The Intersex People in Malawi: A Situational Analysis

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Contents

Acknowledgement

This report is based on the study that was conducted Assoc. Prof Eric Umar, Department of Health Systems and Policy, Kamuzu University of Health Sciences (KUHeS), Blantyre, Malawi

ACRONYMS AND ABBREVIATIONS

AIS	Androgen Insensitivity Syndrome
CAH	Congenital Adrenal Hyperplasia
CAIS	Complete Androgen Insensitivity Syndrome
CSO	Civil Society Organization
DHT	Dihydrotestosterone
DSD	Disorder of Sex Development
ICD	International Statistical Classification of Diseases and Related Health Problems
IGM	Intersex genital mutilation
LGBT	Lesbian, Gay, Bisexual and Transgender
MOH	Ministry of Health
NGO	Non-Governmental Organization
PAIS	Partial Androgen Insensitivity Syndrome
SOGI	Sexual Orientation and Gender Identity
UN	United Nations
WHO	World Health Organization

TERMS AND DIFINITIONS

Gender identity	A person's internal sense of their own gender, which may or may not align with the sex assigned to them at birth. Intersex people may identify as male, female, or non-binary (neither male nor female).
Disorders of sex development (DSD)	A term used to describe medical conditions that involve atypical development of genitalia, gonads, and/or chromosomal patterns. DSDs can occur in people who are intersex, but not all intersex people have DSDs.
Intersex	A term used to describe individuals who are born with physical or biological sex characteristics that do not fit typical male or female classifications. Intersex people may have genitalia, gonads, and/or chromosome patterns that do not align with traditional notions of male and female.
Intersex genital mutilation (IGM)	A term used to describe surgical procedures performed on intersex infants and children for the purpose of "normalizing" their genitalia. These procedures are often performed without the informed consent of the child or their parents and can have negative physical and psychological effects.
Organization Intersex International (OII)	A global intersex-led organization that advocates for the human rights of intersex people and works to end discrimination and stigma against intersex people.
Chromosomes	Structures in cells that contain genetic material. Humans typically have 46 chromosomes, which are organized into 23 pairs. Intersex people may have variations in their chromosomal patterns, such as having more or fewer than 46 chromosomes or having variations in the structure or number of individual chromosomes.
Hormones	Chemicals produced by glands in the body that regulate various functions, including sexual development and behaviour. Intersex people may have variations in their hormone levels or differences in their sensitivity to hormones.
Gonads	Reproductive organs that produce gametes (sex cells). In males, the gonads are the testes, which produce sperm. In females, the gonads are the ovaries, which produce eggs. Intersex people may have gonads that are not clearly male or female, or they may have a combination of male and female gonads
Sexual orientation	A person's emotional, romantic, and/or sexual attraction to others. Intersex people can have any sexual orientation, just like non-intersex people.

Executive Summary

Background

Socio-cultural barriers and insufficient knowledge about Intersex lives are among various factors that account for the lack of attention on issues of intersex people in Malawi and indeed globally. The need for this report stems from the recognition that Intersex people are a neglected population in Malawi, despite their unique circumstances. The report contains invaluable information relevant to push for policy and practice adjustments aimed at improving the well-being of intersex people in Malawi.

Methodology

The study was conducted in June to October 2023. A comprehensive desk review that included peer reviewed literature about intersex persons, legal documents related to sexuality and gender in Malawi, policy documents that include health and related to gender, media reports such as newspapers, maternal guidelines, birth registries in selected health facilities and grey literature. Also, qualitative exploratory research employing key informant interviews and in-depth interviews also called life worlds, was conducted with intersex people. Guided by phenomenological qualitative design, the key informants included: Health professionals – midwives and clinicians especially in the maternity services, Justice system professionals – Lawyers and Judges familiar with issues related to identity will be targeted, Immigration officers, Traditional birth attendants.

Key Findings

Awareness and Management of Intersex

Health care providers, particularly midwives and pediatricians are aware of the intersex phenomena but many never witnessed an intersex child. Health care workers said that it was not a very common phenomena and that it is not a topic that is given any prominence during midwifery or general nursing training. In terms of awareness, all participants said that they were aware although without much detail. This is epitomized in this statement "…everyone who has had medical training at least has an idea that intersex people do exist."

Sex assignment

The current practice / policy is that the mother assigns sex. It was explained that when the child is born, the midwife would present the child, including the child's genitalia and asked her to declare the sex. The midwives check to confirm and write in the birth registry. The participant said that chances are high that children with marginal intersex characteristics would be registered "wrongly" based on what the mother stated. In cases where the features are conspicuously intersex, the midwife would still write the sex the mother assigns or what they think is the nearest. The registry has only male or female space. Sometimes, midwives would scribble a note, indicating that the child's genitalia did not conform to male or female.

Proportion of Intersex births in Malawi

The study made an attempt to estimate the population of children born as intersex in in the four tertiary health facilities in Malawi. This effort was through checking in the birth registries. It turned out the birth registry did not indicate children born with variations in sex features as the birth registry contain on two gender, male and female. Furthermore, the birth registry does not contain space where midwives could indicate that the child was born with “ambiguous” sex characteristic. The birth registers did not yield an information. However, it was discovered that there is a birth defects surveillance project going on in Malawi since 2018. Data from the Blantyre site, Queen Elizabeth Central Hospital showed that among the defects, 16 children were identified as intersex. No analysis beyond knowing the number of children identified as intersex was feasible as that would have required more processes.

Legal identify of intersex people

it was established that there are no laws in Malawi that accommodate or acknowledge intersex issues and how to deal with them. Whether it is in hospital or elsewhere. *“There hasn’t been a specific act of parliament that has actually touched that issue, to my knowledge.”*

The law does not exclude the intersex people because it recognizes them as whatever sex they end up choosing. It also does not stand in the way of this process. The IS can be man or woman but not both. There are no laws regarding IS in terms of registration at birth.

The law operates under the understanding that genders exist. As far as the law of Malawi is concerned, there are only two. Namely; male and female. The law could not have anticipated that there could be more than one gender to an individual. As it stands the law does not recognize any other gender apart from the two but it also does not prohibit that possibility.

Conflict of Intersex and LGBTQ

The legal respondents said that there was misunderstanding between the LGBTQ community that is more noticeable as opposed to the intersex. They argued that intersex issues are different from the LGBTQ given intersex is a biological phenomenon from birth and not by choice. *“Our law still criminalizes to some extent the gays and the lesbians. So if you do both, you will definitely be caught up in that law. So you have to choose an identity at that point of whether you want to be male or female"*

Immigration identity of Intersex

Intersex people are not recognized by immigration because even the passports and visas only recognize male or female. An intersex individual would have to identify as one of the two sexes to get a passport or visa.

Challenges experienced by intersex people in Malawi

Through lifeworld interviews, participants highlighted various challenges that they face. The challenges include:

Identity Confusion

Majority of the participants indicated that their gender identity was decided or chosen by their parents. Nevertheless, as they grow up, they would find themselves identifying differently. The participants explained that while the parents or guardian would have found them more like a particular gender, they would find themselves more suited to a different gender. This brings considerable confusion.

The confusion also stems from parents’ unwillingness to talk about their child’s intersex status. Majority of the participants indicated that, growing up, their parents did not engage them to discuss their sex. This is epitomized in this quote:

Social challenges

Intersex people meet challenges such as being laughed at by neighbors and being the topic of a family meeting in the family that they are different and they fear for their lives if people know that they have two private parts. Most of the people are curious to see how they look like. And on part of sexual relationships, most of the people would want to get in a sexual relationship with them just on point of curiosity so that they can have sex with them and see how their private parts look like.

Psychological challenges

Some people conclude that these people are lesbians or gays just by noticing that their names do not match their physical appearance. They also feel that they are not safe and would not want people to know of their identities. One of the IS said that;

Health related challenges

Intersex study participants tend to be stigmatized by health care providers at the hospital especially in public hospitals. Intersex only feel comfortable to be assisted by only members of staff who already know their status at public facilities. Most of them alluded to be free to get assistance from private facilities. Responders explained that Some of the health challenges are based on the fact intersex people may have two private parts which to some participants are both not well defined or one of it is well defined and the other is not. This results in dysfunction of some of their private parts. The IS also expressed concern over the services that they can acquire from the public facilities, such as female family planning methods, cervical cancer screening because of their appearance. This brings fear that they can conceive or have complication due to lack of more investigations and information on how to take care of themselves in terms of health. One of the study participant said,

Access to Education

Intersex people face challenges with accessing education. Various negative experiences as intersex people navigated the academic landscape, affected them academically. These experiences include hospital visits usually in relation to potential operation, limit their time for going to school. In addition, intersex meet problems in terms of accommodation, where IS who has two private parts are accommodated with boys and end up facing shaming and rape.

Employment and livelihoods

Most of the IS do not work, but some of them have their own business. This is because when people speculate about their status, they end up losing their jobs, because it is regarded as a shameful thing. For those doing business, their status makes them lose business deals or have hindrance to do business in some countries.

1. BACKGROUND

Socio-cultural barriers and insufficient knowledge about Intersex lives are among various factors that accounts for the lack of attention on issues of intersex people in Malawi and indeed globally. The need to produce this report stems from the realization that Intersex people are a neglected population in Malawi, despite their unique circumstances. This report, based on a study conducted in June to August 2023, highlights the challenges that intersex people face and potential strategies that could help empower the population and build resilient intersex individuals. Although lesbian, gay, bisexual, transgender, and intersex (LGBTI) equality and inclusion is now central to global human responses and global development goals for "leaving no one behind", it can be argued that it is the LGBT that dominates the discourses compared to Intersex issues. In Malawi, there is a death of studies or responses focusing on the intersex population. The most important known study that although was not exclusively focused on Intersex population but paid ample attention is the Under wraps survey of public attitudes to homosexuality and gender non-conformity in Malawi (The Other foundation, 2019).

This report is based on a study that set out to explore the context in which the Malawi intersex population live, particularly, to establish the communities' concerns and identify policy and legislation gaps. The report suggests measures for improving intersex people's welfare Malawi. Further, it provides insights that stakeholders could pursue in order to facilitate policy and legal reforms that could ultimately improve Malawi's intersex populations' quality of life.

The study was conducted in two phases. The first phase was a desk review that was followed by in-depth interviews with various stakeholders, including intersex individuals. Through the desk review, it became apparent that there is very little information about the situation surrounding intersex people and issues they face in Malawi. With the intersex community very inconspicuous across Africa, even more so in Malawi, the population's painful personal stories and human rights violations they encounter are undocumented. This study contributes towards the literature that could inform governments on various issues that needs addressing in order to not leave the intersex community behind.

The study set out to achieve the following objectives:

i. To establish the intersex phenomena in Malawi
ii. To establish how the public health system processes children born as intersex in Malawi
iii. To determine the legal gender recognition of Intersex persons by the Department of Immigration
iv. To explore experiences of intersex people in Malawi
v. To examine the rights of intersex people in Malawi and any violations thereof

2. METHODOLOGY

The study adopted a mixed methods approach, combining a comprehensive desk review and field research. The study was undertaken from June to August 2023.

A comprehensive desk review of different documents was conducted. The documents include: Peer reviewed literature about intersex persons globally, Africa and Malawi, Legal documents related to sexuality and gender in Malawi, Policy documents that include health and related to gender, Media reports such as newspapers, Maternal guidelines, Birth registries in selected hospitals, Grey literature – consultancy reports and studies conducted in academic institutions.

Qualitative exploratory research was conducted. The components included key informant interviews and in-depth interviews also called life worlds interviews with intersex people. Guided by phenomenological qualitative design, the key informants included: Health professionals – midwives and clinicians especially in the maternity services, Justice system professionals – Lawyers and Judges familiar with issues related to identity will be targeted, Immigration officers, Traditional birth attendants.

The desk review was conducted in Blantyre at the Kamuzu University of Health Sciences, where the library services allow access to many journals. Peer reviewed articles were searched in Medline, psych info, PubMed. Furthermore, grey literature, inform of dissertation and theses were accessed in the library. Key informants were interviewed in Blantyre, Lilongwe and Mzuzu.

3. LITERATURE REVIEW

Preceding the interviews with various study participants, a comprehensive literature review was conducted in order to explore what literature provides in relation to the objectives of the study. The literature review focused on the questions the study aimed to answer. The literature reviews therefore establish the following: 1) the Intersex phenomena; 2) the medical response to intersex; 3) the legal recognition of intersex people; 4) the identity of intersex people; and 5) the rights accorded to intersex people by the law.

3.1 The Intersex phenomena

Intersex, also referred to diverse sex development (DSD) in medical terms, is understood in incongruous ways. Thus, it is understood as a rare medical phenomenon or as a somewhat ordinary aspect of human diversity (Roen, 2019). Intersex is an umbrella term for human beings that are born with variations of sex characteristics, chromosomes and/or hormones which may not correspond with societal and medical expectations of the gender binary of being male or female. Precisely, intersex people are born with physical or biological sex characteristics -- such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns-- that do not fit the typical definitions for male or female bodies (Rosenwohl-Mack, 2020). Sometimes when a baby is born, it can easily be identified as intersex by its bodily characteristics. Occasionally intersex babies have external (outside) genitalia that appear clearly female or male, but the internal genitalia can be different, malformed or absent. Therefore, in some cases, an intersex body can be discovered during childhood, at puberty or even in adulthood (Carpenter, 2018).

It is estimated that between 0.05 and 1.7 percent of the population is born with intersex traits. However, it is argued that these figures are socially constructed, given that medical definitions of intersex remain contested (Griffiths 2018). Furthermore, surveys in this area are difficult to conduct as they need to contend with the stigma associated with intersex variance. Difficulties with estimating the number of intersex have been documented. Reasons for this include that sex variations may never be apparent; some people may not disclose information when asked; and the absence of consistent definition or approach to collecting data of people with variations in sex characteristics (Monro, 2021).

Carpenter (2018) argues that in practice, intersex bodies are normalized or eliminated by medicine, while society and the law others intersex identities. That is, medicine constructs intersex bodies as either female or male, while law and society construct intersex identities as neither female nor male (Roen, 2019). In essence, being intersex relates to biological sex characteristics, distinct from an individuals' sexual orientation or gender identity (SOGI). An intersex person may be straight, gay, lesbian, bisexual or asexual, and may identify as female, male, both or neither[1].

Historically, intersex people and their bodies were first glorified, then stigmatized and discriminated against. The terms 'hermaphrodite' or 'pseudo hermaphrodite' were used until the beginning of the 20th century, when for the first time the term 'intersexuality' was mentioned in medicine. The term 'hermaphrodite' as applied to plants and animals means having both female and male reproductive organs; when applied to people, this term is incorrect and misleading and can contribute to stigma and misunderstanding.

In modern medicine, variations in the sex characteristics of intersex persons are medically classified and 'treated' with surgeries and hormone therapy. These procedures are common practice in most countries in the world. The goal is to create a 'stable', 'normal' and 'adjusted' person with a standard sex and gender and a heterosexual orientation. These early interventions can cause physical and psychological trauma which affect intersex persons' lives, who often become ashamed and isolated from society. Society does not recognize intersex people in daily life as they are still very invisible, and in some cases have no available mechanisms and legal provisions to protect their rights.

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[1] https://www.undp.org/sites/g/files/zskgke326/files/migration/eurasia/Intersex-Research-Study-UNDP-2017.pdf

3.2 Intersex and LGBT Rights movements

For the first time, with the support of medical specialists, the intersex community was organized in the USA in the early 1990s. The community was organized as support groups for people with the same diagnoses and were named DSD or Androgen Insensitivity Syndrome (AIS) groups. As the intersex community was empowered, it grew into a human rights movement and joined the LGBT community. Being connected with the LGBT community, had various potential advantages that included visibility, solidarity, alliances, main streaming of intersex issues and inclusion. On the other hand, there were disadvantages too. The disadvantages include potential or real backlash, appropriation, misrepresentation, exclusion and deprioritisation in that the intersex community becoming a smaller component of a broader movement. It is on this basis that the Intersex movement have demanded to be considered a separate movement. What links the experiences of intersex people and LGBT people are that they are subject to discrimination based on homophobia and/or transphobia. The LGBT community faces two grounds of discrimination, on the basis of sexual orientation and gender identity. Intersex is not a sexual orientation or a gender identity. Intersex people have all kinds of sexual orientations, gender identities and gender expressions. Intersex people, just like trans people, are primarily discriminated against on the grounds of physical appearance and gender expression that arise from their ambiguous sex characteristics. In many cases, they are discriminated against from birth when they are subjected to invasive, irreversible treatment without their consent.

Intersex people do not necessarily see themselves as part of the LGBT community and do not see what is common between their life experiences and those experienced by LGBT people. However, they collaborate for a unified response where they have identified common challenges.

3.3 Intersex diagnosis

There are at least 40 types of intersex variations with differences regarding genes, chromosomes, anatomy and hormones. All these variations are grouped under the term ‘intersex’. It is very important that intersex persons are not classified into a new collective category of sex such as ‘other’ or ‘third sex’ which exists in parallel with the categories of ‘men’ and ‘women’. Such categorization would be wrong due to the large number of different intersex variants and the fact that some intersex persons are identified as men or women, some as one and the other, and some as none (Carpenter, 2016).

A diagnosis of an intersex variation can be very stigmatizing and have a great impact on the emotional, sexual and cognitive well-being of intersex individuals. The ICD which is the international “standard diagnostic tool for epidemiology and health management guides the diagnosis (Carpenter, 2018). The

ICD is the basis for the identification of health trends and statistics globally, and the international standard for reporting diseases and health conditions. It is the diagnostic classification standard for all clinical and research purposes. The ICD defines the universe of diseases, disorders, injuries and other related health conditions.

The diagnostic categories, which are codes in the ICD, play a crucial role in expressing scientific understanding, establishing medical approaches, forming clinical protocols, and defining surgical, hormonal and other treatments. Those categories defining intersex bodies incorporate differences between stereotypical female and male bodies on one hand that are considered to be healthy and bodies that vary from female and male standards on the other hand considered to be “disordered”, “malformed” and “abnormal”. The current classification therefore contributes to stigma, discrimination and violence against intersex people and the ICD endorses medical attempts as appropriate to “fix” or “normalize” intersex bodies through surgery and hormones, which has a direct role in determining how intersex bodies are treated in society at large.

3.4 Human rights and intersex

Intersex people endure various human rights violations. Historicized as hermaphrodites, gods and monsters, perceptibly intersex people have been subjects of infanticide and freak shows (Carpenter, 2016). A pattern of changes in terms describing intersex people in the last century emerge as clinical decision-makers have been determining pre-existing language to be imprecise or pejorative: that affected persons were not hermaphrodites, not pseudo-hermaphrodites, not intersex, but disordered children whose bodies need finishing or disambiguating (Carpenter, 2016). Various issues around intersex are controversial, predominantly in the area of discrimination, access to justice, access to information, and legal recognition (Carpenter, 2016). Intersex people’s most often violated rights include: the right to life, the prohibition of torture and inhuman or degrading treatment, the right to respect for private and family life, and the right to freedom of expression.[2]

Intersex people are vulnerable to structural exclusion from access to health care, education, adequate accommodation, and employment. This is due to Intersex person’s invisibility in society, a phenomena caused by a combination of individual and/or familial isolation, social and institutional stigma, discrimination and violence and the traumatic experiences associated with medicalization and their chronic consequences. The great fear of stigmatization and social exclusion for most intersex people is a reason to “stay in the closet” even when they become aware of their gender (Carpenter, 2020).

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[2] https://www.undp.org/sites/g/files/zskgke326/files/migration/eurasia/Intersex-Research-Study-UNDP-2017.pdf

In 2022, the African Commission on Human and Peoples' Rights (ACHPR) passed a resolution affirming the rights of intersex people. The ACHPR resolution affirms that human rights violations against intersex persons are contrary to key human rights frameworks such as the African Charter on Human and People's Rights, the African Charter on the Rights of Women in Africa, and the African Charter on the Rights and Welfare of the Child. Further, the resolution states that "non-consensual and unnecessary surgical and other genital normalization procedures have irreversible consequences similar to genital mutilation and should be considered as such." Furthermore, the ACHPR calls for an end to discrimination against intersex people in competitive sport – an important recommendation as World Athletics, the global governing body for track and field competitions, has recently released a tighter and arbitrary version of its eligibility regulations, which disproportionately impact African women for "sex testing." Under this policy, women runners from the continent have been deemed ineligible from competition simply because they have an intersex trait and endogenous testosterone levels higher than the arbitrary and unscientific World Athletics threshold[3]

3.5. Sex assignment and sex markers in personal documents

'Sex' refers to the biological and physical aspect of a person. Sex of a newborn is typically assigned at birth on the basis of genital appearance (Raveenthiran, 2017). Sex assigned at birth is what is listed on a person's identification card, certificates, passport and other means of identity, certification and credentials. The sex assigned at birth becomes a legal and social fact and can represent the identity of a person. While the importance of assigned sex does not present an issue for most people, it becomes a serious problem for those who cannot fit into one of the two categories 'male' or 'female'.

On the other hand, 'gender' corresponds to the social aspect of a person, who that particular person considers themselves to be. Administrative laws, such as birth registration, and legal gender and administrative processes can put pressure on parents and medical professionals to choose and assign the sex of an intersex child[4].

The obligation to assign a baby's sex puts pressure on parents and medical professionals in relation to an intersex baby, particularly as parents are often not adequately or not at all informed about their intersex baby's status and the process of treatment. Globally, majority of societies do not usually recognize a person who does not belong to one of the two sexes. The sex/gender marker in personal documents is therefore limited to two categories "F" (female) or "M" (male). For passports, the International Civil Aviation Organization (ICAO) has allowed for sex to be registered as "F", "M" or "X" (i.e. "unspecified") since 1945. However, few countries have adopted "X" as another sex/gender category in their passports.

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[3] https://www.hrw.org/news/2023/04/06/african-human-rights-commission-affirms-intersex-peoples-rights

[4] https://embryo.asu.edu/pages/biological-sex-and-gender-united-states

4. FINDINGS

4.1 Awareness and Management of Intersex phenomena

Among the core objectives of this study was to establish the overall management of intersex person in Malawi's health system from birth, including sex assignment, gender recognition at birth, medical decision and post discharge support to the child and /or family.

4.1.1. Intersex phenomena awareness

Midwives in the major referral hospitals were asked if they were aware or had ever experienced an intersex child being born during their career. Majority indicated that they were aware of the intersex phenomena but they had never seen one. Few indicated ever witnessing an intersex child being born. A matron at the referral hospital maternity department said that it was not a very common phenomena and that it is not a topic that is given any prominence during midwifery or general nursing training. In terms of awareness, all participants said that they were aware although without much detail. This is epitomized in this statement "…everyone who has had medical training at least has an idea that intersex people do exist."

Another participant explained that, being a not very common phenomenon, chances for witnessing would depend on where the health provider was working. It was argued that "workers in central hospitals were likely to witness this compared to in district hospitals or health centers. Intersex children born in non-referral facilities are usually referred to the central hospital for referral where there is at least a pediatric surgeon and pediatrician…."

4.1.2. Sex assignment

Sex assignment, also referred to as gender assignment is the discernment of an infant's sex at birth, usually based on the phenotypic sex. Sex assignment can be based on the baby's external genitalia after inspection. In some cases, additional diagnostic steps may be required and sex assignment is deferred. In the current study, midwives, were asked how and what sex was assigned to children who were born intersex. In response, several midwives said that the current practice / policy is that the mother assigns sex. It was explained that when the child is born, the midwife would present the child, including the child's genitalia and asked her to declare the sex. The midwives check to confirm and write in the birth registry. The participant said that chances are high that children with marginal intersex characteristics would be registered "wrongly" based on what the mother stated. In cases where the features are conspicuously intersex, the midwife would still write the sex the mother assigns or what they think is the nearest. The registry has only male or female space. Sometimes, midwives would scribble a note, indicating that the child's genitalia did not conform to male or female. The participant explained:

> *"it is written as ambiguous genitalia but in pediatric surgery they document it as DSD (disorder of sexual differentiation), that is 'disorder of sexual development." When this is the case, the child's sex is indeterminate at that time until further research is conducted to determine the sex of the child.*

After birth, children with intersex characteristics would reviewed further by pediatricians at the ward. Participants mentioned that the review is basically on the surface and no decisions are made in relation to medical interventions, such as operation.

4.2. Proportion of Intersex births in Malawi

The study made an attempt to estimate the population of children born as intersex in in the four tertiary health facilities in Malawi. This effort was through checking in the birth registries. It turned out the birth registry did not indicate children born with variations in sex features as the birth registry contain on two gender, male and female. Furthermore, the birth registry does not contain space where midwives could indicate that the child was born with "ambiguous" sex characteristic. The birth registers did not yield an information. However, it was discovered that there is a birth defects surveillance project going on in Malawi since 2018[5]. Data from the Blantyre site, Queen Elizabeth Central Hospital showed that among the defects, 16 children were identified as intersex. No analysis beyond knowing the number of children identified as intersex was feasible as that would have required more processes.

4.3. Legal identify of intersex people

Another important question the study wanted to establish the legal identity of intersex people in Malawi. In order to establish this, lawyers and immigration officers were interviewed.

4.3.1 Malawi laws on intersex

From the interviews with lawyers, it was established that there are no laws in Malawi that accommodate or acknowledge intersex issues and how to deal with them. Whether it is in hospital or elsewhere.

> *"There hasn't been a specific act of parliament that has actually touched that issue, to my knowledge."*

The law does not exclude the intersex people because it recognizes them as whatever sex they end up choosing. It also does not stand in the way of this process. The IS can be man or woman but not both. There are no laws regarding IS in terms of registration at birth.

> *"There hasn't been a framework so far that recognizes that we can have IS people and they should be registered as such."*

The law operates under the understanding that genders exist. As far as the law of Malawi is concerned, there are only two. Namely; male and female. The law could not have anticipated that there could be more than one gender to an individual. As it stands the law does not recognize any other gender apart from the two but it also does not prohibit that possibility.

The respondents explained that the law does not recognize intersex people because at the time it was enacted, there was no need for it. The respondents contended that it was possible to promote intersex people rights, through a process where the first step would be to identify and understand intersex people's specific rights. That is, the distinction of intersex rights as human rights in general that would allow them to enjoy their human rights better.

> *"When trying to regulate a profession like medicine, which has on its own vast levels of knowledge that govern what they have to do." "You leave off some room to allow the professionals to make certain decisions. They use this create regulations, operating procedures, etc. that govern the conduct in their delivery of services."*

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[5] https://www.go2itech.org/2022/03/birth-defects-surveillance-in-malawi/

> *"The law does not compel the doctors or medical practitioners to ask the parents or individual to choose what they want to be."* They are compelled by the knowledge that they have on this person surviving in society without problems.

4.4 Conflict of Intersex and LGBTQ

The legal respondents said that there was misunderstanding between the LGBTQ community that is more noticeable as opposed to the intersex. They argued that intersex issues are different from the LGBTQ given intersex is a biological phenomenon from birth and not by choice.

> *"Our law still criminalizes to some extent the gays and the lesbians. So if you do both, you will definitely be caught up in that law. So you have to choose an identity at that point of whether you want to be male or female"*

4.4.1Immigration identity of Intersex

Intersex people are not recognized by immigration because even the passports and visas only recognize male or female. An intersex individual would have to identify as one of the two sexes to get a passport or visa. In of experiences in form of encountering and intersex person or hearing about them, an interview said had never. This is encapsulated in the quote below:

> *"Never had any experience and it was only brought up during a training conducted by Aviation Department that sometimes we may come across people who are not male not female"*

4.6. Challenges experienced by intersex people in Malawi

Through lifeworld interviews, participants highlighted various challenges that they face. The challenges include 1) identity confusion,

4.6.1. Identity Confusion

Majority of the participants indicated that their gender identity was decided or chosen by their parents. Nevertheless, as they grow up, they would find themselves identifying differently. The participants explained that while the parents or guardian would have found them more like a particular gender, they would find themselves more suited to a different gender. This brings considerable confusion.

Participants indicated that parents were very supportive of their decision to identify different from how they had identified them. Furthermore, majority indicated that parents accepted their undefined or dual private parts status and did not seek to choose one status.

One of the participant who looks more like a man said,

> "*I was born like a girl, we are twins and born with two private parts, but our parents chose that they will raise us as girls, but when I was about 15 years old, I started growing more beards and changed our clothes to male clothes and I changed my name too. But the part that is more dominant is a female part.*

The confusion also stems from parents' unwillingness to talk about their child's intersex status. Majority of the participants indicated that, growing up, their parents did not engage them to discuss their sex. This is epitomized in this quote:

> *"My parents cannot even talk about it, they never told me that I was different until one day I went to the hospital"*

4.6.2. Social challenges

Intersex people meet challenges such as being laughed at by neighbors and being the topic of a family meeting in the family that they are different and they fear for their lives if people know that they have two private parts. Most of the people are curious to see how they look like. And on part of sexual relationships, most of the people would want to get in a sexual relationship with them just on point of curiosity so that they can have sex with them and see how their private parts look like.

> *"new neighbors came and when we were taking a shower together with the girls they started laughing at me that am different from them".*

Another participant explained:

> "*I have been drugged before through beer so that they can see my private parts and also rape me"*

Some even after being operated on while young and having been assigned one gender through removal of one genital, they felt comfortable being with the person they like even if it's the same gender as theirs. They also face stigma such that if they had friends, their friends' parents would deny them from being friends. Their family members also stigmatized and discriminate them. Most of IS do not attend social and religious gatherings like weddings, church activities and funerals to avoid being the topic of discussion.

> "*one day I heard that my name was mentioned in church intimations that they have excommunicated me because I am a gay. My family went to tell the church that I am an IS and not a gay, the church said they didn't know that I was that"*

Where one looks like a male but the female part dominates; expressed that socialization with the females is very difficult because the society already assigned duties and behaviors of the female and same with those who look more like females but they feel that they are male. For instance, one participant said:

> *"people wondered to which group I belong to, since I was fond of performing female house chores, playing netball and being in women groups.*

4.6.3. Psychological /emotional challenges

Some people conclude that these people are lesbians or gays just by noticing that their names do not match their physical appearance. They also feel that they are not safe and would not want people to know of their identities. One of the IS said that;

> "*I am mostly sad and this confuses me, and I asked myself what God was thinking when he was creating me."*
>
> *Another IS said that, "I am not happy when people think I am a gay when actually I have two private parts and I don't know how to define myself."*

4.6.4. Health challenges

Intersex study participants tend to be stigmatized by health care providers at the hospital especially in public hospitals. IS only feel comfortable to be assisted by only members of staff who already know their status at public facilities. Most of them alluded to be free to get assistance from private facilities.

> *"I still remember I had a stomachache and I went to the hospital for assistance and the doctor was a male. He started examining me and took his phone and started taking pictures. I asked him the purpose for taking pictures and he said he wanted to send to his friends. I told him it was not fair."*

Responders explained that Some of the health challenges are based on the fact that intersex people may have two private parts which to some participants are both not well defined or one of it is well defined and the other is not. This results in dysfunction of some of their private parts. The IS also expressed concern over the services that they can acquire from the public facilities, such as female family planning methods, cervical cancer screening because of their appearance. This brings fear that they can conceive or have complication due to lack of more investigations and information on how to take care of themselves in terms of health. One of the study participant said,

> "*you can see me that I look more of a man but I also have hips, and at first my grandmother had a friend in South Africa who was asked by grandmother to be sending medication to suppress the growth of breasts. I have a male part which is not very well defined and cannot function for sexual activities and a female part that I use for sexual activities but a male part cannot penetrate properly. I look more of a man but I also get monthly periods through the vagina, but this period brings menstrual pains. I would love if the public hospitals were able to operate and let me have one private part to relieve me from the pain I go through."*

Another commented:

> *"I am afraid to go to the hospital to access services like female family planning methods and cervical cancer screening and breast screening because the health workers always ask me why do I need them since I am a man. I am afraid that if I show them my private parts they will go call one another to embarrass me."*

Through the interviews, it was learnt that most of the hospital facilities in Malawi cannot conduct operations on the intersex, hence parents tend to leave them the way they were born.

4.6.5. Access to Education

Respondents pointed out that they faced challenges with accessing education. Various negative experiences as intersex people navigated the academic landscape, affected them academically. These experiences include hospital visits usually in relation to potential operation, limit their time for going to school. In addition, intersex meet problems in terms of accommodation, where IS who has two private parts are accommodated with boys and end up facing shaming and rape.

> "*I was sent to a boarding school where one of the boys saw my private parts when I was taking a bath and blackmailed me that I should have sex with him so that he does not tell others about it. We started having sex and later other boys were doing the same, one after the other until I contracted STIs and HIV.*

4.6.6. Employment and livelihoods

Most of the IS do not work, but some of them have their own business. This is because when people speculate about their status, they end up losing their jobs, because it is regarded as a shameful thing. For those doing business, their status makes them lose business deals or have hindrance to do business in some countries.

> "*sometimes you interact with the customers and give them your name and they may be thinking that they are talking to a woman, but when you meet them, they ask if you are indeed the one who was talking to them because I look like a man."*

5. DISCUSSION

5.1 Intersex phenomena

This situational analysis reveals the absence of official Institutional mechanisms management of intersex persons in Malawi's health system spanning from gender recognition at birth and the medical decisions and management, and any support upon discharge. It is apparent that the Malawi health system does not recognize intersex immediately a child is born specifically, the sex they assign to the child, "corrective" measures. There are various factors that lead to this situation. Prominent is the reality that intersex births are not very common making it a phenomenon that receive limited attention. The rarity of intersex phenomena is subsumed in a more encompassing topic of birth defects in during medical, midwifery or general nursing training. While many clinicians might be aware of the phenomenon, few have adequate detail on what it is.

52. Sex assignment

This analysis depicts a void in policy for assigning gender to new born. There is no policy that guides gender assignment and declaration in the birth register or certificate. In this study it was established that the current practice, is that the mother assigns gender. Sex assignment is based on the baby's external genitalia after inspection. After birth, the mother is shown the baby and its genitalia. The mother then is supposed to pronounce the gender of the child. The midwife confirms and writes in the birth register. In the Malawi health system, no additional diagnostic steps are conducted in order to assign sex in the advent that the genitalia are not clearly male or female. This study also revealed that in cases where the genitalia is conspicuously intersex, the midwife would still write the sex assigned by the mother or what they think is the nearest in the birth registry. Children with "unclear" genitalia would be further reviewed at the neonatal ward. The clinician would note the fact that the genitalia was unclear. However, the pediatrician's observations would not be reflected in the registry and such observations remain in the newborn's file. In the pediatrician's notes, what is written is disorder of sexual differentiation (DSD). This designation automatically intersex unrecognized gender. The fact that the birth registry has only male or female space, and not space to provide any information regarding any observations, limits the clinicians or midwives' ability to have intersex reflected in this important document. Sometimes, midwives would scribble a note, indicating that the child's genitalia did not conform to male or female. This situation depicts the needs for universally available non-binary sex markers (Carpenter, 2018).

5.3. Proportion of Intersex births in Malawi

It is evident that very little has been in the Malawi health system in terms of recognizing the intersex population at birth, further attention on intersex neonates, and follow ups after discharge from health facilities. Furthermore, there is a dearth of research and health projects focusing on intersex population. However, although not focusing specifically in intersex, in 2016, a Malawi Birth Defects Surveillance

(BDS) project was initiated in Malawi. BDSs overall objective of the is to establish to establish a surveillance system to estimate the prevalence of external birth defects and adverse pregnancy outcomes. From 2018, sixteen children were identified as intersex. It is apparent that this surveillance does not involve internal defects, implying that neonates whose genitalia was identified as unclear, they do not establish the nature of internal organs. This is data collected at Queen Elizabeth Central Hospital (QECH).

5.4. Legal identify of intersex people

Probably not coming as a surprise, there is legal identity for intersex people in Malawi. This study reveals that there are no laws that accommodate or acknowledge intersex issues and how to deal with them. Whether it is in hospital or elsewhere. However, the law does not exclude the intersex people because it recognizes them as "whatever sex they end up choosing". However, the choice is limited in that it can only be male or female. As pointed out, there are no laws regarding intersex in terms of registration at birth. The law operates on the premise that gender is male and female. Probably due to lack of knowledge the law could not have anticipated that there could be more than one gender to an individual. From the interviews, law experts explained that while the law does not recognize any other gender apart from the two but it also does not prohibit the possibility of another. Furthermore, it was explained that the law does not recognize IS people because at the time it was enacted, there was no need for it. The law experts highlighted the need to promote intersex specific right. In this case the understanding of intersex rights as human rights. It was also clear from the interviews that intersex rights that could be unique compared to the LGBTQ as a whole are not highlighted since it the LGBTQs rights that are more heard of or discussed as opposed to the intersex. The lack of recognition of intersex identity is also reflected in the immigration documents, thus the passport. Malawi's passport identifies male or female genders only.

5.5. Challenges experienced by intersex people in Malawi

Our study exposes several challenges that intersex people face in Malawi. These challenges inextricably violate various human rights. These challenges include:

5.5.1. Identity confusion

It is apparent that one of the main challenges faced is confusion regarding gender identity. The confusion is particularly compounded by scenarios where they the gender assigned to them by their parents do not resonate with how they identify. These are situations where parents or guardian would have found them more like a particular gender while they personally identify or feel more suited to a different one. Intersex people who find themselves in a situation where they would rather change their gender marker from the one assigned by parents to the one they felt more suited cannot do so. Malawi does not have laws that allows a transgender person to change the gender marker in their identity document. However, the National Registration Act 13 of 2010, section 21 (1[6]) has provisions that could speak to rectifying the situation. Section 20(1) of the ACT provides that where a change in particulars of a registered person materially affect his registration, the district registrar shall record the change and notify the Director of the circumstances and recommend that the person be issued with a new identity card. In terms of section 20(2), if the director is satisfied that the change materially affects the registration, he will cancel the identity document and issue a new one. Section 21(1) provides that every registered person may,

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[6] https://www.southernafricalitigationcentre.org/wp-content/uploads/2017/08/Transgender-rights-in-Malawi.pdf

whenever he is satisfied that his appearance has changed so as to make it likely that his identity may be questioned, apply to the district registrar for the issue of a new card with a more recent photograph".

5.5.2. Social challenges

Perhaps, due to lack of knowledge and awareness, intersex people suffer are stigmatized in various ways including being laughed at by neighbors. People, especially in intersex peoples' cycles are curious to understand or see how they look like. Furthermore, stigma is experiences when people would want to get in a sexual relationship purely out of curiosity so they can have sex with them and see how their private parts look like. Worse scenarios are when intersex people are manhandled by a group in order to see their private parts and raped. Stigma at family level would involve family meetings to discuss their situation, based fears for their lives if people know that they have two private parts. Some even after being operated on while young and having been assigned one gender through removal of one genital, they felt comfortable being with the person they like even if it's the same gender as theirs. They also face stigma such that if they had friends, their friends' parents would deny them from being friends. Their family members also stigmatized and discriminate them. Most of intersex do not attend social and religious gatherings like weddings, church activities and funerals to avoid being the topic of discussion.

Where one looks like a male but the female part dominates; expressed that socialization with the females is very difficult because the society already assigned duties and behaviour of the female and same with those who look more like females but they feel that they are male.

4.6.3. Psychological /emotional challenges

The participants in this study expressed being sad and feeling down so often. This is an indication of individuals who struggle with mental health. Furthermore, the narratives from intersex people in this study depicts a population that is exposed to various life events that render it vulnerable to mental health problems. The confusion experienced early in life as the intersex people begin to know themselves, the challenges and frustrations of not being able to identify a gender they could "naturally" identify with among many other challenges in childhood until late childhood when they discover that they are different create a cluster of experiences could either instantly lead to mental disorders particularly common mental disorders like Depression and anxiety. Furthermore, these experiences could lead to major mental health illnesses later in life. These findings, also reveal experiences such as people labeling intersex people as homosexuals especially based on names and body appearance mismatch. They also feel that they are not safe and would not want people to know of their identities. These findings in consonant with what literature recognizes intersex as having particular psychosocial implications, often relating to childhood experiences of medical intervention, parenting experiences that involve new and unexpected challenges, a sense of shame and secrecy, and a negotiation of bodily difference (Roen, 2019).

4.6.4. Health challenges

Further to Malawi health system's no recognition of intersex population, conspicuous in the absence of comprehensive topic in its curriculum, birth registry not acknowledging the potential of a child being born with a sex / gender that does not conform to the binary divide, this study found that intersex people are stigmatized as the navigate the system. The findings suggest that health personnel in health facilities, especially public stigmatize intersex people. The inhumane treatment of the intersex people is encapsulated in this quote: "I *still remember I had a stomachache and I went to the hospital for assistance and the doctor was a male. He started examining me and took his phone and started taking pictures. I asked him the purpose for taking pictures and he said he wanted to send to his friends. I told* *him it was not fair."* Due to various health problems emanating from the nature of sexual organs where complications in form of being not well defined could result in health issues requiring medical attention. With the undue, stigmatizing curiosity of the health personnel, intersex people are reluctant to seek sexual and reproductive health care. The fear of being stigmatized leading to reluctance to access such as family planning methods, cervical cancer screening usurps intersex people's health rights. We also learnt that most of the hospital facilities cannot conduct operations on the IS, hence parents tend to leave them the way they were born.

4.6.5. Challenges Accessing Education

It is obvious from the findings that intersex peoples' opportunities to succeed in school are made limited by a plethora of reasons. First, from early on in life, their attendance in school is disturbed especially where they have to seek health services to be operated. This can be a tedious and convoluted process especially in a country where there are limited health personnel and facilities very conversant with intersex health issues. Furthermore, other challenges make life at school unbearable and conducive for learning. These challenges include where they are allowed to sit in primary school, which uniforms they wear, which toilet they can access. If they were to attend boarding school, situations of having two distinct genitalia raises questions as to where they could be accommodated, thus or girls. Being accommodated with boys could end up facing shaming and rape.

4.6.6. Employment and livelihoods

This study reveals that most of the intersex people were not employed while some had business. As pointed, this is because when people speculate about their status, they end up losing their jobs, because it is regarded as a shameful thing. For those doing business, their status makes them lose business deals or have hindrance to do business in some countries. It is very likely that majority of intersex people are unable to attain education and be employable. This is due to various challenges they face as they navigate the Malawi education system.

6. CONCLUSIONS AND SUGGESTED PRIORITIES

6.1 Conclusion

This study reveals major disregard for Malawi's intersex population that cut across different facets of human life. Probably the main area in which intersex people in Malawi suffer the most and their rights trodden upon is in the health sector. In terms of health care, there are challenges for intersex people

Legislation and administrative procedures regarding intersex persons are not in place

6.2 Recommendations

1. The Malawi health system just as many other, may not manage to provide the optimum attention to medically normalize intersex people to fit into the binary divide of male or female. Besides, there might be circumstances where this is not possible. It is therefore strongly recommended that a gender markers other than male or female should be included. The markers would help in defining

the intersex people contributing to the elimination or reduction of various psychosocial challenges experienced.

2. It is apparent that by being entirely entwined with the LGBTQ, the intersex community in Malawi may not adequately advance its agenda. It is therefore strongly recommended that the intersex community should consider intersex exclusive programs in order to avoid the potential backlash associated with the larger LGBTQ community.
3. Studies, such as the Under Wraps 2019 survey, suggests that Malawians are much more favorably disposed to gender diversity than sexual diversity. In this survey, a large majority of Malawian accept intersex people and think their rights should be protected. It is therefore safe to claim that campaigns to raise awareness of the existence of the intersex population would be largely supported by the Malawian population. Awareness of intersex people and their needs in relation to education and health would considerably reduce stigma and discrimination, creating a conducive context for intersex people seek medical services. Furthermore, intersex people would be protected in the community.
4. The study reveals that healthcare providers might not be conversant with intersex health care needs. As highlighted elsewhere, a health provider advised parents wrongly "*my parents were told by a health worker to kill me but my parents said they didn't want since I am also a human being and a gift from God and also that they didn't ask for me to be in this state."* This highlights the need for refresher, with more biopsychosocial aspects, training for health providers in Malawi. The same should be incorporated in their curricula for health sciences students. Also include intersex health as part of mandatory CPD trainings for health professionals in Malawi.
5. The findings reveal SRH challenges where intersex people fear that they could conceive or have complication due to lack of more investigations and information on how to take care of themselves as pointed out by a participant "*I am afraid to go to the hospital to access services like female family planning methods and cervical cancer screening and breast screening because the health workers always ask me why do I need them since I am a man. I am afraid that if I show them my private parts they will go call one another to embarrass me."* In addition to making this a topic for health sciences students, it is strongly recommended that intersex organizations should mount projects that provide information on various SRH issues.
6. It is strongly recommended that there should be advocacy to ensure various services to be available to the intersex community. These services include;
    a. Medical insurance to cover medical interventions, tests and medications for the treatment of intersex conditions
    b. Ensure mental health services for intersex people
7. There is need for data on various intersex related needs in order to build evidence useful for decision making. It is therefore recommended that the health system should be collecting data on intersex-related diagnoses and practices in health facilities.
8. Most of the needs of the intersex community in Malawi would be realized through advocacy work that civil society organizations could champion. It is therefore strongly recommended that efforts should be made to CSOs awareness and knowledge about intersex for them to adequately support intersex's rights.
9. Given that the intersex community is usually a small population, most people might be isolated and without the support they might need. It is therefore strongly recommended that efforts should be

made to create a network that would act as a support system. The support system might include help lines and/or social media networks.

10. Create awareness among authorities and state bodies responsible for the protection of human rights to be able to provide adequate protection of intersex persons. These groups could include the police, immigration and the judiciary.
11. Train the media on how to report on intersex issues and how to raise the awareness of the general public on this topic.
12. Advocate for Malawi laws to recognize sex characteristics as grounds of discrimination in anti-discrimination law and other provisions (e.g. related to education, labour and health) that tackle discrimination.

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