

Review Article

# Intersexuality: The Role of Political Elite in Recognizing, Respecting, Protecting and Affirming Persons Born with Intersex Variations' Human and Citizenship Rights in Tanzania

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**Abstract:** 'Intersex' is an umbrella for persons born with variations of sex characteristics which may not correspond with societal and medical expected 'male' or 'female' bodies. Persons with intersex variations, therefore, are born with physical or biological characteristics that do not fit the typical definition for 'male' or 'female'. In this paper I establish that there is no vivacious evidence that the Tanzania Government has taken stern measures to end discrimination against persons born with intersex variations in the country, and to ensure the right of bodily integrity, physical autonomy and self-determination as per demands and calls by 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 Public Statement by the African Intersex Movement, 2017, and The African Commission on Human and Peoples' Rights, 2023. Incontestably, awareness of intersex conditions and persons born with intersex variations' human and citizenship rights is increasing among this population group, researchers, parents/guardians, activists and in the media in this country. Increase of awareness is likely to come with increasing revolt, which may provide the impetus for legal reform. The Tanzania government, therefore, ought not to wait for this ignominy 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:** Intersex, intersexuality, persons born with intersex variations, intersex variations, intersex (human/citizenship) rights, political elite, 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 24<sup>th</sup> to 26<sup>th</sup> November 2017. Twenty-two persons born with intersex variations (PBWIVs) from seven African countries attended representing their intersex organizations. The participants drafted a Public Statement to extend demands aiming to end discrimination against 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,

*“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,*

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*political and legislative changes that concern us ...”*

The Public Statement extends 16 demands: 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 include intersex education in antenatal counseling and support; 4) “To put an end to non-consensual sterilization of intersex people”; 5) “To depathologise variations in sex characteristics in medical practices, guidelines, protocols and classifications, such as the World Health Organization’s International Classification of Diseases”; 6) “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”; 7) “To raise awareness around intersex issues and the rights of intersex people in communities and society at large; and 8) “To create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings”.

Other demands included in The Public Statement are: 9) “To ensure that intersex people have the right to full information and access to their own medical records and history”; 10) “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”; 11) “To acknowledge the suffering and injustice caused to intersex people; 12) “To build intersex anti-discrimination legislation in addition to other grounds, and to ensure protection against intersectional discrimination”; 13) “To ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family”; 14) “To ensure that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex. Intersex athletes who have been humiliated or stripped of their titles should receive reparation and reinstatement”; 15) “To recognize that lexicalization and stigmatization of intersex people result in significant trauma and mental health concerns”; and 16) “In view of ensuring the bodily integrity and well-being of intersex people, autonomous non-anthologizing psycho-social and peer support be available to intersex people throughout their life (as self-required), as well as to parents and/or care providers”.

In addition, The African Intersex Movement called on: 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; 3) National, regional and international human rights institutions to take on board, and provide visibility to intersex issues in their work; 4) Community leaders to engage in intersex education to dispel misconceptions and stigma around intersex people; 5) Human rights organizations to contribute to build bridges with intersex organizations and build a basis for mutual support and meaningful engagement. This should be done in a spirit of collaboration and no-one should instrumentalize intersex issues as a means for other ends, and 6) Funders to engage with intersex organizations and support them in the struggle for visibility, increase their capacity, the building of knowledge and the affirmation of their human rights.

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 SEXUALITY IN TANZANIA NOW THAN BEFORE — A LEGISLATIVE AND POLICY PERSPECTIVE**

On June 25, 1993 the World Conference on Human Rights in Vienna adopted The Vienna Declaration and Programme of Action which, among other demands, mandated states to take stern measures including legislative and policy establishment and or 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). 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 PBWIVs from discrimination and abuse, including medical interventions, more than 50 countries signed it.

A series of Intersex Fora: 1<sup>st</sup> Brussels, Belgium in 2011; the 2<sup>nd</sup> Stockholm, Sweden in 2012; the 3<sup>rd</sup> Valletta, Malta 2013 and the 4<sup>th</sup> Amsterdam, The Netherlands in 2017 reiterated 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 a call to

“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 24<sup>th</sup> to 26<sup>th</sup> November 2017. Similarly, the meeting extended demands aiming to end discrimination against PBWIVs in Africa, and to ensure the right of bodily integrity, physical autonomy and self-determination and called African National governments to “address the concerns raised by the African Intersex Movement and draw adequate solutions in direct collaboration with intersex representatives and organizations”.

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 interventions [surgery, sterilization intersex genital mutilating (IGM), and treatment] without their full informed consent. The Statement emphasizes, “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 virtually 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 not clear what measures has the Tanzania government 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 national governments to end discrimination against PBWIVs and to ensure the right of bodily integrity, physical autonomy and self-determination of PBWIVs in Tanzania, Africa and globally. It was clear, however, that to date Tanzania has no enacted law banning harmful medical and clinical interventions (which have the sole purpose of altering external genitalia to match societal norms) on infants and children born with intersex variations in this country.

Undoubtedly, this legal silence is not at all impartial. Actually, it facilitates harmful practices to take place unnoticed and uncontrolled. It further suggests that primary and specialized care providers in this country are continuously subjecting infants and children born with intersex variations to unnecessary, forced, coercive and harmful normalization surgeries [including IGM and sterilization] and treatment (See CHESO, 2019). In addition, it suggests that parents, traditional and religious leaders continue performing harmful cultural practices, such as tradition-led mutilations and killings of infants and children born with intersex variations.

There is evidence that intersex activism and movement are in the rudiment stage in Tanzania (CHESO, 2019), hence, there are no significant signs 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 activists outlined in the Clinical Guidelines for the Management of Disorders of Sex Development (CMDSD 2006). 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) and advocate for holding governments and doctors responsible for harm done to victims of scientifically unjustified and unconsented surgeries and treatments.

Inopportunately, Tanzania lacks data on types of harmful and 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. Similarly, Tanzania lacks evidence on consequences of 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. 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 the role of political elite in recognizing, respecting, protecting and affirming PBWIVs' human and citizenship rights in Tanzania.

### ***Being born with intersex variation is quite different from being homosexual (LGBTQ)***

Erroneously, intentionally or unintentionally, many people, the lay and (political) elite alike, confuse 'homosexual', 'transgender' and 'transsexual' people with PBWIVs because of superficial, important but insufficient similarities to blur the two groups (Fair Planet, 2014; Thomas, 2016; Wasike & Mwadzaya, 2019; Victoria, 2019c; Koigi, 2019; Hegarty & Smith, 2023). For example, the two groups face similar but varied degrees of stigma, exclusion and discrimination (Kakande, 2016; Segawa, 2020) and would require to choose their own gender identity and often their choices necessitate hormonal treatments and or surgery (Hegarty & Smith, 2023). It is also true, albeit rare, that some PBWIVs also decide to change genders at some point in their life (RHO, 2011; Kakande, 2016; Thomas, 2016; Soko Directory Team, 2019; ng.boell.org. 2021; Kaggwa, 2016a; Soko Directory Team, 2019). So, some PBWIVs might also identify themselves as 'transgender' or 'transsexual' (Klein, 2021). Majority of PBWIVs, however, identify as 'male', 'female' and 'heterosexual' (Amnesty International, 2018a; Victoria, 2019c). More important, perhaps, is that "Some policies designed for LGBT may apply to intersex, while others may not ... Simply adding the letter 'I' or the word intersex to an LGBT 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 transgender activist stated,

For intersex individuals in Uganda, there is no real safe place ... The conservative, elusive, and vehemently repressive society considers us 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).

It should be noted, however, that PBWIVs could share characteristics with LGBT, the latter are not born with atypical sexual and reproductive systems and do not have the same history of surgical intervention during their childhood as PBWIVs (4intersex.org, n. d; Dittmann, 2008; Koyama, 2008; Marven, 2018). In fact, while PBWIVs 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.

Despite these similarities, these two groups should not be and cannot be thought of as one [*my emphasis*]. Being intersex has nothing to do with being 'homosexual', 'transgender' or 'transsexual' (Amnesty International. n.d.; PHO, 2011; Thomas, 2016; Amnesty International, 2018a; ERT, 2013). That is, intersex is a biological factor and a naturally occurring characteristic and is NOT a sexual desire. More clearly, intersex variation is atypical from gender identity (the inner sense of feeling 'male' or 'female') and sexual orientation (physical and or sexual attraction). The reality is that 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. The vast majority of PBWIVs identify as 'male' or 'female' rather than 'transgender' or 'transsexual' (Amnesty International. n.d.; Amnesty International, 2018a; Bashforth, 2022). Thus, where all people who identify as 'transgender' or 'transsexual' experience problems with their gender identity, only a small portion of PBWIVs experience these problems (Bashforth, 2022; Cleveland Clinic, 2022). PBWIVs, therefore, have specific needs different from LGBT's. Lawmakers in countries such as Australia, "Have understood differences among 'transgender', 'transsexual' and PBWIVs and have publicly acknowledged that people with intersex conditions have distinct needs from people who identify as 'transgender' or 'transsexual'" (InterACT. n.d. d.).

### ***Intersex face (severe) life-course challenges and human rights violations***

PBWIVs have inborn (not acquired) sex characteristics that do not suit social and medical taxonomies of 'male' or 'female' bodies that trigger risks or experiences of killings, abandonment, hatred, discrimination, stigma, harm and homophobia (when perceived as part of the LGBTQ). PBWIVs' rights are consistently erroneously, intentionally or unintentionally violated. Table 1 summarizes challenges PBWIVs face in their life course: before birth, at birth and post birth experiences that justify why the political elite in Tanzania ought to recognize, respect, protect and affirm PBWIVs' human and citizenship rights in the country more now than before.

#### ***Before birth/unborn***

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

persistently seek such services within and outside their countries of residency. Again, all these actions — abortion and medical interventions — jeopardize the fetus’ (human) rights.

**At birth and after**

Traditionally, in many societies on the globe, children identified to have any intersex variation at birth were (and still are) killed, mystified ‘semi-gods’ or ‘half-humans’, mothers accused of witchcraft or sorcery

(Wilson, 2012; Segawa, 2020). In Africa, some infants born with intersex variations are taken to traditional therapists or traditional healers (THs) for cure (Kakande, 2016; Kaggwa, 2016a; 2016b; BBC, 2017; Ausserer, 2021). One of the traditional healers in Uganda, for instance, 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).

**Table 1: Intersex Persons’ Life Pathways and Experiences\***

Developmental Stage	Risks/Experiences
<b>Before birth/unborn</b>	Being aborted; exposure to hormonal therapy; hormonal therapy risks to fetus’ growth; chances of developing intersex-related medical problems.
<b>At birth</b>	Infanticide/killed as taboo; baby dumping/abandoning; received with shock by parents and care providers; unprocessed slips when born; no sex identification assigned; intersex variation perceived a disorder; immediate surgical procedures; no name given; mothers accused of witchcraft; marriage/union tests and dissolution; forced intersex genital mutilation.
<b>Post-birth</b>	<i>Family/community reactions:</i> stigma and discrimination to intersex and family; kept indoor; limited socialization; perceived cursed or outcast; mistakenly regarded LGBT; ill mental health for mothers.
	<i>Intersex’s daily life:</i> life-long stigma and discrimination; intersex secrecy impact; abandonment; poor socialization; exclusion; self-denial; withdrawn lifestyles; low self-esteem; suicide consideration/attempts; mental illness; psychosocial trauma; lack of societal recognition and visibility; fear to disclose status.
	<i>Health:</i> frequent, unconsented and costly surgeries; prolonged costly hormonal therapy; frequent and costly counselling sessions; traumatic patient experiences.
	<i>Education:</i> lack of or conflicting documentation for school registration; sexed (binary) school systems and facilities; possibility of mishandling, harassment stigma, discrimination and bullying by teachers, support staff and colleagues.
	<i>Legal/Policy Challenges:</i> difficult applying for IDs (birth certificates, National IDs and passports); ‘invisible community’ (with no records, no correct size estimates where data is available it is aggregated and uncategorized); (mistakenly) criminalized/illegal due to LGBT inclusion; physical identity conflicts their IDs, hence denied accesses to services needed.
	<i>Employment:</i> difficult applying for gendered (fe/male vacancies) jobs, if they do have to disclose status that furthers stigma and discrimination; body shaming; bullying and stigmatization.
	<i>Religious perspectives:</i> some religious leaders subject intersex infants and children to prayers to rinse curse; difficulties giving religious names; some discriminate PBWIVs against religious services.
	<i>Sexual life:</i> many PBWIVs identify ‘make’, ‘female’ or heterosexuals; have families and children; some may identify transgender or transsexual.
	<i>Support:</i> PBWIVs lack support from families, communities and governments; in Africa, intersex are double disadvantaged facing stigma and poverty; intersex-led groups/ organizations operate in harsh environment.
<i>Sports:</i> choosing category (fe/male) to compete in challenge; forced to endure intrusive and unwelcome tests; total withdrawal from social space and activities.	

\*Adopted and modified from RoK (2018), Figure 5.18, p. 190.

**PBWIVs’ daily life**

On the daily basis, children, adolescents and adults born with intersex variations face (life-long) stigma and discrimination in all spheres of life, abuse, intersex secrecy impact, abandonment, poor socialization, exclusion, self-denial, withdrawn lifestyles, low self-esteem, suicide consideration or attempts, develop and suffer from mental illness and psychosocial trauma. In addition, PBWIVs lack societal recognition and visibility in the communities and struggle with fear to disclose their status. In short,

PBWIVs live in conditions that persistently violate all aspects of their (human) rights including 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).

### ***PBWIVs' health conditions***

PBWIVs generally live healthy and happy lives, in all treads of life. Intersex is not a medical problem and being born with intersex variation is not a health risk. However, being intersex can come with unique stressors that impact mental health. Due to stigma and lack of awareness, PBWIVs face unique health challenges. 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, known as interventions, include any action to change intersex variation. 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). It can get worse when there is a lack of accurate information and limited opportunities for contact with peers, which can increase social isolation. Sometimes PBWIVs can create other physical health issues that can then become their own source of stress. Occasionally, PBWIVs experience unwanted or sensitive medical interventions that can also have serious impacts on mental health. In history, 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 orthodox sex and gender norms. However, this practice is no longer regarded as acceptable in the contemporary world (headtohealth.gov.au,n.d).

### ***PBWIVs and education***

PBWIVs lack or possess (sex and gender) conflicting documentation for school registration; hence they face difficult enrolling in schools. Those who manage to, encounter challenges adjusting to sexed (binary) school systems, facilities and possibility of mishandling (Carpenter, 2019b). As a norm, intersex pupils/students face body shaming, harassment, stigma, discrimination and bullying by teachers, support staff and colleagues (Kaggwa, 2016a). There is evidence that pupils/students born with intersex variations keep moving from school to school to hide their identifies; miss classes to attend (unnecessary) medical appointments or treatments and thus demonstrate low cognitive abilities (Carpenter, 2019b). In some instances, some pupils/students born with intersex variations drop out of school completely (Kaggwa, 2016a; Wasike & Mwadzaya, 2019) that unfavorably affects their adult lives. Some intersex school dropouts turn to substance use and abuse that pushes some of them into adversative poverty-ridden living conditions (Intersex Nigeria, n. d; Kaggwa, 2016b; Segawa, 2020).

### ***PBWIVs and employment***

Intersex variations are quite different and each type would come with varied (workplace) experiences (Carpenter, 2014). Lacking legal identifications or having identity that is informed by their body, physical characteristics or life experience, PBWIVs (potential) workers may face difficulties applying for gendered (female or male vacancies) jobs. Those who dare, do have to disclose their intersex status that furthers stigma and discrimination. In addition, working PBWIVs are likely to experience body shaming, bullying and stigmatization from employers, customers or clients and co-workers (Carpenter, 2014).

### ***PBWIVs and sports***

Like in other spheres of life, 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 example, with a lifelong social and legal status as women are not permitted to compete or blacklisted from competing as women. To avoid mixed-sex and women's sport participation by men, sex testing of women athletes involves examinations of women's genitals and other sex characteristics (Carpenter, 2019c). Women athletes suspected 'too masculine' have been forced to endure intrusive and unwelcome tests and public humiliation often leading to their total withdrawal from competitive sports and other social space and activities (CHR UP, n.d. b; BBC, 2011; Carpenter, 2019c; Intersex Nigeria 2021).

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

Generally, the number of PBWIVs is contested; what is for sure 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 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) PBWIVs 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). 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 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, 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 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 PBWIVs in the country further attests this population group is real and exists in Tanzania.

Furthermore, 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. ‘*Jinsi tata*’, ‘*Jinsi 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* (Kikibosho, Kilimanjaro Region).

## DISCUSSION

According to ERT (2013) and Human Rights Watch (2021), PBWIVs in Africa continue to face human rights violations which include infanticide and baby abandoning; non-consensual, medically unnecessary genital normalizing surgeries and genital mutilation on minors; lack of appropriate legal recognition and administrative processes allowing PBWIVs to acquire or amend identity documents; and unfair discrimination in schools, health care facilities, competitive sports, work, access to public services, detention and many other spheres of life. Some PBWIVs face torture and other cruel, inhuman or degrading treatment or punishment and are often “subjected to irreversible sex assignment, involuntary sterility, involuntary genital normalizing surgery without their informed consent, or that of their parents, in an attempt to fix their sex, leaving them with permanent, irreversible infertility and causing severe mental suffering” (ERT, 2013). PBWIVs’ lives are strongly shaped by everyday discriminatory experiences, which do not allow them to pursue the professional or family life they are dreaming about. In addition, “consistent denial of basic rights has led majority of them [intersex] sink into depression, go into hiding and in some instances take their lives” (Koigi, 2019).

PBWIVs are in many aspects quite different from and should not be confused with ‘homosexuals’, ‘transgender’ or ‘transsexual’ (Intersex Nigeria, n. d; Carpenter, 2021b). 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, *et al.*, 2021; Kamazima, 2023a; Kamazima, 2023b). On contrast, intersex is a biological factor and a naturally occurring characteristic and is NOT a sexual desire (Amnesty International, 2018).

Claiming intersex is a subset of the LGBTQ group has more harm than the benefit expected. Kaggwa (2016b) 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”.

For example, in countries like Tanzania (Kamazima, *et al.*, 2021a; 2021b; 2021c; Kamazima, 2023b) 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 intersex conditions and life struggles. In turn, this situation could push PBWIVs further to the margins, keeping them neglected, discriminated and criminalized through a homosexual lens (Kaggwa, 2016; CHR UP, 2017). In the same perspective, intersex activists in Kenya say they want to be separate from the LGBTQ community as their condition is a congenital condition, not a sexual orientation (Wasike & Mwadzaya, 2019). The rekindled (from March 2023) and ongoing anti-homosexuality movements in Africa could adversely impact PBWIVs' rights and wellbeing if they remain visible through the LGBTQ lens.

Repeated and unnecessary consultations and counseling recommended by doctors are costly and intersex interventions services (surgeries) are unavailable in many African countries. In Ghana, surgeries on PBWIVs are expensive as high as about GH¢70,000.00 (appr. \$5,926 (Aryeetey, 2021). 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 from Germany or South Africa. A couple interviewed in Nairobi, for instance, reported spending nearly KSh. 4 million (\$40,000) treating their eight years old intersex child (Agade, 2019). In Uganda, 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).

However, some African countries — Ghana, Kenya, Nigeria, South Africa, and Uganda, for instance — have outlawed surgical intervention for intersex toddlers. In 2015, the Ugandan Parliament issued guidelines to the Ministry of Health recommending against such interventions 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).

Some PBWIVs went to or are in school; others have used their vocational skills to earn their livelihood but they all have been prevented from exploiting their potentials fully because of who they are. Due to lack of birth registrations and certificates, some PBWIVs are unable to enroll at (public) schools (Carpenter 2019 a;

Koigi, 2019). Those who get enrolled, face abuse, bullying and discrimination from fellow pupils/students, teachers and other school-workers and face unfriendly school environment (BBC, 2017; Wasike & Mwadzaya, 2019; GenderGP. 2020). Some school-going intersex children miss several class sessions to attend (unnecessary) appointments with doctors and counselors that affect their school performance. Intersex children from poor families and with low self-esteem face difficulties coping with school schedules and teaching-learning activities (Carpenter, 2019a; Kaggwa, 2016a).

An independent sociological survey conducted among PBWIVs in Australia in 2015 showed, on the one hand, that 18 percent the survey population did not complete secondary school education. Respondents reported "bullying on the basis of physical characteristics, and the impact of coercive 'normalizing' medical interventions during puberty" (IHRA, 2016) reasons for failing to complete secondary education. On the other hand, "those respondents that completed secondary school are better qualified than the general population, particularly at postgraduate level" (*ibid.*).

Other children born with intersex conditions are forced to switch between and among schools to undercover their intersex situations. In the worst situations, some intersex children drop out of school completely (Kaggwa, 2016; Wasike & Mwadzaya, 2019), which deters them from leading successful adult lives. Research conducted by Support Initiative for People with Atypical Sex Development (SIPD Uganda), showed that 90 percent of intersex youth were forced to drop out of school because of the immense stigma and discrimination associated with the non-binary development of their intersex body (Kaggwa, 2016). Koigi (2019)'s interviewee, for instance, recalled, Still grappling with [my] ambiguous genitalia and facing ridicule [I] went into depression and considered suicide. [Adding] I have never recovered from those episodes in school ... I always dreaded going to the toilet or showering with the rest of my classmates because they would tease me and slap me. At one time they called almost everyone in school to watch me naked."

PBWIVs are not spared from stigma and discrimination in sports (Carpenter 2019b). Intersex Nigeria (2021), for example, reported on intersex female who was a professional footballer but was dropped from her team because of her physical variation. The same source added, "Communal living in the training camp meant that her physical features were apparent to other female teammates ... Rumors spread in the camp, this led to their training coach interrogating her and subsequently asking her to leave the team ... This experience had a huge impact on her life and career because she was subsequently stigmatized and discriminated against by the football community in Nigeria ... This led her to withdraw completely from public spaces" (Intersex Nigeria, 2021).



The Mokgadi Caster Semenya case is worth presenting here to cement my argument on intersex bodies' discrimination in international and (maybe) national competitive sports (for details see Carpenter, 2019b; CHR UP, n.d. b). In April 2018, the International Association of Athletics Federations (IAAF) issued Eligibility Regulations on Female Classification (Athlete with Differences of Sexual Development) for events from 400m to the mile, including the 400m, hurdles, 800m and 1,500m events (CHR UP, n.d. b). On April 30, 2019, the world witnessed discrimination of intersex bodies through a judgement against Ms. Semenya by the Swiss Federal Supreme Court. According to CHR UP, n.d. b), "The judgement effectively banned the athlete from participating in certain competitive sporting events (400m to the mile) unless she reduces her testosterone levels to 'acceptable female' levels".

Further, The Swiss Supreme Court made unjustified decision "subjecting hyper-androgenic female athlete to unwanted and non-consensual hormonal treatment (with the possibility of side effects), in order to reduce the testosterone levels to 'acceptable female levels'" (*ibid.*). The judgement, "came as an infringement on her right to human right to dignity, bodily autonomy and physical integrity not necessitated by the argument for competitiveness" (*ibid.*). In addition, the 800m World Champion Ms. Semenya was forced to undergo gender testing to prove she was a woman (BBC, 2011). Indeed, the Swiss Federal Supreme Court decision is a set-back to PBWIVs' achievements as it came amid increased global knowledge and greater understanding of intersex bodies and sex characteristics.

There is evidence that PBWIVs in Africa are double disadvantaged facing stigma and poverty. PBWIVs living in Northern Uganda, for instance, "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).

Without empirical data on the intersex population in Tanzania, one cannot conclude on their legal-lived experiences. However, national and international sources available and documented best practices on PBWIVs in other countries facilitate building a case I make. Some countries allow registration of a baby's sex to be delayed if the sex of a new born cannot be immediately determined at birth. For example, in Belgium "sex" is registered at a maximum period of three months from the birth of an intersex child. France allows a maximum period of three years to register a new born sex from the birth of an intersex child. Finland and Portugal do not impose a time limit on registration of sex when it cannot be clearly determined at birth. The

Spanish law enacted in 2023 gives parents up to a year to register the sex of babies who are neither clearly male nor female at birth; includes a complete ban on unnecessary intersex surgeries for children under 12 years and older children can request to undergo surgery if wanted (Middleton, 2023).

For the purposes of registering sex of an intersex child, countries in Africa and around the world such as Australia, Malaysia, Nepal, New Zealand and South Africa have amended their existing or enacted new health policies and laws by putting "X" or other sign to show sex of intersex child. The Indian passport application form, for example, has been revised to allow three gender categories: "Female", "Male" and "Others". The South Africa's Judicial Matters Amendment Act 2005 amended the Promotion of Equality and Prevention of Unfair Discrimination Act 2000, defining "'sex' to include intersex". The Australian Federal Law on Gender Identity and Intersex Status Act 2013 extends its definitions of "sex" or "gender identity" to include "intersex status".

According to Kaggwa (2016a; 2016b), Kakande (2016) and Ausserer (2021), The Registration of Births and Deaths Act, 2015 provides for reassignment operations in Uganda for persons under 21 years only if a physician performs a thorough examination and attests that the gender assigned at birth is not the dominant one based on cytogenetic data and a psychological evaluation. After the 21st birthday, PBWIVs in that country are no longer allowed to have this medical procedure. Similarly, the same Act has a provision that restricts persons above 21 years from changing their sex details in the National Births Register.

The Tanzania Births and Deaths Registration Act, 1920 (CAP 108, R.E 2002) states that a birth is required to be registered within 90 days of the occurrence [and a death within 30 days], and that event must have occurred within Tanzania Mainland borders. Clause 14: Change of name provides,

Where the birth of any child has been registered before it has received a name, or the name by which it was registered is altered, the parent or guardian of such child may, within two years of the registration on payment of the prescribed fee and on providing such evidence as the district registrar may think necessary, register the name that has been given to the child.

Unfortunately, PBWIVs in Tanzania have no space in the births and deaths registry. It suggests, to meet this requirement, "Health officials and parents who have intersex children that they have no choice but to select the sex which they think is appropriate for the children" (Thomas, 2016). It is obvious that PBWIVs who undergo surgeries after registration and decide to change their sex, face challenges to de-register sex assigned at birth. In Thomas' (2016) view, one's sex

determines citizenship and legal rights to enjoy as ‘male’ or ‘female’. PBWIVs, therefore, are denied such enjoyment like the endosex do, just because “they do not conform to the appropriate sex which is either male or female” (Thomas, 2016).

Importantly, perhaps, is that Tanzania lacks intersex-specific healthcare provision guidelines and strategies that has allowed primary and specialized care providers to continue managing intersex variations 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’, unfortunately, conceptualizes gender identity as workable and early surgery as necessary and asserts there are ‘universally accepted sizes, shapes and standards of vagina and penis (Pareira, 2022). As a result, the model encourages violation of PBWIVs’ human and citizenship rights.

However, the Tanzania government is recommended to ensure medical personnel follow the model for the medical management of intersex supported by many intersex activists as outlined in the Clinical Guidelines for the Management of Disorders of Sex Development (CMDSD 2006) (ISNA, 2006). The recommended model aims to empower PBWIVs to make their own decisions affecting their own bodily integrity, physical autonomy and self-determination. Specifically, the Patient-Centered Model recommends:

- 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.

There is, however, light at the end of the tunnel. Success recorded by national governments, intersex-led organizations, movements and activist groups supporting, and working for and with PBWIVs in ten African countries with recognized organizations, activist groups or movements working with and for PBWIVs [DRC (*Groupe Intersexe Désirs*), Ghana (Intersex Ghana Movement, IGM), Kenya (Intersex Persons Society of Kenya, IPSK); Malawi (Ivy Foundation, IF); Nigeria (Intersex Nigeria); South Africa (Intersex South Africa, ISA and Iranti); South Sudan (Intersex Persons Of South Sudan, IPSS); Uganda (Support Initiative for People with Atypical Sex Development, SIPD); Zambia (Intersex Society of Zambia, ISZ) and Zimbabwe (Intersex Community of Zimbabwe, ICZ)] demonstrate that intersex awareness raising interventions could build positive and comprehensive understanding and acceptance of PBWIVs among community members’ (the lay and elite alike) on the Continent.

Auspiciously, Kenya and South Africa have paved the way in this direction. Kenya became the first country in Africa to recognize persons whose sex characteristics do not fit what is traditionally accepted ‘male’ or ‘female’ bodies as ‘a third sex’. Thus, the Kenyan Government collected data on PBWIVs in its national population census in July 2019. Tanzania and the rest of Africa would wish to take the same path. The Tanzania Government, therefore, should be prepared, ready and committed to contribute towards achieving this global goal. To attain this long-term objective, the Tanzania Government must demonstrate recognition, unconditional love, respect, acceptance and support to PBWIVs and their families in the country and beyond. In turn, this commitment would enable PBWIVs to grow up and live free of shame, stigma, harm and pain in a world where their (human) rights are treasured 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.

## CONCLUSION AND RECOMMENDATIONS

PBWIVs are real, and exist in Tanzania. The Tanzania (political) elite should know that PBWIVs exist in all (administrative) regions in this country and in all countries around the world. The (political) elite in this country, therefore, should recognize, respect and support PBWIVs to be the drivers of social, political and legislative changes that concern intersex community and their families. It is evident that Tanzania is lagging behind in fulfilling obligations regarding protecting PBWIVs' 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.

Importantly, perhaps, is that Tanzania faces paucity of intersexuality research to inform PBWIVs-friendly policies and (public) health interventions. Also, 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 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 Public Statement by the African Intersex Movement, 2017, and The African Commission on Human and Peoples' Rights, 2023. 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.

Irrefutably, awareness of intersex conditions is (slowly) increasing among PBWIVs, researchers, parents/guardians, activists and in the media in this country. Increase of awareness is likely to come with increasing revolt, which may provide the stimulus for legal reform. The Tanzania government ought not to wait for this ignominy 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 demands and calls by (just to name a few) The UN Human Rights Declarations and Resolutions, The Vienna Declaration and Programme of Action 1993, The Malta Declaration, 2013, The African Intersex Movement, 2017 and The

African Commission on Human and Peoples' Rights, 2023.

Based on demands and calls made by different bodies mandating governments to protect and affirm PBWIVs' human rights and intersex facts in Tanzania generated through this study, I recommend the Tanzania political elite to introduce explicit laws and policies that aim to:

1. Raise intersex variations awareness, recognition and understanding among the lay and (political) elite Tanzanians that would facilitate changing deep-rooted negative beliefs, attitudes and perceptions towards PBWIVs. Intersex variations are innate/biological and naturally occurring characteristic NOT sexual orientation or gender identity. PBWIVs, therefore, are quite different from 'homosexuals', 'transgender' or 'transsexual'. The two populations should not be (politically) considered the same in all aspects of their lives.
2. End harmful, human rights violating (including infanticide), unnecessary and costly IGM and "normalizing" practices such as genital surgeries, psychological and other medical treatments, including infanticide and selective abortion.
3. Ensure personal, free, prior, and fully informed consent of the PBWIVs is an obligatory requirement in all medical practices and protocols meant for PBWIVs in the country.
4. Provide for PBWIVs' access to own medical records and any documentation, and the affirmation of PBWIVs' right to honest, respectful, confidential and non-intersex discriminatory [to intersex, parents/guardian and their (extended) families] healthcare services].
5. Protect and grant all human rights and citizenship rights to PBWIVs including: the right to live, access to quality and equitable healthcare; access to education and participation in workforce and competitive sports.
6. Stop medical doctors from conducting elective surgeries to intersex infants, babies and children to be registered in the normative 'boy' or 'girl' or 'male' or 'female' socially constructed binary bodies. Law must also provide for appropriate support services for people who have been forcefully subjected to these operations, including access to quality and equitable healthcare and social, psychological and financial support.
7. Register children born with intersex variations immediately after birth leaving sex box empty. Sex registration of children born with intersex variations should be delayed with no time limit till the child is mature enough to understand the nature, risks and alternatives to a treatment to consent and be involved in the decision-making process. In turn, this opportunity will enable PBWIVs to make informed decision and

voluntarily register preferred ‘male’, ‘female’ or ‘intersex sex’.

8. Amend birth (sex) registration Laws to define sex to include intersex and births (sex) registration forms should include I or any other sign for sex of an intersex child.
9. Recognize and include PBWIVs in national census counts. Enumeration data generated would inform on intersex size in the country, developing intersex-friendly government policies and planning to enable PBWIVs and their families to access rights that they were traditionally denied including: healthcare, education, employment, sports, legal recognition and amending identity documents at the age of majority and after.

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