Disclaimer

This publication has been developed with the technical assistance from the International Development Law Organisation (IDLO), with financial support from the United States Agency for International Development (USAID) and Danish International Development Agency (DANIDA). The printing of the publication has been undertaken by IDLO with funding from the Danish International Development Agency (DANIDA). The views expressed herein do not necessarily reflect the views or policies of IDLO or its Member Parties. Similarly, the views expressed in this publication do not necessarily reflect the views of USAID and DANIDA.
FOREWORD BY THE CHAIRPERSON

I am very pleased to be associated with the work and publication of this report of the Taskforce on Legal, Policy, Institutional and Administrative Reforms regarding Intersex Persons in Kenya. The Taskforce was constituted by the Hon. Attorney-General in May 2017, with its membership drawn from various State and non-State institutions from the governance, medical and religious sectors as well as representation from the Intersex community. Primarily, the Taskforce was to investigate and make recommendations aimed at addressing the plight of Intersex Persons in Kenya. Indeed, this is the first time the country is undertaking such a bold step of documenting the number and distribution of intersex persons for policy interventions.

The Taskforce adopted various strategies in pursuit of its goals. Key among them were: a comprehensive and comparative desk review; stakeholder consultation; targeted awareness fora; a field survey; key informant interviews; field visits and use of ICTs. The approaches were also supported by a functional Secretariat, co-option of new members, hiring of a research consultant and partnership with relevant agencies and Development Partners. The Taskforce observed with keenness the nature and sensitivity of the subject matter. It was also confronted firsthand with the realities and stigma associated with the Intersex condition as meted out on the intersex persons, especially the children. It is evident that intersex persons as a “marginalised”, “minority” and “vulnerable” group face a multitude of challenges and human rights violations from birth that includes: stigmatisation, ridicule, discrimination and inadequate medical attention. There is also a general lack of awareness about the intersex condition and the appropriate ways of supporting an intersex child and the immediate family. This report documents these challenges based on a first person encounter with intersex persons and families.

It was noteworthy that an inadequate policy and legislative framework has hampered development of supportive systems for intersex persons in the country. This had led to whatever advocacy efforts which may have been made to go unnoticed and ultimately fail to make the intended gains. However, the growing demonstration on the human aspects and appreciation of the need for integration of intersex persons has summoned society’s attention. In recent times, the country has witnessed positive legislative, judicial and administrative pronouncements that partially informed the work of the
Taskforce. Specifically, the court decisions in the RM Case of 2010 and the Baby ‘A’ Case prompted the establishment of the Taskforce.

In spite of challenges encountered due to the nature of work required by discharge of the Taskforce’s mandate, there was remarkable progress and poignant success stories. The Taskforce findings further outline a number of recommendations that need to be implemented in order to guarantee that intersex persons achieve equality in law, human dignity and legal protection. Beyond meeting all the set goals, the Taskforce opened up the space for constant dialogue and engagement with intersex persons. This was achieved by working closely with the Intersex Persons Society of Kenya (IPSK). The Taskforce also developed a comprehensive and broad-based definition of the intersex status. This definition will no doubt inform the recognition debate and the response to the challenges associated with the intersex status. These and other milestones are detailed in this report.

These achievements, realised amid the obvious inherent and encountered challenges, were a product of collaboration, consultation and cooperation with many agencies and persons. The priceless input of all Taskforce Members, the Secretariat and the various experts and agencies is deeply appreciated. The Taskforce is further grateful to our partners particularly, the Office of the Attorney- General and Department of Justice (OAG&DOJ), International Law Development Organisation (IDLO) and the Open Society Initiative of Eastern Africa (OSIEA).

Mbage Njuguna Ng’ang’a
Chairperson of the Taskforce
<table>
<thead>
<tr>
<th>Name</th>
<th>Designation</th>
<th>Institution</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mbage Njuguna Ng’ang’a</td>
<td>Chairperson of the Taskforce</td>
<td>Kenya Law Reform Commission (KLRC)</td>
<td></td>
</tr>
<tr>
<td>Maryann Njau-Kimani, OGW</td>
<td>Member</td>
<td>Office of the Attorney-General &amp;Department of Justice (OAG &amp;DOJ)</td>
<td></td>
</tr>
<tr>
<td>John M. Kinyumu</td>
<td>Member</td>
<td>Ministry of Interior and Coordination of National Government</td>
<td></td>
</tr>
<tr>
<td>Jimmy Edwin Nyikuli</td>
<td>Member</td>
<td>Ministry of Interior and Coordination of National Government</td>
<td></td>
</tr>
<tr>
<td>Sylvester Mbithi</td>
<td>Member</td>
<td>National Gender and Equality Commission</td>
<td></td>
</tr>
<tr>
<td>Lavina Achieng Oluoch</td>
<td>Member</td>
<td>The CRADLE –Children Foundation</td>
<td></td>
</tr>
<tr>
<td>Caroline Towett</td>
<td>Member</td>
<td>Ministry of Labour and Social Protection</td>
<td></td>
</tr>
<tr>
<td>Petronella Mukaindo</td>
<td>Member</td>
<td>Kenya National Commission on Human Rights (KNCHR)</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
<td>Organization</td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>-------------------</td>
<td>---------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Jedidah Wakonyo Waruhiu</td>
<td>Co-opted Member</td>
<td>Kenya National Commission on Human Rights (KNCHR)</td>
<td></td>
</tr>
<tr>
<td>James Karanja</td>
<td>Co-opted Member</td>
<td>Intersex Persons Society of Kenya (IPSK)</td>
<td></td>
</tr>
<tr>
<td>Samwel Odiwuor Kaumba</td>
<td>Joint Secretary</td>
<td>Office of the Attorney-General &amp; Department of Justice (OAG &amp; DOJ)</td>
<td></td>
</tr>
<tr>
<td>Veronica Mwangi</td>
<td>Joint Secretary</td>
<td>Kenya National Commission on Human Rights (KNCHR)</td>
<td></td>
</tr>
</tbody>
</table>
# TABLE OF CONTENTS

1.0 INTRODUCTION AND BACKGROUND. 10

1.1 Contemporary Definitions of Intersex. 12
1.2 Legal Definitions of Intersex. 12
1.3 Medical Definitions of Intersex. 13
1.4 Religious Definition of Intersex.
  1.4.1 The Biblical Perspective. 13
  1.4.2 The Quranic Perspective. 14
1.5 Manifestations of Intersex.
  1.5.1 Congenital Adrenal Hyperplasia (CAH).
  1.5.2 Clitoromegaly.
  1.5.3 Ovo-testes (formerly called “true hermaphroditism”). 16
  1.5.4 Androgen Insensitivity Syndrome (AIS) 16
  1.5.6 Partial Androgen Insensitivity Syndrome 17
  1.5.7 Hypospadias 17
  1.5.8 Progestin Induced Virilisation (PIV) 17
  1.5.9 Aphalia 17
  1.5.10 Klinefelter Syndrome 18
  1.5.11 Micropenis 18
  1.5.12 Mosaicism involving “sex” chromosomes 18
  1.5.13 Swyer Syndrome 18
  1.5.14 Turner Syndrome 19
  1.5.15 Mosaic Turner Syndrome 19
  1.5.16 Mayer, Rokitansky, Kuster, Hauser Syndrome 19
1.6 The Difference between Intersex, Sex, Gender and Transgender 19
1.7 Taskforce Definition of an Intersex 19
2.0 INTERNATIONAL LEGISLATIVE AND HUMAN RIGHTS FRAMEWORK

2.1 International Human Rights Frameworks

2.1.1 Recognition and Freedom from Discrimination

2.1.2 Treatment of Intersex Persons Amounting to Torture, Cruel, Inhuman or Degrading Treatment

2.1.3 Concept of ‘Informed, Free and Voluntary Consent’ in Medical Procedures

2.1.4 Principle of ‘Best Interests of the Child’ in Care and Treatment of Intersex Children

2.1.5 The Intersex and Sports

2.1.6 Right to a Legal Remedy

2.1.7 Data Privacy and Protection

2.1.8 Education and Training

2.2 Regional Human Rights Systems on Protection of Intersex Persons

2.2.1 The Inter-American Human Rights Framework

2.2.2 The European Human Rights Framework

2.3 A Comparative Review of International Practices

2.3.1 Germany

2.3.1.1 Legal Framework

2.3.1.2 Policy Recommendations

2.3.2 Switzerland

2.3.2.1 Informed Consent and Recognition/Documentation

2.3.2.2 Corrective Surgeries

2.3.3 France
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.3.1 Principal Directions</td>
<td>31</td>
</tr>
<tr>
<td>2.4 The African Human Rights Framework</td>
<td>31</td>
</tr>
<tr>
<td>2.4.1 Overview and Key Provisions</td>
<td>31</td>
</tr>
<tr>
<td>2.4.2 Comparative African Practices</td>
<td>32</td>
</tr>
<tr>
<td>3.0 KENYA LEGAL AND POLICY FRAMEWORK</td>
<td>34</td>
</tr>
<tr>
<td>3.1 Introduction</td>
<td>34</td>
</tr>
<tr>
<td>3.2 Kenyan Case Law</td>
<td>34</td>
</tr>
<tr>
<td>3.2.1 RM's Case</td>
<td>35</td>
</tr>
<tr>
<td>3.2.2 Baby ‘A’ (Suing through the Mother E A) &amp; another v Attorney General &amp; 6 others [2014]</td>
<td>36</td>
</tr>
<tr>
<td>4.0 NUMBERS, DISTRIBUTION AND CHALLENGES OF INTERSEX PERSONS IN KENYA</td>
<td>38</td>
</tr>
<tr>
<td>4.1 Introduction</td>
<td>38</td>
</tr>
<tr>
<td>4.2 Findings</td>
<td>38</td>
</tr>
<tr>
<td>5.0 RECOMMENDATIONS</td>
<td>43</td>
</tr>
<tr>
<td>5.1 Introduction</td>
<td>43</td>
</tr>
<tr>
<td>5.2 Recommendations</td>
<td>43</td>
</tr>
<tr>
<td>5.2.1 Recognition</td>
<td>43</td>
</tr>
<tr>
<td>5.2.2 Documentation</td>
<td>43</td>
</tr>
<tr>
<td>5.2.3 Criminal Justice Sector</td>
<td>44</td>
</tr>
<tr>
<td>5.2.4 Health</td>
<td>44</td>
</tr>
<tr>
<td>5.2.5 Education and awareness</td>
<td>44</td>
</tr>
<tr>
<td>5.2.6 Statistics</td>
<td>45</td>
</tr>
<tr>
<td>5.2.7 Social, Economic and Legal Protection</td>
<td>45</td>
</tr>
</tbody>
</table>
1.0 INTRODUCTION AND BACKGROUND

The recognition of a person on the basis of sex is often pegged on the binary categorisation of one being either male or female at childbirth. This, however, is not the case for all births. In some cases, a child’s sex cannot be clearly ascertained at birth due to marked differences in their sex characteristics, therefore they are referred to as intersex. Worldwide an estimated 0.05 to 1.7% of new born babies are born intersex. In Kenya, the current population of intersex persons are estimated at between 23,925 and 813,425 nationally.

Within the UN framework, the Convention on the Rights of the Child (CRC) proposes the establishment of a comprehensive data collection system to facilitate analysis of vulnerable children with a focus on disaggregated data on, among other things, sex. The Bill of Rights (Chapter 4 of CoK, 2010) provides an array of fundamental freedoms and human rights every person, including intersex persons is entitled to. Judicial decisions in Kenya have upheld and promoted the realisation of the rights of intersex persons with specific focus on protection against discrimination and from torture, cruel, inhumane and degrading treatment (See both R.M v Attorney General & 4 others [2010], eKLR and Baby ‘A’ (Suing through the Mother E A) & another v Attorney General & 6 others[2014], eKLR). The cases also outline the need for empirical data on intersex persons in Kenya to inform relevant reforms to address challenges faced by intersex persons as a marginalized group. The Kenyan Parliament has similarly formulated safeguards for intersex persons stemming from the Persons Deprived of Liberty Act (2014), which recognises the need for recognition before the law through introduction of an Intersex (I) marker, public awareness, generation of statistics, access to healthcare and redress for human rights violations. Following its own study, KNCHR wrote an advisory to the Kenya National Bureau of Statistics (KNBS) on 9th March 2018, which highlighted the recommendations directed to the Registrar of Persons, Kenya National Bureau of Statistics and Ministry of Health to provide statistics of all intersex persons and ensure they are captured in the national census or other socio-economic surveys to facilitate planning. In that regard, the Office of the Attorney-General and Department of Justice (OAG&DOJ) established the Taskforce on Policy, Legal, Institutional and Administrative Reforms regarding the Intersex Persons in Kenya on 26th May, 2017 vide Gazette Notice No. 4904.
The Taskforce was mandated to:

i. **Compile comprehensive data** regarding the number, distribution and challenges of Intersex persons;

ii. **Provide a comparative analysis of approaches to care, treatment and protection of intersex persons**;

iii. **Conduct an analysis of the policy, legal, medical, administrative and institutional frameworks governing structures and systems with regard to Intersex persons**;

iv. **Recommend reforms to safeguard the interests of intersex persons**;

v. **Present a prioritized implementation matrix based on the immediate, medium and long term reforms governing the intersex persons**; and

vi. **Undertake any other activities required for effective discharge of the mandate**.

The Taskforce was constituted on May 2017 with an initial term of 6 months and subsequent extensions to facilitate comprehensive fulfilment of its mandate, which expired on 30th November 2018. Its membership was drawn from various MDAs, the CRADLE and Intersex Persons Society of Kenya (IPSK). It was headed by the Chairperson of the Kenya Law Reform Commission (KLRC) with a designated Secretariat based at the KNCHR led by two joint secretaries drawn from KNCHR and OAG/DOJ. In order to fulfil its objectives, the Taskforce adopted strategies and interventions that included: consultative fora; advocacy and awareness raising (using print and broadcast media; digital and online communication platforms, opinion leaders, drama, public lectures, Social Media and local language community and international radio stations for public awareness and sensitisation); comparative studies and surveys, including through a benchmarking mission to Uganda; partnership-building, especially with Development Partners, notably IDLO and OSIEA, which supported the Taskforce with both financial and technical expertise; planning, monitoring and evaluation; feedback mechanisms and reporting, and regional validation meetings between 8th and 11th October 2018 in Nairobi City, Mombasa and Kisumu; five retreats to interrogate its findings, and; development of its final Taskforce Report, including reform proposals and an implementation matrix.

1.1 Contemporary Definitions of Intersex

The intersex is:

“... people who are born with sex characteristics (including genitals, gonads and chromosomal patterns) that do not fit typical binary notions of male or female bodies.” (UN Human Rights Office of the High Commissioner)

“... a variety of conditions in which individuals are born with (or develop later in life) ambiguous external genitalia and/or a combination of chromosomes, gonads, external genitalia and hormones that do not align as typical male or typical female.” (Sociologists for Women Society)

“... genetic conditions identifiable at birth that result in the birth of a child with anatomical or biological sex differentiation which varies from that most commonly found in male and female births.” (The Androgen Insensitivity Support Group Australia, AISSGA)

“... a person born with sexual anatomy, reproductive organs and/or chromosome patterns that do not fit the typical definition of male or female.” (Joint dialogue of the African Commission on Human and Peoples Rights, the Inter-American Commission on Human Rights and the United Nations)

1.2 Legal Definitions of Intersex

The international human rights framework safeguarding the protection against discrimination on the basis of sex characteristics defines the intersex as:

“... each person's physical features relating to sex and including genitalia, as well as other sexual and reproductive anatomy, chromosomes, hormones and secondary features that emerge from puberty.” (Yogyakarta Principles + 10)

“a congenital sexual differentiation which is atypical to whatever degree.” (South Africa's Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000)

“the chromosomal, gonadal and anatomical features of a person which include primary characteristics such as reproductive organs and genitalia and/or in chromosomal structures and hormones; and secondary characteristics such as muscle mass, hair distribution, breasts and/or structure.” (Gender Identity, Gender Expression and Sex Characteristics Act, 2015 of Malta)

“the status of having physical, hormonal or genetic features that are neither wholly female nor wholly male or a combination of female and male or
neither female nor male. (Australia's Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status Act, 2013).


“a person certified by a competent medical practitioner to have both male and female reproductive organs.” (Section 2, the Persons Deprived of Liberty Act, 2014)

1.3 Medical Definitions of Intersex

In 2006, the European and American Society for Paediatric Endocrinology arrived at a consensus term, “disorders of sex development” (DSD), denoting congenital conditions with chromosomal, gonadal and anatomical sex development that is atypical. The Intersex Society of North America defines it as conditions involving the following elements: congenital development of ambiguous genitalia; congenital disjunction of internal and external sex anatomy; incomplete development of sex anatomy; sex chromosome anomalies, and; disorders of gonadal development. The different elements are indicative of the variety of manifestations of DSD /intersex which include anomalies of the sex chromosomes, the gonads, the reproductive ducts and the genitalia.

1.4 Religious Definition of Intersex

1.4.1 The Biblical Perspective

In the Christian faith, the Scripture speaks to creation of human beings as the works of God. For instance, in the story of creation, it provides that: “So God created man in his own image, in the image of God created he him; male and female created he them.” (Genesis 1: 27, KJV). In the Gospels, the Bible alludes to sex characteristics when it says:

“For there are eunuchs who were born that way, and there are eunuchs who have been made eunuchs by others—and there are those who choose to live like eunuchs for the sake of the kingdom of heaven. The one who can accept this should accept it.” (Mathew 19:12, NIV)

Lastly, in addressing the question of congenital guilt or curse from God, parents or other sources as a possible reason for children born intersex, Jesus gives an emphatic and enlightened answer on the matter thus:
“And his disciples asked him, saying, Master who did sin, this man, or his parents, that he was born blind? Jesus answered, ‘neither hath this man sinned, nor his parents: but that the works of God should be made manifest in him’.” (John 9:2-3, KJV)

In summary therefore, the Bible recognises and expresses respect for all creation which, after all, was created by God Himself, who at the end of His divine labours, pronounced it all good: “God saw all that he had made, and it was very good…” (Genesis 1:31, NIV) It is important to note that this summation came after the creation of humanity as the epitome of all creation that had proceeded in the first five days. In fact, in placing man as the regent of the earth and all creation, God seems to put all issues of judgement, including acceptance or otherwise of the intersex, squarely on us, humanity:

Then God said, “Let us make man in our image, in our likeness, and let them rule over the fish of the sea and the birds of the air, over the livestock, over all the earth, and over all the creatures that move along the ground.” (Genesis 1:26, NIV)

God blessed them and said to them, “Be fruitful and increase in number; fill the earth and subdue it. Rule over the fish of the sea and the birds of the air and over every living creature that moves on the ground.” (Genesis 1:28, NIV)

From the above context, it is clear that God does not discriminate among His creations, which are all good. It is thus incumbent upon us, humanity, to bring out the good in each creation, even the seemingly ‘not good’, and to ‘avoid judging, that we be not judged”. Intersex is a birth status, and not a choice made by the parents or the innocent children. It simply is, and we need to recognise it for itself and make room for it, just like for every other creature.

1.4.2 The Quranic Perspective

The Holy Quran unequivocally states that Allah has dominion over all creatures:

“To Allah belongs the dominion of the heavens and the earth; He creates what He wills. He gives to whom He wills female [children], and He gives to whom He wills males. Or He makes them [both] males and females, and He renders whom He wills barren. Indeed, He is Knowing and Competent. (Qur’an 42:49-50)

Classical Islam recognises four genders among human beings: male, female, Khusna, and the effeminate male. Khusna is a person who has somatic sex ambiguity due to a disorder of sex development. Khusna has been described
as a person with both male and female sex organs or with an opening in place of a sexual organ from which they urinate. This is further categorised into two types: wadhih (discernible) and musykil (intractable). In summary, it can be argued that, in the Islamic perspective everything is made by Allah, who is Al-`Aleem – the All-Knowing:

“They said, ‘Exalted are You; we have no knowledge except what You have taught us. Indeed, it is You who is the Knowing, the Wise.’” (Surah al Baqarah, 2:32)

Since He is All-Knowing, Allah has complete knowledge of all the heights and depths of the visible and invisible worlds, the known and the unknown, the understood and the baffling. He knows what is and what could be, what was and what could have been.

“And with Him are the keys of the unseen; none knows them except Him. And He knows what is on the land and in the sea. Not a leaf falls but that He knows it.” (al-An`aam 6: 59)

Since Allah surely knows every leaf that falls, He also knows the deepest longings of our souls, our feelings, struggles and situations. Allah does not forget either, but some things need patience and Allah subhanahu wa ta`ala teaches us with time:

“And most certainly shall We try you by means of danger, and hunger, and loss of worldly goods, of lives and of [labor’s] fruits. But give glad tidings unto those who are patient in adversity – who, when calamity befalls them, say, ‘Verily, unto God do we belong and, verily, unto Him we shall return.” It is they upon whom their Sustainer’s blessings and grace are bestowed.’” (Surah Al Baqarah, 2:155-157)

Allah knows the most intimate details of all things hidden and manifest, every generality and every particular, while humanity’s knowledge is but like a speck in comparison: “What you (O humanity) have been given of knowledge is but little.” (Al-Isra’ 17: 85) In conclusion, to help us understand the deeper things which otherwise baffle us, the Quran teaches us to make du`a (prayer) in this manner: “Say: ‘My Lord! Increase me in knowledge’.” (Ta-Ha 20:114)
1.5  Manifestations of Intersex

1.5.1  Congenital Adrenal Hyperplasia (CAH)

The Congenital Adrenal Hyperplasia (CAH) is a variation that occurs in both males and females (XY and XX), characterised by virilisation of the external genitalia in females and hence ambiguous genitalia at birth. As a result, the female embryos may have larger than average clitorises, or a clitoris that looks rather like a penis, or labia that look like a scrotum.

1.5.2  Clitoromegaly

Clitoromegaly, also referred to as large clitoris, occurs when the clitoris is larger than expected.

1.5.3  Ovo-testes (formerly called “true hermaphroditism”)

Ovo-testes are not evident through a visual examination at birth. It occurs when gonads (sex glands) contain both ovarian and testicular tissue. As a result, a person might be born with two ovo-testes, or one ovary and one ovo-testis, or some other combination. Some people with ovo-testes look fairly typically female, some fairly typically male, and some look fairly in-between in terms of genital development.

1.5.4  Androgen Insensitivity Syndrome (AIS)

Androgen Insensitivity Syndrome (AIS) is a variation where individual tissues fail to respond to hormones hence lack of virilisation of the external genitalia. An infant with Complete Androgen Insensitivity Syndrome (CAIS) has external genitalia of normal female appearance with un-descended or partially descended testes and, in most cases, a short vagina with no cervix. Often-times, it is not easily identified at birth or childhood. During puberty, most women suffering from CAIS may not have pubic or underarm hair. The variation occurs in approximately 1 in every 20,000 individuals. Its cause has been linked to a genetic condition except for occasional spontaneous mutations.

1.5.5  Partial Androgen Insensitivity Syndrome

Partial Androgen Insensitivity Syndrome (PAIS) results in “ambiguous genitalia” that presents itself as a large clitoris or a small penis and hypospadias. It may be quite common, and has been suggested as the cause of infertility in many men whose genitals are of typically male appearance.
1.5.6 **Hypospadias**

Hypospadias occur when a urethral meatus (‘pee-hole’) is located along the underside of the penis rather than at the tip. In some hypospadias, the meatus may be located on the underside of the penis i.e. sub-coronal, mid-shaft and peno-scrotal. In more pronounced hypospadias, the urethra may be open from mid-shaft out to the glans, while in some cases the urethra may even be entirely absent, with the urine exiting the bladder from behind the penis. Early correction of hypospadias is associated with higher success rates.

1.5.7 **Progestin Induced Virilisation (PIV)**

Progestin Induced Virilisation (PIV) occurs when XX people (female) affected in-utero by virilising hormones are born into a continuum of sex phenotype that ranges from “female with larger clitoris” to “male with no testes”. Occasionally, a female neonate will have an excess of male hormones that she is given a male identity at birth and raised as a boy. This may result from maternal use of male hormones (androgens) during early pregnancy.

1.5.8 **Aphalia**

Aphalia occurs when a person is born without a penis yet they have an otherwise typical male anatomy.

1.5.9 **Klinefelter Syndrome**

This an intersex variation is quite common in male births with an occurrence rate of approximately 1/500 to 1/1,000. Whereas most men inherit a single X chromosome from their mother and a single Y chromosome from their father, men with Klinefelter syndrome inherit an extra X chromosome from either their father or mother thus their karyotype is 47 XXY. It presents itself through small testes, about half the typical size, which are quite firm. However, after puberty, the ejaculate contains no sperm. As a result, boys with Klinefelter syndrome may not virilise very strongly at puberty (they may not develop much body hair, or they may experience breast development).

1.5.10 **Micropenis**

The Micropenis condition occurs when a person has a penis that is completely differentiated, that is, it has developed like a typical penis with the urethral meatus (‘pee-hole’) at the tip, but it is very small. Micropenis is apparent when a person has a 46, XY karyotype which is a typical male karyotype and testes
that are either descended or un-descended with a urethral meatus (‘pee-hole’) at the tip of the glans penis, unlike in hypospadias. It may also include a stretched penis length at or below 2.5cm standard deviation for age and stage of development.

### 1.5.11 Mosaicism involving “sex” chromosomes

This occurs when a person has one kind of karyotype in some of his or her cells, and a different karyotype in other cells. For instance, when a person is said to have a 45, X/46, XX karyotype, it indicates that he or she has 46, X in some cells, and 46, XX in other cells.

### 1.5.12 Swyer Syndrome

Also known as XY gonadal dysgenesis, Swyer syndrome occurs when a person is born without functional gonads (sex glands), but they have gonadal streaks, which are minimally developed gonad tissue in place of testes or in the ovaries. A child born with Swyer syndrome looks like a typical female, but will not develop most secondary sex characteristics without hormone replacement. This is because streak gonads are incapable of producing the sex hormones that bring about puberty.

### 1.5.13 Turner Syndrome

Turner syndrome occurs when a person has only one X fully functional chromosome as opposed to what a typical female karyotype would have, that is, 46, XX. When a person has Turner syndrome, the female sex characteristics are usually present but underdeveloped compared to the typical female. Turner syndrome presents as: short stature, lymphodema, broad chest and widely spaced nipples, low hairline, low-set ears, and infertility. However, the presentation varies in different people, thus some signs associated with the syndrome may be more obvious in one woman than in the next.

### 1.5.14 Mosaic Turner Syndrome

This type of variation occurs when the person usually doesn’t have all the associated signs of Turner syndrome but may have other signs of being intersex. It can also occur where some cells have two “sex” chromosomes (XX)
while others only have one X, or when a person has 46, XY/45X. Other mosaic types are also possible.

1.5.15 Mayer, Rokitansky, Kuster, Hauser Syndrome

The Mayer, Rokitansky, Kuster, Hauser Syndrome (MRKH) (also known as Mullerian agenesis, vaginal agenesis or congenital absence of vagina) occurs when the ovaries are present but with an absent, missshapen, or small uterus. MRKH is associated with kidney and spine anomalies in a minority of individuals.

1.6 The Difference between Intersex, Sex, Gender and Transgender

In its various manifestations, intersex has been with humanity since the dawn of history and is so recognised in various religions and communities over the ages. Usually, the sex of a child (as the primary biological characteristic in respect to ones physical genital organ, hormones and the gonads) is determined and recorded at birth as either female or male. However, later on in life, due to environmental, religious, cultural or political socialisation or conditioning, these two sexes are allocated certain behavioural traits and roles that ideally affirm the gender. An intersex person and a transgender person are different in terms of their sex characteristics. An intersex person has no clear female or male sex characteristics due to the mix either of their physical genitalia (fe/male), hormones, chromosome (X or Y) or gonads (ovary and testes). In contrast, a transgender person is biologically born either female or male, but their feelings are not congruent with their body. Crucially, therefore, intersex is linked to in-born biological sex characteristics, not gender identity. Intersex status is now universally recognised as a human rights issue that requires recognition and protection by all state and non-state parties.

1.7 Taskforce Definition of an Intersex

The Taskforce examined the above definitions, variations, and the relevant social, medical and legal developments. The Taskforce further noted the evolving and increasingly informed understanding as well as the emerging consensus that persons born intersex are human beings with inherent rights
and dignity. Therefore, the Taskforce adopts this definition to inform and guide the policy, legal and administrative structures and systems in Kenya. An intersex person is:

“A person who is conceived or born with a biological sex characteristic that cannot be exclusively categorised in the common binary of female or male due to their inherent and mixed anatomical, hormonal, gonadal (ovaries and testes) or chromosomal (X and Y) patterns, which could be apparent prior to, at birth, in childhood, puberty or adulthood.”
2.0 INTERNATIONAL LEGISLATIVE AND HUMAN RIGHTS FRAMEWORK

2.1 International Human Rights Frameworks

Kenya is a state party to all the nine core international human rights instruments. All the treaties and conventions ratified by Kenya as well as the general rules of international law form part of the law of Kenya by dint of Article 2(5)(6) of the Constitution of Kenya, 2010. The following rights and principles are recognised and developed in the international UN framework as well as in regional human rights systems on protection of intersex persons, including the inter-American human rights framework and the European human rights framework.

2.1.1 Recognition and Freedom from Discrimination

- The Universal Declaration of Human Rights (UDHR) of 1948 provides for the inherent dignity and worth of all persons. The Declaration underscores that: “All human beings are born free and equal in dignity and rights.”

- The International Covenant on Civil and Political Rights (ICCPR) ratified by Kenya in 1972, provides that, “Every child shall be registered immediately after birth and shall have a name” (Article 24(2)). Article 7 of the ICCPR is categorical that, “No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.”

- The provisions of the International Covenant on Economic, Social and Cultural Rights (ICESCR) ratified by Kenya in 1972 guarantees the right to self-determination (Article 1) and the enjoyment of all other rights in the ICESCR to all without discrimination on the basis of, inter alia, sex, birth or other status (Article 2(2)).

- The Sustainable Development Goals (SDGs) under SGD 16 are to, ‘provide legal identity for all, including birth registration’ and to ‘promote and enforce non-discriminatory laws and policies for sustainable development’ by 2030.
• The Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity (The ‘Yogyakarta Principles’) 2007 affirm binding international legal standards with which all States must comply. The Principles are endorsed by the African Commission on Human and Peoples’ Rights.

2.1.2 Treatment of Intersex Persons Amounting to Torture, Cruel, Inhuman or Degrading Treatment

• Article 16 of the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment prohibits “other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture” likewise committed by any person acting in an official capacity. Torture is a non-derogable right under both national and international law that cannot be waived even in times of state emergencies that threaten the life of a nation and constitutes one of the crimes of jus cogens.

• In his report to the Human Rights Council in February 2013, Juan E Mendez, the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment observed that special attention should be paid to vulnerable groups”.


• Principle 10 of The YP+10 secures the Right to be Free from Torture or other Cruel, Inhuman or Degrading Treatment. The Committee on the Rights of the Child (CRC) has repeatedly recognised Intersex Genital Mutilation (IGM) as a ‘harmful practice’.

*The Universal Declaration of Human Rights was adopted by resolution of the United Nations General Assembly on 10 December 1948, and was ratified by Kenya on 31 July 1990.*
2.1.3 Concept of ‘Informed, Free and Voluntary Consent’ in Medical Procedures

- Principle 32 of The YP+10 on The Right to Bodily Integrity stipulates that:
  - “Everyone has the right to bodily and mental integrity, autonomy and self-determination ... No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.”

- The WHO recommends that, in the absence of medical necessity, treatments that result in sterilisation should be postponed until the “person is sufficiently mature to participate in informed decision-making and consent”.

2.1.4 Principle of ‘Best Interests of the Child’ in Care and Treatment of Intersex Children

- The UN Committee on the Rights of the Child General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1 of the Convention on the Rights of the Child) adjoins all member States to, ensure that the requirement to consider the child's best interests is reflected and implemented in all national laws and regulations. The CRC has clarified that: “…the right of the child to have his or her best interests taken as a primary consideration means that the child’s interests have high priority and [is] not just one of several considerations.”

2.1.5 The Intersex and Sports

- Various international Conventions recognise the right of every person to leisure and creative activity. In April 2016, the UN Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health issued a report that notes that intersex persons experience multiple human rights violations including, for example, ‘sex testing’.

---

2 Article 10, ICCPR.
3 A term coined to refer to cosmetic, un-consented and unnecessary surgical intervention carried out by doctors on infants and/or older children born with ambiguous genitalia with the aim of assigning them a gender that fits within the binary notion of male and female sex.
4 Ibid. at 10.
5 UN CRC, General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1), UN Doc. CRC/C/GC/14 (29 May 2013), online: <http://www2.ohchr.org/English/bodies/crc/docs/GC/CRC_C_GC_14_ENG.pdf> (accessed 18th October, 2017).
• The Yogakarta +10 Principles require sporting organisations to integrate the Yogakarta Principles (2006) and the Additional Principles (2017), as well as all relevant human rights norms and standards in their policies and practices.

• Article 7 of the ICCPR expressly provides that, “…no one shall be subjected without his free consent to medical or scientific experimentation.”

• The Taskforce notes that requirements such as the controversial International Association of Athletics Federations (IAAF) ‘Hyperandrogenism Regulations, which require women athletes with specific differences in sex development to medically reduce their blood testosterone levels are punitive, disproportionate and intrusive. Indeed, these Regulations have been challenged by the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health; the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; and the Working Group on the issue of Discrimination Against Women in Law and in Practice. In a joint Communique to the President of the IAAF, Mr Sebastian Coe, the Special Rapporteurs are categorical that the IAAF eligibility criteria:

  • “...appear to contravene international human rights norms and standards including the right to equality and non-discrimination, the right to the highest attainable standard of physical and mental health, the right to physical and bodily integrity and the right to freedom from torture, and other cruel, inhuman or degrading treatment and harmful practices.”

• The Taskforce notes that sporting activities are an expression of culture, which serves as an important means of self and cultural expression as well as of employment and livelihood for an individual. For Kenya, athletics has for a long time remained an important source of national pride. There is need to amend the Kenya Sports Act, which is silent regarding participation and protection of the rights of athletes, to come up with appropriate regulations that prohibit discrimination and intrusive medical procedures.
2.1.6 Right to a Legal Remedy

• It is a general principle of international law that every wrong must attract a remedy. The Yogyakarta Principles task states to, “ensure that victims of human rights violations have access to full redress through restitution, compensation, rehabilitation, satisfaction, guarantee of non-repetition, and/or any other means as appropriate.”

• Further, the Special Rapporteur on Health also notes the responsibility of States to provide victims with effective remedy and redress, including measures of reparation, satisfaction and guarantees of non-repetition as well as restitution, compensation and rehabilitation, including all acts of ill-treatment in a healthcare setting whether they meet the definition of torture or not.

• The WHO Interagency Statement report on Eliminating Forced, Coercive and Otherwise Involuntary Sterilization emphasizes that:

• “Accountability ... rests with states, to prevent coerced sterilisation, to explicitly prohibit such practices, to respond to the consequences of these practices, to hold the perpetrators responsible, and to provide redress and compensation in cases of abuse.”

2.1.7 Data Privacy and Protection

• Data regarding intersex persons must be safeguarded and handled in an ethical manner and with confidentiality. Article 12 of the UDHR provides that, ‘No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, or to attacks upon his honour and reputation’ and that, ‘Everyone has the right to the protection of the law against such interference or attacks.’ Similar provisions are reiterated under Article 17 of the ICCPR.

• The United Nations High Commissioner for Human Rights ‘Guidance Note to Data Collection and Disaggregation: A Human Rights Based Approach to Data Leaving No One Behind in the 2030 Agenda for Sustainable Development’ sets out six principles which are key towards ensuring data collection, that is: lawfulness, transparency, fairness, confidentiality, data minimization, purpose limitation.
• Chapter II of The Convention on Cyber Security and Personal Data Protection of the African Union (May 2014) provides for protection of personal data and calls upon State parties to establish a legal framework “aimed at strengthening fundamental rights and public freedoms, particularly the protection of physical data, and punish any violation of privacy.”

• Closer home, Article 31 (c) of the CoK 2010 guarantees the right not to have information relating to family or private affairs unnecessarily revealed. At the time of publishing this report, Kenya’s Draft Privacy and Data Protection Policy 2018 and the Data Protection Bill, 2018 were under discussion. The Draft Policy defines sensitive personal data to include information relating to the racial, ethnic or social origin, political opinions, religious belief or matters of conscience, culture, dress, language or birth of the data subject, gender, disability, sexual life or orientation, pregnancy, health status, etc.

2.1.8 Education and Training

• Article 2 of Principle 23 of the United Nations Guidelines on IDPs as incorporated in the Act provides that every human being has the right to education.

• Principle 16 of the YP+10 Principles on The Right to Education provide that states shall: “Ensure inclusion of comprehensive, affirmative and accurate material on sexual, biological, physical and psychological diversity”.

2.2 Regional Human Rights Systems on Protection of Intersex Persons

2.2.1 The Inter-American Human Rights Framework

Despite the absence of laws expressly protecting the rights of the intersex at the regional level, various states in the Americas have made policy progress with regard to care, treatment and protection of intersex persons. In Colombia, for instance, the courts have defined the extent of ‘informed consent’ with specific reference to intersex persons. In Sentencia SU 337/99, Constitutional Court of Colombia (12 May 1999) , the Court found that constitutionally, consent could not be substituted if a child had achieved full cognitive, social, and emotional
understanding of their body and had a gender identity firmly in place. The Court therefore required that:

1. A medical team be established to help support both the plaintiff and the child and ensure that they were both completely informed of all treatment options;

2. If the medical team then found the child to be sufficiently autonomous to provide informed consent, she could have surgery before the age of majority, and;

3. In the alternative, the ability for informed consent could be approached on a sliding scale, with less invasive procedures taking place first and the rest following as the child matured.

Similarly, in Sentencia T-912/08, Pedro v. Social Security et al., Constitutional Court of Colombia, Chamber of Revision (18 December 2008), the Court in assessing the right to autonomy vis a vis the rights of the beneficiary in intersex cases involving surgery found that the decision of the child was paramount, while the right of the parent to make decisions in a protective capacity was secondary. The Court therefore stated that if the child was five years or older, it became the right of that child to make the decision subject to the considerations set out. As a consequence, when they are not met, the surgery is deferred.

2.2.2 The European Human Rights Framework

The EU provides general protection of human rights through its various instruments. Foremost among these is the Charter of Fundamental Rights of the European Union, which affirms the rights that arise from the national and international obligations that are common to the Member States of the EU, including the European Court of Human Rights (ECHR).

- Article 1 of the EU Charter provides that human dignity is inviolable and must be respected and protected. Article 3 provides for the right to physical integrity, expressly including the right to ‘free and informed consent of the person concerned’ in the field of medicine. Article 7 provides for the right to respect for one’s private life, and Article 21 prohibits discrimination on any ground including, among others, sex, ‘genetic features’ and birth.


17 EU Charter, supra note 8 at Preamble.
Further, the Court of Justice of the European Union (CJEU) has held that the principle of free and informed consent is an element of the right to physical integrity.

2.3 A Comparative Review of International Practices

2.3.1 Germany

Different studies in Germany have highlighted the challenges and complications arising from corrective procedures often performed on intersex persons. In a 2013 report entitled “Children’s right to physical integrity” to the Committee on Social Affairs, Health and Sustainable Development of the Parliamentary Assembly of the Council of Europe, Rapporteur Marlene Rupprecht noted in part that,

“[m]any had been submitted to a series of operations and were confronted with post-operative complications. Relevant treatment was traumatising for them and often involved humiliating procedures such as being exposed to large groups of medical professionals and students studying this curious phenomenon. For many, the interventions linked to their syndrome had long-term effects on their mental health and well-being.”

2.3.1.1 Legal Framework

Intersex persons have been recognised in German canon law since the late 18th century. Section 19 (I) 1 of the Prussian General Land Law of 1794 provided that parents could choose the sex of their hermaphrodite child, but section 20 (I)1 provided that the child could change their sex upon reaching the age of 18. The 2013 Regulation on the Implementation of the Civil Status Act (PStV) provides that the sex indication on a birth certificate may be left blank if the child has been diagnosed as being “affected by [Disorders of Sex Development]”. Section 47(2) of the Act provides that a child’s registered sex could be changed if it turns out that the sex had been wrongly registered, proof of which is required. However, the only options remained male and female, and once changed it cannot be changed again.
2.3.1.2 Policy Recommendations

The German Ethics Council made a number of policy recommendations with respect to the civil status and medical treatment of intersex persons (referred to by the Ethics Council as “persons with DSD”) as follows:

1. Diagnosis and treatment, along with medical and psychological counselling, should be provided to intersex persons by relevant experts and medical practitioners at specialised interdisciplinary centres distributed throughout the country;

2. The basic and continuing training of doctors, midwives, psychotherapists and other medical staff should include the avoidance of discrimination and insensitivity towards intersex persons;

3. Any decision to undergo corrective surgery should only be made by the intersex person, at a time when that person is competent to decide. Where the wishes of the child conflict with the wishes of those who have the right to care for the child, the law should require a ruling to be made by the Family Court;

4. An intersex person and their parent/guardians must be provided complete information on all options for treatment, including no treatment, and must be given a reasonable amount of time in which to weigh those options and make a decision;

5. Comprehensive documentation of all treatment options and measures must be taken and retained for a minimum period of 40 years, with a right of access for the intersex person;

6. A fund should be established to provide relief and assistance to intersex persons for both current treatment (such as hormone therapy) and long term effects on their quality of life;

7. The law should be amended to provide for intersex persons to register as ‘female’, ‘male’ or ‘other’ once they have reached an age whereby they are capable of making the decision for themselves.
Following the release of this report, in 2013 Germany became the first European nation to allow babies with characteristics of both sexes to be registered as indeterminate gender on birth certificates. In this respect, on 31st January 2013, the Deutscher Bundestag (German Federal Parliament) amended section 22 of the PStG to include a new subsection (3), which now provides that “[i]f the child can be assigned to neither the female nor the male sex, then the child has to be entered into the register of births without such a specification.” Further, in a famous case on the intersex (Re: Volling) the majority of the Constitutional Court acknowledged the submission of the German Society for Psychology’s statement that an “assumption that a person’s gender can only be male or female is neither psychologically nor biologically and sexually sound.”

2.3.2 Switzerland

2.3.2.1 Informed Consent and Recognition/Documentation

The Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) in a 2012 opinion recommends that any irreversible sex assignment treatment should be deferred until “the person to be treated can decide for him/herself”, so long as no urgent intervention was necessary. In the NEK-CNE's opinion, children reach decision-making capacity between the ages of 10-14, but should nevertheless participate in decision-making even before they have attained full capacity, and parents should never be allowed to veto a child’s decision if that child can understand the purpose, appropriateness and effects of surgery.

2.3.2.2 Corrective Surgeries

The United Nations Committee Against Torture in its concluding observations on Switzerland’s periodic report welcomed the NEK-CNE’s recommendations as outlined above. In its concluding observations on the State party report, the CRC urged Switzerland to,

“[i]n line with the recommendations of the National Advisory Commission on Biomedical Ethics on ethical issues relating to intersexuality, ensure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to the children concerned, and provide families with intersex children with adequate counselling and support.”

24GEC Opinion, supra note 82 at 118.
25See ibid. at 163-167.
Finally, in its November 2016 concluding observations on Switzerland’s report, the UN Committee on the Elimination of Discrimination Against Women (CEDAW) welcomed Switzerland’s introduction of measures to combat intersex genital mutilation, but further urged the country to combat involuntary and medically unnecessary and disfiguring surgical procedures especially on intersex babies and children. Finally, the Committee recommended that intersex persons be included in national surveys and registers in order to address disparities in local access to health services for this vulnerable group.

2.3.3 France

2.3.3.1 Principal Directions

In France, the Women’s Rights and Equal Opportunities for Women and Men Committee of the Senate released a report entitled Variations in Sexual Development: lifting a taboo, combating stigma and exclusions in February 2017. The report’s recommendations include: the need to refrain from using terms that pathologise and therefore “unnecessarily stigmatises” the intersex status; amend the law to extend the period within which births must be registered and birth certificates issued, and provide for changes of sex registration to be made easily; collecting accurate, scientifically based statistics on intersex persons; creation of a dedicated fund for compensation of persons who have suffered the consequences of corrective surgeries; training of medical professionals and development of a protocol for the treatment of variations in sexual development, and; raising awareness on the difficulties experienced by those affected by variations in sexual development, in order to break taboos and to prevent exclusion and marginalisation.

2.4 The African Human Rights Framework

2.4.1 Overview and Key Provisions

- The African Charter on Human and Peoples’ Rights (ratified by Kenya on 23 January 1992) safeguards all people against discrimination and sets out the right to equal treatment and protection before the law for all individuals and inviolability of a person’s physical integrity. In addition, Article 5 states that human dignity is inherent and that every individual is entitled to recognition of his [their] legal status.

31Ibid. at paras. 38(c) and 39(c).
• The African Charter on the Rights and Welfare of the Child (ACRWC) commits member states to the protection of all children against discrimination, child abuse and torture, harmful social and cultural practices and sexual exploitation among others. A child is defined as a human being below the age of eighteen.

• The African Commission on Human and Peoples’ Rights Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and Peoples’ Rights guidelines explicitly recognise intersex people as a vulnerable and disadvantaged group of people, who face or continue to face significant impediments to their enjoyment of economic, social and cultural rights.

• A panel discussion: ‘Intersex human rights: Challenges and opportunities’ convened in Banjul, the Gambia on the sidelines of the 61st Ordinary Session of the African Commission on Human and Peoples’ Rights noted that:

“Intersex persons in Africa continue to face human rights violations which include non-consensual medically unnecessary genital normalising surgeries and genital mutilation on minors; infanticide and baby abandoning; lack of appropriate legal recognition and administrative processes allowing intersex persons 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.”

2.4.2 Comparative African Practices

South Africa, Zimbabwe, Kenya and Uganda are the only African countries that have made attempts to explicitly recognise the existence of intersex persons within their societies, while Zimbabwe’s Constitution indirectly underscores the need for consent in medical procedures generally. In South Africa, the Promotion of Equality and Prevention of Unfair Discrimination Act (2000) provides a broad categorisation of grounds for non-discrimination and, as amended by the Judicial Matters Amendments Act, 2005, includes a definition of intersex and the provision that sex shall include intersex. The Act defines

"rapport d’information fait au nom de la délégation aux droits des femmes et à l’égalité des chances entre les hommes et les femmes sur les variations du développement sexuel : lever un tabou, lutter contre la stigmatisation et les exclusions par Mmes Maryvonne Blondin et Corinne Bouchoux, Sénatrices (Enregistré à la Présidence du Sénat le 23 février 2017), online: <https://www.senat.fr/rap/r16-441/r16-441-syn.pdf> (accessed 18th October 2017) [note: translated from French using Google Translate].

33Ibid. (recommendation 1)
36Article 2
37Ibid. at 8 (para. 1(e)).
intersex as “a congenital sexual differentiation which is atypical to whatever degree.” The Alteration of Sex Description and Sex Status (ASDSS) Act (2003) similarly provides for the alteration of the sexual description of individuals in certain circumstances.

While Zimbabwe does not have any laws specific to intersex persons, the Zimbabwean Constitution of 2013 addresses informed consent for medical procedures that apply to all persons, including intersex. With respect to ‘medical treatment for therapeutic purposes’ undertaken to “cure or alleviate any disease or disability”, Article 247 provides that a patient must consent or, if the patient is unable, then consent of a person capable in law of doing so on behalf of the patient must be given. Such consent must comply with the requirements set out in Article 52 and the treatment must be “carried out competently in accordance with recognised medical procedures.”

According to a baseline survey on intersex persons in East Africa (2015), it is estimated that at least two intersex children are born every week in East Africa. Even so, the report notes that it is impossible to get accurate figures due to the stigma and “cultural practice of concealment”. The survey report makes the following recommendations: end Intersex Genital Mutilation, and document other sex- and gender-based violence against intersex persons; include information regarding the intersex in health and social development education, service access and employment policies to prevent harassment, abuse and discrimination; and include intersex in health and human rights initiatives.

---

39 Ibid.
3.0 KENYA LEGAL AND POLICY FRAMEWORK

3.1 Introduction

In Kenya, the legal and human rights framework comprises the Constitution and other statutes. The Constitution of Kenya, 2010 (Part Four, the Bill of Rights) and Article 19 clarifies that the purpose of “recognising and protecting human rights and fundamental freedoms is to preserve the dignity of individuals and communities and to promote social justice and the realisation of the potential of all human beings.” The Constitution is categorical that the rights secured under the Bill of Rights are inherent in every individual and are not given by the State (Article 19(3)(a)). Article 28 provides that, “every person has inherent dignity and the right to have that dignity respected and protected.” This position has been upheld in the Baby ‘A’ Case, which highlighted the need to interpret Article 27(4) as broadly as possible in order to include intersex persons. In the Court’s words:

An inclusive provision is not exhaustive of all the grounds specifically mentioned therein, including sex. That finding will therefore have to mean that intersexuals (sic) ought not to be discriminated against in anyway including in the issuance of registration documents such as a birth certificate. [Emphasis added]

The Report reviewed the current state of sectoral laws within Kenya that are likely to impact directly or indirectly on the rights of intersex persons in Kenya. The specific recommendations for reform in each sector are given in the relevant part of the Report.

3.2 Kenyan Case Law

In Kenya, two cases particularly stand out with regard to the judicial interpretation of the rights of intersex persons. One such case is Richard Muasya v Hon. Attorney General, High Court of Kenya (Nairobi High Court Petition No. 705 of 2007), and the other is Baby ‘A’ (Suing through the Mother E A) & another v Attorney General & 6 others [2014] eKLR (Petition 266 of 2013). Notably, in the RM Case, the cause of action arose prior to the 2010 Constitution and the Court was guided by the repealed Constitution. On the other hand, the Baby A Case was decided post-the 2010 promulgation. This is apparent in the interpretation of the two cases.

41 Ibid at 9.
3.2.1 Richard Muasya v Hon. Attorney General High Court of Kenya 
(Nairobi High Court Petition No. 705 of 2007)

The petitioner ("RM") was born with both male and female genitalia and was given a male name by his parents at birth. Due to his ambiguous genitalia, RM was unable to secure a birth certificate, identity card, or any travel documents. The petitioner dropped out of school at Class 3. He later attempted to marry but could not live with the wife, nor could his attempted marriage be given legal recognition. RM ended up in conflict with the law and was charged with an offence of robbery with violence in Kitui Chief Magistrate Court Criminal Case No.144 of 2005. While RM was in prison remand awaiting determination of his case, he was subjected to the usual statutory search at the prisons. It was realised during the search that he had both male and female genital organs. At a loss as to where to confine RM, prison officers referred the matter to the Kitui Magistrate's Court. The Court ordered that RM be taken to Kitui District Hospital for sex verification. The doctor's report confirmed that the petitioner had ambiguous genitalia.

An order was therefore made for the RM to be remanded at Kitui Police Station during the pendency of his trial. After trial, RM was convicted and sentenced to death for robbery with violence and committed to Kamiti Maximum Prison, which is reserved for male death row convicts. The petitioner was made to share cells, beddings and sanitary facilities with male inmates, and was exposed to constant abuse, mockery and ridicule. RM told the Court that he was also sexually molested by curious male inmates. RM then petitioned the High Court to seek redress for infringement of several rights including the right to dignity, freedom against inhuman treatment, discrimination on grounds of sex, and rights to freedom of association, freedom of movement and right to fair hearing and protection under the law.

In the ruling of 2nd December, 2010, a three judge bench of the High Court (Okwengu, Dulu and Sitati JJ) defined the term ‘intersex’ as “an abnormal condition of varying degrees with regard to the sex constitution of a person” (para. 109), but noted that the Court was not presented with any evidence of the existence of an “identified class or body of persons known as intersex in [Kenya]” (para.112) and therefore the Court was not persuaded that RM could bring a constitutional challenge in the public interest. They determined that RM's ambiguous genitalia did not negate the fact that “his” biological sexual constitution had already been fixed at birth (i.e. male) (para.128).
The Court further ruled that, “an intersex person falls within one of the two categories of male and female gender included in the term sex. To introduce intersex as a third category of gender would be a fallacy” (para. 130), and accordingly, with respect to RM specifically, “the petitioner as an intersex person is adequately covered by the law and has suffered no discrimination or lack of legal recognition” (para.133). The Court did however find that the strip searches RM had been subjected to during incarceration were “cruel and brought ridicule and contempt” and as a result constituted inhuman and degrading treatment in violation of the constitution (paras.167-168). The Court made the following statement in (para.145):

“...Few seem to appreciate the fact that the issue of gender definition for an intersex person, unlike a transsexual or a homosexual, is a matter of necessity and not choice. Tolerance and acceptance in this area will come with dissemination of appropriate information ...” [Emphasis added]

3.2.2 Baby ‘A’ (Suing through the Mother E A) & another v Attorney General & 6 others [2014], eKLR (Petition 266 of 2013)

This case was brought pursuant to the CoK, 2010 and in particular the fundamental rights and freedoms in the Bill of Rights. Baby A was born with both male and female genitalia. Hospital records indicated the baby's sex by a question mark and as a result, the child could not be issued a birth certificate or, concomitantly, an identity card (para.1). The petition alleged that this offends the child's rights to legal recognition, erodes its dignity and violates the right of the child not to be subjected to inhuman and degrading treatment as guaranteed in both the CoK, 2010, and the Children Act (para.1). In a progressive move away from the RM Case, the High Court (Lenaola J.) in Baby A case opined that Article 27(4) of the CoK, 2010 is an,

“... inclusive provision [that] is not exhaustive of all the grounds specifically mentioned therein, including sex. That finding will therefore have to mean that intersex persons ought not to be discriminated against in any way including in the issuance of registration documents such as a birth certificate.” (para.61)

Similar to the RM Case, the High Court however left the specific addition of a third category of sex up to the legislature (para. 62). The Judge noted that he was not presented with any evidence upon which he could make a finding that Baby A was specifically subjected to discrimination on the basis of intersex
status (para.63). That notwithstanding, the Court made a note that there is “clear evidence that there is an urgent need to address the plight of intersex persons,” including “an obvious lack of appropriate guidelines and regulations on how medical examinations and eventual corrective surgery, if needed, would be carried out” (para.65). Accordingly, The High Court directed the government to consider developing an appropriate legal framework governing issues related to intersex children:

“[T]here is currently no legal framework on intersex persons or any policies in place for them. It is the duty of the State to protect children born as intersexuals by providing a legal framework to govern issues such as their registration under the Births and Deaths Registration Act, examinations and tests by doctors, corrective surgeries, etc. It is on this basis that it behoves upon me to direct the Government towards an appropriate legal framework governing issues related to intersex children based on internationally acceptable guidelines. These guidelines would inform those minded to carry out medical examinations and corrective surgeries on intersex persons of the procedures and guidelines to follow so as to act within the law and in line with the best interests of the child. I would therefore strongly urge Parliament to consider enacting legislation in that regard. This in my view ought to be done in close consultation with various interested stakeholders ... in recognition of the principle of public participation.” (Para.67)

Further, the High Court urged the government to consider the issue of collecting data relating to intersex persons with a view to designing policies to protect them as a marginalised group in society (para.68). It is pursuant to this Court's ruling that the Hon. Attorney-General constituted the Taskforce on Policy, Legal, Institutional and Administrative Reforms Regarding Intersex Persons in Kenya. The above two cases are evident of the jurisprudential milestones that the country has made with regard to the recognition and protection of the intersex persons. The Taskforce is optimistic that, a decade after the RM Case, the full recognition and protection of the rights of intersex persons has gained momentum and will be realised sooner rather than later.
4.0 NUMBERS, DISTRIBUTION AND CHALLENGES OF INTERSEX PERSONS IN KENYA

4.1 Introduction

Based on Kenya’s population of 45.9 million (KNBS Statistical Abstract, 2017) the number of intersex persons in Kenya was estimated at 779,414 using the upper limit of 1.7% of the population as per the UN guideline, which approximates the population of intersex persons at 0.05-1.7% of global births. To help develop specific statistics for the country, the Taskforce commissioned a field survey to establish their present status in Kenya. Based on the nature of the target population and the stigma surrounding the intersex conversation, the study applied the non-probability sampling technique, Snowball Sampling, which yielded a study sample through referrals. To compliment data from the Key Informant Interviews, the survey reached out to various institutions across the country through purposive sampling using the following categories: Professional Regulatory Officers; National Government Administrative Offices; County Government Offices; Ministry of Labour and Social Protection; National Police Service; Correctional Facilities; Health Facilities; Educational Institutions; Religious Institutions, and; Civil Society Organisations. Wananchi were reached through by random sampling using online and face-to-face questionnaires.

4.2 Findings

• 16.3% of respondents had no/not completed any formal education, 4.1% had attained university (undergraduate) education, while 3.1% of them had garnered various levels of technical education. These low levels of education and low transition rates among the intersex can be attributed to, among others, the presence of systematic biases in the population as well as in key institutions of society such as the educational system.

• The majority (77%) of intersex persons are in the youth category (ages 18-35). Nearly all the adult intersex persons interviewed (90%) were either in secondary (36%), primary (23%) or had never completed any level of formal education (31%). Only 10% of the adult intersex sampled had attained college or university education. Thus, many intersex people may drop out of school much earlier due to negative
peer pressure and societal stereotyping: they find no place to belong as they can neither fit in the boys’ or girls’ schools, and there are no dedicated intersex educational facilities in Kenya.

- Most key informants (71%) became aware of the intersex status of their children at birth and/or during the early days of childhood; 23% of them discovered it at puberty/teenage, while 6% of them realised it in adulthood. This bears out the Taskforce’s definition of the intersex, which argues that the intersex status, “...can become apparent prior to, at birth, in childhood, puberty or adulthood.”

- Self-cognition or awareness of intersex status by the intersex also came at various times in their lives. In all cases encountered, the respondents admitted to being confused and not clearly understanding the intersex status and its causes, with many relating it to a curse or a punishment for some sins committed either by them or their parents/forefathers. During such times, as indeed throughout their life, non-judgmental community perceptions and attitudes, psychosocial support, and overall facilitation through the legal, educational and vocational systems is critical in helping them adjust and settle down as productive adults and citizens.

- The common belief and feeling patterns shared by the parents/caregivers include: thoughts and regrets, blaming birth of the intersex child on a curse or a taboo broken; family break-up or abandonment of the mother by the husband and their relatives, seeing her accursed; resort to traditional healers, priests and herbalists, many of whom may prescribe various ‘purification’ rituals or downright infanticide. Others may seek help from various medical facilities, where the intersex may run the risk of misdiagnosis and suspect surgical interventions to ‘normalise’ the child. In all this, dedicated psychosocial support, publicly-funded medical aid schemes, multidisciplinary medical support teams, the existence of accessible medical centres of excellence with the right mix of skills and attitudes for handling intersex-related cases, as well as a generally enlightened legal and administrative regime could greatly help.
• 63% of the intersex persons sampled self-identified themselves as male and actively cultivated a male gender, while 20% recognised themselves as female; 5% as of these respondents recognised themselves as intersex and sought to make the best of their lives, while a further 12% were not ready to self-recognise as male/female/intersex. It is important to note that this self-recognition is not always in accord with that of the parent, or even the assigned sex as recorded at birth in the civil registration documents. Where the self-recognised status of the child varies from that of the parents or the assigned status, the law and society must be willing to facilitate readjustment of the affected person in all ways, including through non-bureaucratic procedures for amending birth and other official civil documents.

• 34 (29%) of all the key informants indicated that they/their intersex charges had undergone surgery. Out of this, 30% were happy with the outcomes, 24% were unhappy with the surgical interventions, while 43% did not provide comprehensive feedback on the status of the surgery. In addition, many intersex persons reported feeling that they were treated as “specimens” of curiosity due to too much exposure to the doctors, nurses, student interns, who often posed many unnecessary, intrusive and embarrassing questions. Thus, there is need for systematic reform of the healthcare sector to better take care of the needs of the intersex, including through identification and operationalisation of intersex centres of excellence in the Level 5 and Level 6 hospitals across the country.

• Parents and caregivers who had their children undergo corrective surgeries reported having mixed feelings on the decision to have surgery, the procedures and the outcomes thereof. Some felt that medical intervention had to be done urgently when the child is young in order to ‘fix’ the sex of the child and thus ‘normalise’ them into the accepted binary of male/female. Others felt all non-emergency surgeries should wait until the child is of age. There is need for sensitisation on the concept of ‘the best interest of the child’ among all segments of the population.

• Presently, most of the diagnostic and therapeutic interventions related to the intersex persons in Kenya are carried out at a few
leading hospitals clustered around the major cities of Kenya. These are: Kenyatta National Hospital; Moi Teaching & Referral Hospital; Jaramogi Oginga Odinga Teaching & Referral Hospital; Wajir County Referral Hospital; the Agha Khan Hospital; Kijabe Mission Hospital; St. Mary’s Hospital in Langata, Nairobi; and Gertrude’s Children’s Hospital.

- On access to education, school teachers and administrators, as role models, can help to recognise, facilitate, promote and affirm the status and rights of the intersex in the school environment. Thus, there is an urgent need to re-examine all facets of the educational system as presently constituted to remove all stigmatising and problematic statutes, rules and procedures, and to replace these with progressive alternatives that better recognise, support and promote the diversity of the Kenyan population.

- On legal recognition and documentation of intersex persons, 44% of Key Informants ranked their access to key civil documents as generally good, 45% found them poor, while 15% did not express a clear opinion on the matter. This points to the need for legal, policy and administrative reforms to institute more flexible and friendly processes for the intersex to both acquire and change their particulars in all civil registration documents.

- On employment, a majority (57%) of intersex persons and their parents/caregivers expressed dissatisfaction with access to employment opportunities. This suggests the need for reforms to equalise the employment space and to remove any lingering cultural and social biases and other systematic impediments that render the intersex uncompetitive.

- On access to institutions for administration of justice, intersex people find themselves exposed to intrusive and unnecessary searches and placed in mixed remand with other male and female inmates, exposing them to sexual harassment and other dangers. Therefore, there is a clear case for the reform of the prison and remand system, all the way from admission through search and registration, to assignment in specific prisons with appropriate intersex-friendly facilities, the training of at least some key personnel in each such
facility in the handling of intersex persons, and consideration where possible, of preferring non-custodial sentences for intersex persons, among other measures.

- **societal/customary/religious awareness challenges** facing intersex persons in Kenya, these primarily emanate from low public awareness levels and unenlightened religious and customary beliefs and practices. These findings corroborate the concern about the role of backward religious beliefs and practices in contributing to the plight of the intersex in Kenya. Thus, religious and faith-based organisations must be specifically engaged and reached with approved intersex-friendly messages.

- The study found the highest levels of professional awareness among government officers (72%), and the lowest among religious and faith-based institutions at only 6%. This gap can be bridged through targeted IEC materials and advocacy. The role of professional societies in this effort could be crucial.

- 94% of respondents from the Mwananchi questionnaire survey (both online and face to face) expressed their feeling that intersex children were a taboo, a curse on their parents and community and not ‘normal’. Such widespread ignorance and mistaken beliefs suggest the need for a comprehensive and systematic public awareness campaign in partnership with key institutions and stakeholders.

- The majority of respondents (51%) reported their source of information on intersex persons and their related issues as the media; 36% got their information from the surrounding community/society, while only 13% had encountered intersex persons and learnt firsthand from them. These findings indicate the vital role played by the mass media in shaping public perceptions and attitudes about a myriad of issues in society, including on the treatment and perception of minorities and the marginalised such as the intersex. Any solution must thus have a robust media component to help drive the behaviour and culture change required to bring effective improvement in the lot of the intersex and other marginalised segments of the population in Kenya.
5.0 RECOMMENDATIONS

5.1 Introduction

- In view of the status (number, distribution and challenges) of intersex persons in Kenya; taking into account the lessons and milestones gleaned from a comparative analysis of international, regional, and selected States’ approaches to the care, treatment and protection of intersex persons, and arising from an analysis of the policy, legal, medical, administrative and institutional frameworks governing structures and systems with regard to intersex persons in Kenya, the Taskforce identified and puts forward the following thematic reforms:

5.2 Recommendations

5.2.1 RECOGNITION

- 1. The Legislature in consultation with stakeholders to facilitate recognition of intersex persons in the law. This could be realised through the introduction of an Intersex (I) marker in all official documents that require identification of sex. This will involve amendment and introduction of a comprehensive definition of who an intersex person is:

"Intersex" means a person who is conceived and born with a biological sex characteristic that cannot be exclusively categorised in the common binary of female or male due to their inherent and mixed anatomical, hormonal, gonadal (ovaries and testes) or chromosomal (X and Y) patterns, which could be apparent prior to, at birth, in childhood, puberty or adulthood.

5.2.2 DOCUMENTATION

- 2. Effecting expeditious provision of birth certificates, identification documents, passports and other official personal documentation by including provisions for the intersex (I) marker. This should include flexible legislative and administrative procedures for amending sex markers in official documents and correcting the original official documentation.
5.2.3 CRIMINAL JUSTICE SECTOR

3. The Legislature to facilitate review of laws to ensure equal treatment, respect and protection of the dignity of intersex persons within the criminal justice sector.

5.2.4 PUBLIC HEALTH

4. The Ministry of Health in consultation with relevant agencies to formulate specialised programmes to provide for intersex persons’ care and protection in health facilities to facilitate their access to the highest attainable standard of health.

5. Surgical and hormonal interventions for children in relation to their intersex status should only be carried out in case of medical emergency based on informed consent. The Director of Medical Services in consultation with the relevant regulatory body (Kenya Medical Practitioners and Dentists Board, KMPDB) to develop a protocol on surgical and hormonal interventions that constitute medical emergencies.

6. The Ministry of Health to work with other regulatory agencies towards the protection against involuntary medical intervention and ensure effective remedy for persons otherwise affected.

7. The Ministry of Health in consultation with the KMPDB to formulate a harmonised and comprehensive treatment guideline focusing on a child- and human rights-based approach for the medical care and protection of intersex children.

8. The State to establish a fund to cater for all medical-related interventions for intersex persons due to the high cost implications of specialised intersex medical care. The State to give a free/subsidised medical insurance health cover under the NHIF or any other scheme for intersex persons.

5.2.5 EDUCATION AND AWARENESS

9. Roll out awareness and sensitisation initiatives. This will be carried out through: Promotion of continuous and targeted awareness to the general public and all stakeholders to combat stigma and promote societal acceptance, and; review of the education curriculum in
primary, secondary and tertiary education institutions with the aim of recognising and infusing specific training in the syllabuses and training modules on sex development and categories.

5.2.6 STATISTICAL DATA

10. Collection of accurate and verifiable statistics on intersex persons. This will be achieved through: Kenya National Bureau of Statistics, the principal government agency for collecting, analysing and disseminating statistical data to include intersex as a third sex code/category. And inclusion of intersex (code 3) in the Kenya Population Housing Census scheduled for August, 2019.

5.2.7 SOCIAL, ECONOMIC AND LEGAL PROTECTION

11. Development and review of social protection mechanisms to ensure realisation of social, economic and legal protections for intersex persons and safeguarding against violations on the basis of their 'I' marker. This will be achieved through formulation of special protection mechanisms by State agencies to monitor violations of the enjoyment and realisation of human rights on the basis of a sex marker 'I'.
REPORT OF THE TASKFORCE ON POLICY, LEGAL, INSTITUTIONAL AND ADMINISTRATIVE REFORMS REGARDING THE INTERSEX PERSONS IN KENYA

NAIROBI // DECEMBER, 2018