or perceived too masculine) face a specific set of obstacles in national and international level sports. There have been several cases of female intersex athletes — the Mokgadi Caster Semenya's case on April 30, 2019, for instance (for details see CHR UP, n.d.; Carpenter, 2019b; Kamazima, 2023b) — who have been disqualified from sports competitions on the basis of their intersex variations (CHR UP, n.d.; BBC, 2011; Carpenter 2019b; Intersex Nigeria, 2021; Kamazima, 2023b). Certainly, being intersex per se does not entail better performance, other physical variations that do affect performance — height and muscle development, for instance — are never subjected to such scrutiny and restrictions (ISNA, 2008).

Parents, guardians and community members in Tanzania should understand that intersex stigma, discrimination and rights' violation do not stem from the variations they have; rather, from the society that expects them to conform to the socially constructed prototypes. Changing community members' negative attitudes, correcting deep-rooted intersex variations' misconceptions and increasing awareness and understanding of intersex variations would improve PBWIVs' life and wellbeing in this country.

Understand and use PBWIVs' preferred terms/words and language

Like other minority population groups — female sex workers (FSWs, Kamazima & Kazaura, 2012; Kamazima & Kazaura, 2018); women who have sex with women (WSW, Kamazima, 2023d) and the homosexuals, for example — PBWIVs have terms/words and language they prefer to use to describe their variations, their families, when interacting with friends or when seeking healthcare. Some PBWIVs, for instance, prefer terms like — 'an intersex person', 'man with an intersex variation', 'woman with an intersex condition' or as 'having an intersex variation' — and may prefer to use different words for themselves, with their family, friends or when accessing medical services (Head to Health, n.d.; Meyer-Bahlburg, 1994; IHRA, 2013; Gender GP, 2020).

For example, some PBWIVs prefer medical or diagnostic terms used by their doctors such as androgen insensitivity, congenital adrenal hyperplasia or 5 α

reductase deficiency (Head to Health, n.d.). However, some PBWIVs find those terms offensive and avoid them in their personal lives (APA, 2006). Consultations with other parents and guardians of PBWIVs, intersex activists, intersex-led organizations in the country — The Children Education Society (CHESO 2006) and The Tanzania Voice of Humanity (2020), for instance — and beyond and utilizing proposed public health intersexuality research findings in Tanzania (Kamazima, 2023c) could facilitate establishing and using PBWIVs'-favored language.

This preference is not unique to PBWIVs in Tanzania; other minority and vulnerable groups have taken the same course. For example, the traditionally called *Malaya/(ma)kahaba/(ma)changu doa/ (ma)dada poa* in Kiswahili — the national language — or 'prostitutes' now prefer FSWs term. The habitually referred to as '*zeruzeru/wenye ugonjwa wa ngozi*' or 'the albino' have chosen and prefer the term '*watu wenye albinism*'/'*watu wenye ulemavu wa ngozi*' or 'persons with albinism' and the previously known as '*kiziwi/viziwi*' or 'the deaf' prefer the term '*wenye ulemavu wa kusikia*'/'*wenye usikivu hafifu*'. Similarly, the traditionally named '*bubu*' or 'dumb' and '*pofu/kipofu/vipofu*' or 'the blind' currently favor '*wenye ulemavu wa kuongea*' and '*wenye ulemavu wa kuona*'/'*wenye uoni hafifu*' terms respectively. Furthermore, the previously identifying 'homosexuals' — 'men-who-have-sex-with-men' or 'gays' (MSM) and 'women-who-have-sex-with-women' or 'lesbians' (WSW) — are currently pushing for 'men/women at risk' identity.

In the absence of a preferred term for intersex in Tanzania, I opted and use 'persons born with intersex variations or PBWIVs' for this group in my initial works. The ultimate goal is to avoid terms/words and language that further stigma, discrimination and PBWIVs' rights violations in this country.

CONCLUSION AND RECOMMENDATIONS

Progressively, PBWIVs, intersex activists, researchers, members of the public (the lay and elite alike) and the media are showing increasing awareness of the existence of PBWIVs and who they are in Tanzania and beyond. However, the change pace remains poky, but promising to overcome the secrecy and shame which surround intersex variations. Habitually, parents and influential leaders killed infants and children born with intersex variations or parents were told to hide the truth from children born with intersex variations.

I have a dream, it will reach a point where increasing awareness is likely to lead to amassed outrage about violation of PBWIVs' human and citizenship rights in this country — including unconsented surgeries, IGM and forced sterilization. Tanzania government, therefore, ought to reform the law now to avoid a scandal

in the future. This is especially true given the increasing trend towards centering the importance of patient autonomy and self-determination that medical law is demonstrating. Legislative reform itself is not enough; this must be coupled with a concerted and government-led effort to educate and improve the understanding and recognition of intersex variations in the country and beyond.

Infants and children born with intersex variations' parents or guardians should be knowledgeable of what intersex variation means and requires. Parents and guardians, therefore, should be aware and understand that they have infants and children born with naturally occurring characteristics that do not fit the typical definitions for 'boy' or 'girl', 'man' or 'woman' or 'male' or 'female' body binary. This infant/child might have come with a shock to you and you may be facing pressure from your spouse, family members, influential leaders and communities around you on what (traditional and modern interventions) should be performed to your children. All you should know is that intersex variation is not a disorder that requires immediate or emergency correction. In general, and other factors held constant, your child is normal and health; should be loved and cared for like other children without intersex variations (the *endosex*).

As expected, when your child is born with intersex variation, the care provider may suggest an intervention to make his/her genitals look more like a common penis or vagina or to look 'normal'. What you should keep in mind is that genitals come in all shapes and sizes and there is no universal definition of 'normal genital shape, size or morphology'. Always remember, nature presents us with sex anatomy spectra. Breasts, nipples, vaginas, clitorises, labia, gonads, penises and scrota come in varied sizes, shapes and morphology. Only, and only if, your underage intersex child's health is at risk, the decision to undergo elective surgery should be delayed till when the child is old enough (to understand the nature, risks and alternatives to a treatment) to consent and be involved in the decision-making process.

Consistently, parents and guardians should demand for their infants and children born with intersex variations' accurate and comprehensive diagnostic information on their surgical and other medical histories. In addition, parents and guardians should ensure healthcare providers understand conditions their children are facing and must deliver ethical medical support that is honest, confidential and non-discriminatory to PBWIVs, parents or guardians and your (extended) families. When necessary, it is the care providers' responsibility to suggest need-appropriate referrals.

I am aware; it is difficult and demanding to raise children born with intersex variations. However, as much as possible be honest with your children and answer their

(often disturbing, exasperating and even offending) questions or identify a trusted and unbiased person (fellow parent, family friend, intersex group or organization leader, intersex activist) or professional (doctor or social worker) who can. Be sincere to them: avoid lying or mislead them about their innate intersex variations or medical history. Remember, being intersex does not mean your child will grow to become 'homosexual', 'transgender' or 'transexual'; thence, do not force your children to live a gender they do not identify with. Whenever possible, parents and guardians should seek and share support and correct intersex information from parents and adult intersex with similar experiences, media, internet (intersex factsheets, for example) and intersex-led groups and organizations and institutions within and outside Tanzania. The Children Education Society (CHESO 2006) and The Tanzania Voice of Humanity (2020) that are working with and for PBWIVs in the country could be the starting points in this direction.

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