

## Review Article

# 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

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**Abstract:** Intersexuality includes a variety of conditions in which individuals are born with, or develop later in life, ambiguous external genitalia and or a combination of chromosomes, gonads, external genitalia, and hormones that do not align as typical male or typical female. Persons born with intersex variations, therefore, are real and exist in all countries around the globe. What is missing in most countries like Tanzania is the comprehensive understanding of who persons born with intersex variations are; their (health) needs; the parents/guardians', families', communities' experiences and governments' roles in recognizing and protecting human rights and citizenship rights this group is entitled to. Low awareness and understanding of persons born with intersex variations among the general public, policy makers and the (public) health professionals; lack of empirical research on this group and intersex-LGBTQ confusion explain, in part, why there is paucity of data on this population in Tanzania and other countries mainly where LGBTQ is illegal. Data presented in this paper come from desk research I conducted on intersexuality in Tanzania and beyond. I conclude public health experts in this country stand a better chance to bridge gaps identified in existing intersexuality research to enable Tanzania realize demands and calls made by The African Intersex Movement, 2017. I recommend public health intersexuality research to move towards a psycho-social framework which accepts persons born with intersex variations, because the problem is not with this population; it is, rather, with the society expecting them to conform to their socially constructed archetypes.

**Keywords:** Intersexuality, intersex rights, persons born with intersex variations, public health intersexuality research, desk research, Tanzania.

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## INTRODUCTION

Following the preceded four International Intersex Fora (1<sup>st</sup> Brussels, Belgium, 3-5 September 2011; 2<sup>nd</sup> Stockholm, Sweden, 9-11 December, 2012; 3<sup>rd</sup> Valletta, Malta, 29 November and 1 December 2013; and 4<sup>th</sup> Amsterdam, The Netherlands, April 20-23, 2017), 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 24<sup>th</sup> to 26<sup>th</sup> November 2017. The Participants (22 persons born with intersex variations representing intersex organizations from 7 African countries) drafted a Public Statement to extend demands aiming to end discrimination against persons born with intersex

variations 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 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*

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*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 ...”*

The Public Statement extends 16 demands including: 1) “To put an end to infanticide and killings of intersex people led by traditional and religious beliefs”; 2) “To put an end to mutilating and ‘normalizing’ practices such as genital surgeries, psychological and other medical treatments 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”; 3) “To raise awareness around intersex issues and the rights of intersex people in communities and society at large”; 4) “To acknowledge the suffering and injustice caused to intersex people”; 5) “To recognize that lexicalization and stigmatization of intersex people result in significant trauma and mental health concerns”; and 6) “To ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family”.

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”.

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 a Public Statement to extend demands and calls aiming to end discrimination against persons born with intersex variations in Africa. Tanzania would wish to follow the same route to ensure constitutional and human rights to the citizenry without discrimination geared at ending stigma and secrecy around intersex variations. Unfortunately, Tanzania is deficient of empirical data on this population group, a bottleneck that would hamper fulfilling this African mission to ensure the right of bodily integrity, physical autonomy and self-determination (See Malta Declaration, 2013). Since persons born with intersex variations are a minority and the history of secrecy surrounding intersex variations and diagnoses persists, statistically representative data on persons born with

intersex variations is missing in many (African) countries, and in Tanzania in particular.

The fact that about 60 percent of pregnant women in Tanzania give birth outside the health facilities with support from female relatives or the traditional birth attendants (TBAs) (Ngowi & Kamazima, 2019; Ngowi, *et al.*, 2022), suggests that traditional killings of infants and children born with intersex variations could still be going on unnoticed and uncontrolled. Similarly, there is still so much deep-rooted negative norms, misinformation and misconception on who persons born with intersex variations are due to a lack of long-term longitudinal studies on the intersex’s, families’ and communities’ perceptions, caring, psychological and physical impact of various treatment (traditional and modern) models on persons born with intersex variations. As a result, parents, doctors and socially respected individuals continue making decisions that subject persons born with intersex variations to forced and coercive traditional and biomedical care that are not evidence-based.

More important, perhaps, is that Tanzania lacks intersex-specific healthcare provision guidelines and strategies to empower persons born with intersex variations 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. To generate data presented in this paper, I collected and reviewed (desk research) 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 PUBLIC HEALTH LENS**

The year 2023 marks 10 years after the third International Intersex Forum held in Valletta, Malta (29 November to 1 December 2013) that reaffirmed the principles of the First and Second International Intersex Fora that extend demands aiming to end discrimination against persons born with intersex variations and to ensure the right of bodily integrity, physical autonomy and self-determination, including “To put an end to mutilating and ‘normalizing’ practices such as genital surgeries, psychological and other medical treatments through legislative and other means. Intersex people must be empowered to make their own decisions affecting own bodily integrity, physical autonomy and self-determination”. The Public Statement made a call

to “National governments to address the concerns raised by the Intersex Forum and draw adequate solutions in direct collaboration with intersex representatives and organizations”.

Similarly, the year 2023 marks 6 year after The First Ever African Intersex Meeting (Johannesburg, South Africa, 24<sup>th</sup> to 26<sup>th</sup> November 2017). The Public Statement by the African Intersex Movement recalls the principles of the Public Statement by the Third International Intersex Forum and extends demands aiming to end discrimination against persons born with intersex variations in Africa, to ensure the right of bodily integrity, physical autonomy and self-determination. The Public Statement calls “National governments to address the concerns raised by the African Intersex Movement and draw adequate solutions in direct collaboration with intersex representatives and organizations”.

Unfortunately, to date, there is no evidence of what strategies the Tanzania government has put in place and accomplished towards ending negative norms and harmful (traditional and biomedical) practices on infants and children born with intersex variations. In the absence of such data, I use scanty information available and experiences from other countries to demonstrate what public health personnel should know and do to contribute to the protection and preservation of persons born with intersex variations’ human rights and citizenship rights in Tanzania and beyond.

### 1. Intersex-LGBTQ muddle and dilemma

Globally, there are no firm figures for the world’s intersex population (APA n.d.) as the groups is habitually put under the lesbian, gay, bisexual, transgender and intersex (LGBTI) umbrella. Hence, persons born with intersex variations are obscured in this group and at risk of being overlooked, marginalized and criminalized in countries where homosexuality is illegal, like Tanzania (Canada, 2014; Kamazima, *et al.*, 2021a; 2021b). In turn, this confusion can result in further erasure of the existence and needs of persons born with intersex variations (Carpenter, 2012; Carpenter, 2019b; Kaggwa, 2016). For example, in countries like Tanzania (Kamazima, *et al.*, 2021a; 2021b; 2021c; Kamazima, 2023a) and Uganda (Kaggwa, 2016a; 2016b; BBC, 2017; Kamazima, *et al.*, 2021b) where homosexuality is illegal, criminalized and penalized to life imprisonment, intersex being politically labelled as LGBTQ and part of the homosexuals’ rights lobbying and advocacy discourse could adversely impact persons born with intersex variations’ rights, wellbeing and life struggles.

In turn, this situation could push persons born with intersex variations further to the margins, keeping them neglected, discriminated and criminalized through a homosexual lens, thus explaining why links with the

gay community are a ‘double-edged sword’ (Kaggwa, 2016a; CHR/UP, 2017). In addition, as Kaggwa (2016b) observed “Being politically labelled as LGBTQI and part of the gay rights advocacy discourse also has its contribution to pushing intersex people in Uganda further to the margins, keeping us only visible through a homosexual lens”. In the same perspective, intersex activists in Kenya say they want to be separate from the LGBTQ community as their situation is a naturally occurring congenital condition, not a sexual orientation (Wasike & Mwadzaya, 2019). More important, perhaps, is that the recently rekindled (from March 2023) odium and ongoing anti-homosexuality movements in Africa, could adversely impact persons born with intersex variations’ human rights, citizenship rights and wellbeing if they remain visible through the LGBTQ lens. Comprehensive public health intersexuality research to be conducted in Tanzania, therefore, should, from persons born with intersex variations’ perspective, provide answers to the intersex-LGBTQ aenigma to increase intersex visibility and the recognition and respect for the intersex community’s rights in Tanzania.

### 2. Being born with intersex variation is quite different from being homosexual or LGBTQ

‘Intersex’ are in many aspects quite different from and should not be confused with ‘homosexuals’, ‘transgender’ or ‘transsexual’ (Intersex Nigeria, n. d; Carpenter, 2021a). Individuals who identify ‘transgender’ or ‘transsexual’ are born with typical male or female anatomies but feel as though they were born in ‘wrong’ bodies. That is, she who identify ‘transgender’ or ‘transsexual’ may have typical female anatomy but feels like a male and seeks to become male by taking hormones or opting to have sex reassignment surgeries and vice versa (Kamazima, 2023a; 2023b). On contrast, intersex is a biological factor and a naturally occurring characteristic and is **NOT** [my emphasis] a sexual desire (Amnesty International, 2018a).

In the author’s perspective and as Intersex Nigeria (n.d.), ERT (2013), Kaggwa (2016b), BBC (2017) and CHR/UP (n.d.) correctly observed, claiming intersex is a subset of the LGBTQ group has more harm than the benefit expected. Kaggwa (2016b) further asserts,

*Though we [intersex] stand with the gay community in Uganda, the association has become a double-edged sword for us ... Politically, we are considered the same, and we are subject to the same dangers and the same level of harassment ... [irrespective of] our [intersex-] specific needs ... Lately, intersex staunch Church goers have been facing challenges to find acceptance in their Churches as fellow believers increasingly claiming they [intersex] are ‘treading a*

*slippery path' by standing up for the gay community and often warned against integrating Christianity and LGBTIQ activism.*

As a result, this acumen could limit research conducted among and with intersex community to inform societal and public awareness, perceptions, attitudes and understanding of intersex; and to enlighten the formulation of national intersex-friendly policies and (public) health interventions targeting this group. Similarly, LGBTQ (health) surveys suffer from ascertainment bias and low participation rates by persons born with intersex variations (unwillingness to engage in such studies), and poor analysis (Carpenter, 2012; 2021b). Yes, there is intersectionality between the LGBTQ and intersex groups but is weak to override the existing sharp and vivid differences between the two groups. Certainly, people who identify 'transgender' or 'transsexual' also face discrimination and deserve equality. It is also true that persons born with intersex variations and individuals who identify 'transgender' or 'transsexual' can and should continue to work together on human rights issues. However, there are important differences and intersex-specific needs to keep in mind so that both groups can work toward a better future. 'Intersex', therefore, is not another term for 'homosexuality', 'transgender' or 'transsexual'.

Majority of persons born with intersex variations identify 'heterosexual' (Migeon, *et al.*, 2002) and the number of persons born with intersex variations who are gay, lesbian, bisexual, transgender or transsexual is unknown. A survey conducted in the United States (US) in 1968, for instance, "found that 43.5 percent of intersex women reported same-sex fantasies" (Ehrhardt, 1968). Another study conducted in 1987 found that "only 2.5 percent of intersex people had engaged in sexual activity with a partner of the same sex" (Mulaikal, 1987). A study conducted in German in 1992 found that "20 percent of women with Congenital Adrenal Hyperplasia (CAH) wished for or had experienced same-sex relationships" (Dittmann, 2008). A study conducted in Canada in 1996 reported "that 26.7 percent of intersex women measured as bisexual on the Kinsey Scale" (Zucker, 1996). It should be noted, however, that persons born with intersex variations could share characteristics with LGBTQ, the latter group are not born with atypical sexual and reproductive systems and do not have the same history of surgical intervention during their childhood as persons born with intersex variations (Dittmann, 2008; Koyama, 2008). That is, while persons born with intersex variations struggle against surgeries and medical treatments they do not want, the homosexuals, transgender and transsexual struggle to access such harmful medical procedures they voluntarily and dearly want. Comprehensive public health intersexuality research in Tanzania, therefore, should generate evidence and correct deep-rooted negative norms,

misconceptions and myths among the public and the (political) elite alike that intersex is synonymous to LGBTQ and that persons with unnormalized intersex variations would grow to become 'homosexual', 'transgender' or 'transsexual'.

### **3. How common are intersex globally and in Tanzania?**

Generally, the number of people born with intersex variations is contested; what is for sure is that they exist (Kheraj & Papisova, 2017a; Posch, 2019). On the one hand, some studies, the Intersex Society of North America (ISNA), for instance, estimated that intersex conditions affect one in 2,000 children (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 hyper-plasia" (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".

Indeed, there is limited data on intersex population in Tanzania. However, scanty information available from reliable sources prove beyond reasonable doubts (no matter how many they are) persons born with intersex variations 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 [intersex] 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). The Tanzania Voice of Humanity (2020), a Dar-es-Salaam-based Non-Governmental Organization working with and for persons born with intersex variations 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, the fact that there are 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. ‘*Huntha*’ [Kenya], *Jinsi tata*, ‘*Jinsi mbili*’ or ‘*Jinsia tofauti*’ are terms in Kiswahili literally meaning ‘intersex’ or ‘two-sexed’ person(s). Connotative terms or euphemisms in first languages include: ‘*Ekibugilane*’, ‘*ekikube*’, ‘*ekimbulimbuli*’ and ‘*ekikulekule*’ (Oluhaya/Oluganda, Kagera Region); *Kisuuku* (*Kikibosho*, Kilimanjaro Region); ‘*Ndebile*’ (*Kisukuma*, Mwanza Region); ‘*Kisaya*’ (*Kimeru*, Arusha Region) and ‘*Sorari*’ or ‘*Puqli*’ (*Kiiraqw*, Arusha Region).

Furthermore, informal conversations with medical doctors – pediatrics obstetric and gynecologists – in Mwanza, Kagera, Morogoro, Dodoma, Mbeya and Dar-es-Salaam-based health facilities 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 persons born with intersex variations exist in Tanzania. Moreover, the fact that there are registered organizations –The Children Education Society (CHESO, 2006) and The Tanzania Voice of Humanity (2020), for instance – striving to improve the welfare of persons born with intersex variations in the country further attests this population group is real and exists in Tanzania. Comprehensive public health intersexuality research to be conducted in the country, therefore, should establish qualitative and quantitative evidence on the existence of persons born with intersex variations and their (health) needs to inform intersex-friendly (health) interventions and policies targeting persons born with intersex variations in Tanzania.

#### 4. Intersex defined: lay nomenclature and group construction

Lightly, an intersex (a term coined by a German Scientist Richard Goldschmidt in 1901 and reclaimed by 1990s intersex activists) person is somebody who was born without falling directly into one of the binary biological sexes assigned at birth – ‘boy’ or ‘girl’ or ‘male’ or ‘female’ (Natracare. n.d.; Anderson, n.d.; Carpenter, 2014; Thomas, 2016; Lundberg, *et al*, 2018; Bashforth, 2022; Weiss, 2023; Hegarty & Smith, 2023). Intersex is an umbrella for people born with variations of sex characteristics chromosomes, and or hormone, which may not correspond with societal and medical expectations (Anderson, n.d.; CHR/UP. n.d.; Leonard, 2012; UNDP, 2017; Amnesty International, 2018; Bashforth, 2022; Felton, 2022; Hartney, 2023). The characteristics may

include primary sex characteristics (internal and external genitalia, reproductive systems, hormone levels and sex chromosomes), or secondary sex characteristics which become apparent at puberty (Gold, 2001; Anderson, n.d.; Carpenter, 2014; Posch, 2019; Lindahl, 2019; Hartney, 2023).

In other words, characteristics can present externally in the appearance of genitals and identified at birth or internally in a person’s reproductive organs realized later in life (at puberty, for instance) due to the way their bodies change and function or “some chance event like paternity testing” (Leonard, 2012; Wilson, 2012; GenderGP, 2020; Hartney, 2023) or after a surgery or imaging test (Cleveland Clinic, 2022). Intersex variations then, might be identified before birth, at birth, in early childhood, at puberty, or later in life, such as when trying to conceive (Head to Health, n.d.; Meyer-Bahlburg, 1994; APA, 2006; DiProperzio, 2014; Carpenter, 2014; Carpenter, 2021a; UNDP, 2018); grow differently than expected (Klein, 2021) or prenatally through the use of genetic screening technologies (Carpenter, 2019).

In some cases, person may never know that they are intersex (InterAct. n.d.; Victoria, 2019b; Leonard, 2012; Carpenter, 2014; Thomas, 2016; Lindahl, 2019; GenderGP, 2020; Aryeetey, 2021; Weiss, 2023; Hartney, 2023) and in rare occurrences, intersex are only diagnosed after they have passed away and are discovered through an autopsy (Felton, 2022). Persons born with intersex variations, therefore, are born with physical or biological characteristics, detected or not, (such sexual anatomy, reproductive organs, hormonal patterns) that do not fit the typical definitions for ‘male’ or ‘female’ bodies (Head to Health, n.d.; Wilson, 2012; Carpenter, 2014; Kheraj & Papisova, 2017a).

However, it is known that persons born with intersex variations may prefer different language to describe their variations – ‘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; GenderGP, 2020). For example, some persons born with intersex variations prefer medical or diagnostic terms used by their doctors such as androgen insensitivity, congenital adrenal hyperplasia or 5 $\alpha$  reductase deficiency (Head to Health, n.d.). However, some persons born with intersex variations find those terms offensive and avoid them in their personal lives (APA, 2006). Comprehensive public health intersexuality research to be conducted should establish persons born with intersex variations’ preferred language to describe their variations and the different words they prefer to use for themselves, with their

family, friends or when accessing medical services to avoid further stigmatization and discrimination against this population in this country.

### 5. Paucity of intersexuality research in Tanzania

Indeed, as is the case in many other (African) countries, there is limited intersexuality-related research in Tanzania. The literature review I conducted, I found only two published research studies: the Meijer and Groeneveld (2007) 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. This finding suggests that comprehensive public health and clinical intersexuality research are mandatory in this country now than before to inform governments’ interventions targeting persons born with intersex variations 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.

## DISCUSSION

The lack of empirical data on persons born with intersex variations, their families and variations-specific experiences is a significant concern in many (African) countries (CHR/UP, n. d) and in Tanzania, in particular. According to Huang, *et al.*, (2010) this shortfall is due to several reasons. First, according to APA, (2006), and UNDP, (2017),

*Given that many elements of sex (chromosomes, genes, hormones) are not apparent without testing, current estimates of the incidence and types of intersex variations seen in humans may be conservative. Some common intersex variations are diagnosed prenatally, some at birth; others may only become apparent at puberty, when trying to conceive, or through random chance; and it is important to emphasize that many people will never know they have intersex variations ... Many individuals with intersex variations have two or more variations.*

Second, intersex numbers are also affected by “the inclusion of congenital variations stemming from hormone-related conditions; some researchers have included extreme polycystic ovary syndrome (PCOS)-related hyperandrogenism within the umbrella of intersex variations” (Huang, *et al.*, 2010). Finally, for known and unknown reasons,

*Researchers have intentionally or unintentionally included individuals who*

*identify as intersex as a gender or political identity choice without having somatic intersex variations ... There is, however, a need in health research to limit the group to only those with somatic intersex variations (regardless of gender or political identity), due to their distinct medical experiences (Huang, *et al.*, 2010).*

Intersex population size estimates, therefore, fluctuate based on the definition researchers use, contexts (homosexuality is illegal, tolerated or legal) within which research takes place and ensuring a representative sample size (outside clinical settings) is relatively difficult (Carpenter, 2012; Hegarty & Smith 2023). Stigma around intersex variations also makes persons born with intersex variations unwilling to disclose their intersex status (Carpenter, 2012). Moreover, some individuals might be unaware that they are intersex; hence, missed in the survey populations and samples (Aryeetey, 2021). Unfortunately, in many African countries, no intersex status questions currently exist on any national census and general population survey tools and population-level data on persons born with intersex variations are unavailable in these countries. Adding intersex-focused questions in the national census and population surveys could facilitate estimating the group’s size. South Africa and Kenya, for instance, have paved way in this direction by legally recognizing existence of persons born with intersex variations and including ‘intersex’ in population counts in 2003 and 2019 respectively. Additionally, there are no nationwide data on the prevalence and consequences of unnecessary surgeries performed on persons born with intersex variations and most hospitals opt not to disclose this information to ‘patients’, parents or guardians, let alone to researchers.

Gaps are apparent existing in intersexuality research around the globe. On the one hand, medical and clinical research on persons born with intersex variations are facility-based; focus on infant, child, and adolescent case studies; have limited ‘samples’; findings are not generalizable and generally not shared for the general population’s consumption. These studies, therefore, fall short of adult persons born with intersex variations’ and their families’ lived-experiences and lack long-term outcome (Carpenter, 2012; Hegarty & Smith, 2023), thus feeble to bring change in intersex awareness, understanding and perceptions among the general public [the lay and (political) elite alike]. On the other hand, LGBTQ/LGBTIQ sexual and gender minorities research and surveys recurrently presume particular experiences of sexuality and gender non-conformity, and focus on their implications for adult populations.

More important, perhaps, is that the illegal status of LGBTQ in many countries, including

Tanzania, may limit persons born with intersex variations' participation in (health) surveys developed from the LGBT perspective. As Carpenter (2012) has correctly observed,

*These approaches [clinical and LGBTIQ] have incommensurate, and sometimes contradictory beliefs about the needs and characteristics of intersex people, with consequences for data quality and interpretation ... Neither approach is firmly grounded in the needs of people with intersex variations ... Framing non-inclusive research as "LGBTI" research can have negative consequences for intersex populations, including misrepresentation.*

Research, therefore, is needed on the lived experiences of persons born with intersex variations in Tanzania (irrespective they have undergone or not undergone multiple surgeries or treatments in childhood and how many they are) and their families to better assess the physical and social effects of the conditions themselves, apart from problems related to traditional and biomedical interventions. There are as many as 40+ conditions contained under the umbrella term "intersex"; hence, comprehensive research is needed on the (health) risks associated with each variation.

## CONCLUSION AND RECOMMENDATIONS

Available and reliable sources presented in this paper vindicate, beyond reasonable doubts, that persons born with intersex variations are real and exist in Tanzania. In addition, these sources demonstrate a lack of awareness and understanding of this group among the general public, policy makers and the (public) health professionals in this country. Lack of empirical research on this group and intersex-LGBTQ confusion explain, in part, why there is paucity of data on this population in Tanzania and other countries especially where homosexuality is illegal. This gap, suggests persons born with intersex variations in this country could be facing unnoticed and uncontrolled life-long challenges as recorded in other African countries and around the globe. Certainly, Tanzania wishes to ensure constitutional rights and human rights to this group as stipulated in The Public Statement by the African Intersex Movement (2017) and other Human Rights doctrines to which, Tanzania is a signatory. To meet this objective, the Tanzania government requires comprehensive empirical data to inform persons born with intersex variations-friendly interventions and policies.

Public health experts in this country stand a better chance to bridge gaps identified in existing intersexuality research to enable Tanzania realize demands and calls made by The African Intersex Movement, 2017. Persons born with intersex variations are not homogeneous, everybody's experience is different, and each of the 40+ variations presents unique

experiences. That is, intersex variations are quite different and each type would come with varied risks and life-experiences. In some cases, persons born with intersex variations have two or more intersex variations suggesting how complex intersex life experience could be. It is important, therefore, to listen to individuals with first-hand life experiences as persons born with intersex variations. This is true because no change is real or sustainable without the holistic empowerment of the beneficiaries. The philosophy behind this perspective is that, "nothing for persons born with intersex variations (in Tanzania) without them". Public health research, therefore, ought to move towards a psycho-social framework which accepts persons born with intersex variations. Such intersex conceptualization and contextualization are cardinal because the problem is not with persons born with intersex variations; it is, rather, with the society expecting them to conform to socially constructed archetypes.

Using Social Sciences methodology (ethnographic, multidisciplinary, longitudinal, experiments), studying accurate populations, selecting representative samples and use of methods such as focus group discussions (FGDs), in-depth interviewing (IDIs), personal narratives or life stories and histories and surveys, public health experts could research on lay people's and elite's understandings of intersexuality and its medicalization consequences on individual persons born with congenital atypical sex characteristics' and their families' health and wellbeing. The definitive goal should be to correct existing negative norms, misinformation, misconceptions and myths on who persons born with intersex variations are, their (health) needs and (human and citizenship) rights they are entitled like their counterparts – the endosex. Public health experts should use generated data to plan, implement, monitor and evaluate (health) interventions to raise persons born with intersex variations' visibility, awareness and understanding among the public and the (political) elite.

Similarly, public health experts should use research-borne data to influence government policy by lobbying and advocating for persons born with intersex variations-friendly laws in the country and training medical professionals on how to address persons born with intersex variations' and their immediate family members' (health) needs without violating their rights. To attain this long-term objective, the Tanzania Government must demonstrate recognition, unconditional love, respect, acceptance and support to persons born with intersex variations and their families in the country and beyond. In turn, this commitment would enable persons born with congenital atypical sex characteristics to grow up and live free of shame, stigma, harm and pain in a world where their human rights and citizenship rights are treasured.

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