



**UGANDA REPORT OF VIOLATIONS  
TO CHILDREN AND PEOPLE BORN  
INTERSEX OR  
WITH DIFFERENCES OF SEX  
DEVELOPMENT**

**— AUGUST 2015 —**

A PUBLICATION OF SUPPORT INITIATIVE FOR PEOPLE WITH  
A PUBLICATION OF SUPPORT INITIATIVE FOR PEOPLE WITH CONGENITAL DISORDERS (SIPD -UGANDA)

# Table of Contents

<b>Glossary</b> .....	<b>3</b>
<b>List of acronyms</b> .....	<b>4</b>
<b>Acknowledgements</b> .....	<b>4</b>
<b>Introduction</b> .....	<b>5</b>
<b>Methodology</b> .....	<b>7</b>
<b>Analysis: Human Rights Violations in Uganda of children and people with DSDs</b> ..	<b>8</b>
a) Surgery without consent.....	8
b) Violation of the rights to non discrimination at school.....	9
c) Violation of a child’s rights to a family (Abandonment).....	10
d) Violation of the right to health (Prejudice and stigma when seeking health services).....	11
e) Family and community discrimination.....	11
f) Lack of legal protection.....	12
<b>Recommendations</b> .....	<b>13</b>
1. To government through the Ministry of Health (MoH).....	13
2. To parents.....	15
3. To Religious Leaders.....	15
4. To Uganda Parliament.....	15
5. To the Ministry of Education and Sports (MoES).....	15
6. To the Uganda Human Rights Commission (UHRC) and other Civil Society Organisations (CSOs).....	1

# Glossary

- **Intersex /DSDs:** Intersex can be looked at as a condition in which a person is born with a reproductive or sexual anatomy that does not fit the typical definitions of female or male or a person born with genitals that lie between male and female.

Medically referred to as Disorders of Sex Development, “Intersex” is a general term for being physically or physiologically “between male and female”. Intersex people are born with a sex differentiation that makes the anatomy of their bodies atypical and their sex classification indeterminate. For many, it’s at the chromosomal level, others at the hormonal level and for the most obvious ones it’s at the genital level.

- **Intersexphobia:** It’s an irrational fear of, aversion to, or discrimination against intersex people.
- **Best Guess Surgical Strategy:** This involves using genetic tests and historical case studies in order to determine what gender (girl or boy) an intersex child will most likely feel most comfortable in. This strategy usually also involves a tape measure test of the infant’s genitals and once the tests are performed doctors choose a gender for the intersex child to be raised in and

then surgery is performed on the intersex infant’s external genitalia to make it physically look either male or female.

- **Best Guess Non Surgical strategy:** This involves using genetic tests and historical data studies in order to determine what gender (girl or boy) an intersex child will most likely feel most comfortable in. The intersex child is then raised in that gender with the understanding that the intersex person may choose a different gender at another point of their life possibly during teenage years. This goes hand in hand with counseling and education for both the family and the intersex person to better understand and deal with the social, cultural and the legal issues related to intersexuality.
- **Sex:** Either of the two main categories (male and female) into which humans and many other living things are divided on the basis of their reproductive functions.
- **Sex Determination:** This is the sex classification or assignment of male or female done either at birth or later on in life.
- **Sexual and Reproductive Health and Rights (SRHR):** Sexual and reproductive health is an integral part of health and it is a personal sense of sexual well being as well as the absence of disease, infections or illness associated with sexual and reproductive activity. As such it includes issues of self esteem, self expression, caring for others and being cared for as well as a feeling of belonging

attached to cultural and social values and associations. Sexual and reproductive health therefore can be described as the positive integration of physical, emotional, intellectual and social aspects of sexuality. Sexuality influences feelings, thoughts, interactions and actions within the self and between the self and community. Our sexuality is part of what motivates us to seek and find pleasure in our body make up, physical contact, emotional and intimate relations, as well as reproduction.

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## LIST OF ACRONYMS

**SIPD:** Support Initiative for People with Congenital Disorders

**HRAPF:** Human Rights Awareness and Promotion Forum

**UHRC:** Uganda Human Rights Commission

**CSOs:** Civil Society organisations

**MoH:** Ministry of Health

**ICESCR:** International Covenant on Economic, Social and Cultural Rights

**DSD:** Differences of Sex Development

# Introduction

**T**he impulsion behind the Uganda report of violations of children and people born with Differences or Disorders of Sex Development (DSDs) is to demonstrate that children and people born with DSDs are greatly affected and discriminated in Uganda compared to other groups and to show the different gaps within the service prerequisite for this particular constituency. This report will be used to educate the general public, religious leaders, Members of Parliament, Ministry of Health (MoH) officials, and the medical fraternity in Uganda, Civil Society, Ministry of Education and Sports (MOES), the international Community as well as informing policies and policy makers on the best ways and practices on how to come up with tools and guidelines that can help integrate children and people born with DSDs in all the development policies and programs of their country.

More so, this report will illustrate cases of lived realities of intersex children and people in Uganda as there have been sections of communities in recent years who have tried to reproof intersex people as a population haunted by witchcraft and whose redemption lies in the same and they have succeeded in doing this using culture, religion and morality. It should be noted that Intersex people perhaps more than any other groups in society are

more prone to manipulations, blackmail, and criminal tendencies, - whether these are directed towards the self (suicide) or at others (as a way of retaliating against society). All of these result in major mental health and sexual violence issues. In fact, the violation of intersex people's rights has led to spiritual, emotional shame and embarrassment.

Intersex or what is medically referred to as Disorders of Sex Development is a general term for being physically or physiologically "between male and female". It should be clearly noted that, intersex people are born with a sex differentiation which makes the anatomy of their bodies atypical and their sexual identity indistinct. For many it's at the chromosomal level, others at the hormonal level and for the most obvious ones is at the genital level. With children born this way, it is usually difficult for delivery personnel – whether midwives, doctors, or traditional birth attendants to determine just by looking at the child whether it is a male or female child.

Most intersex children and people are assigned a female sex at birth and raised to identify as women. However, female biological milestones, such as menses, breast development, and body phenotypically development do not conform to the assigned sex. Instead, androgen – driven milestones – which should occur in males start to manifest, such a beard growth, voice deepening, and body hair growth. These developments are not only a source of immense inner trauma but also a huge attraction for external ridicule and stigma. These often lead to suicidal tendencies, school drop-out, and criminal tendencies.

Inopportunistly in Uganda, when an intersex child is born, the family treats the birth as

a secret and will isolate the child from the general public. In most cases the mother of such a child will be frowned upon and usually superstitions loom large as families consult witchdoctors, mediums and traditional healers for a solution. In many instances, the mother will work with either a traditional medicine practitioner or some other ally to kill the child. The approach that is used by the “elite” is a concealment approach where an intersex child will be hidden and “offered” up for surgery without conclusive and required tests to warrant such surgeries and without proper surgical or psycho-social support facilities. To make the matters worse, in some cultures children with DSDs are never allowed to grow up to be adults. Most mothers of children with DSDs abandon them for dead in pit latrines and deadly forest areas and run away from their homes for fear of possible prejudices from family and in-laws. In fact, intersex may be as common as cystic fibrosis but it is less much spoken about perhaps because sex and gender tend to be considered such fundamental parts of our identity that people are sometimes reluctant to discuss cases where sex is unclear.

While this is totally a genetic and sexual and reproductive health condition, it is not treated as such by both medical personnel and society. It is rather treated a shame and a taboo. As a result, the occurrences of such births and clinical encounters have not yet been recognised by the Ministry of Health because these reports are never documented or communicated from the medical and delivery facilities. There is consequently no intervention policy targeting this population. The violations of the rights of intersex people in Uganda are within almost all walks of life starting from home, schools, health centers and the most worrying scenario is that even the

law in Uganda **discriminates** against them as exemplified by the Registration of Births and Deaths Act, which under **Cap 309** has a provision that restricts people above 21 years of age to change the sex details in the Births Register.

This report seeks to bring to the attention of the Ministry of Health the realities of sex development irregularities and the huge inequities that exist in service provision and information availability to individuals concerned, parents of such children, healthcare practitioners, institutions of learning, and the general public. It generally recommends that the Ministry of Health and the Ministry of Gender, Labour, and Social Development should ensure that there is a Gender harmonisation policy, for the inclusion of children and people with intersex conditions (Disorders of Sex Development) in the national healthcare implementation plan. Such a policy will mean that healthcare practitioners at all levels will work with intersex children and people in an intentional and mutually supportive way that challenges sex and gender norms, catalyses the achievement of gender equality, and improves health.

In Uganda enormous resources from government and international partners have been and are still being put to so many health programs like Malaria and HIV prevention and treatment etc. However, gender is still a key social determinant of inequalities in accessing some of these programs due to lack of appropriate health care, information, and referral services for intersex children and people. For instance by the production of this report, in Uganda there is nothing like a laboratory that makes chromosomal tests for children and people who may need this determinant.

Since sexuality and sexual and reproductive

health is a central aspect of being human throughout life – encompassing sex development in utero, sex determination at birth, gender identities and roles, secondary sex characteristics, intimacy and reproduction – intersexuality needs to be addressed as a critical sexual and reproductive health and rights issue by developing a policy framework that enables research, planning, and programming for this population and this will help to curb down many of the violations facing this population since human dignity for children and people with DSDs in Uganda has not been considered at all.

# Methodology

**T**he research team employed a qualitative approach to collect, analyse and document information for the report. The different qualitative methods of data collection used are discussed as follows: Data used to formulate this report has been collected through the different outreaches done by SIPD. Data was obtained through both primary and secondary sources. The most common sources used to collect data for this report were: media review and personal interviews with intersex youth, intersex adults, service providers, parents, guardians, and civic and religious leaders in 25 districts where SIPD already does outreach and has field based point persons. Some of the data used in the report had been collected over a long period through interactions between SIPD and intersex persons that we serve.

# Findings and analysis: Human Rights Violations in Uganda of children and people with DSDs

the mother was left with the responsibility of looking after her children and this was worsened by the triple role burden of women. In a bid to look for the family support, the mother took the child to hospital for a surgical operation. The operation was not a success as doctors tried to create a penis

## a) **Surgery without consent**

In the case of some intersex people, surgical interventions gone wrong have had cascading consequences that have led to rights violations, including interference with the children's social life.

Some of these surgeries are done without proper or any consent, as usually the parents are driven by fear and they leave the decision in the hands of the medical doctors.

We recorded 22 cases of surgery without consent. An example is the case of a child born in Tororo with a penile agenesis, (born without a penis), this child had a non-consensual surgical operation where the mother was so frightened by the child's case. The mother was always threatened by the husband as he could always blame her for giving birth to such a child. Finally the husband left the family and

for the little boy and after three months the penis fell off yet a lot of money had been spent on this little boy. The current situation for this boy is worrying as he is now oozing pus and his life is in peril. The conditions under which the consent for the surgery was given were not conducive for her to make an informed decision.

In this case therefore, the child's right of making an informed decision is totally denied since many of these discussions are held when the child is still young and can't be part and parcel of the decision making processes. While Ugandan law has a procedure for parents consenting for children, and it is usually okay for them to do so, it is critical to ensure that parents are in an objective and informed state of mind at the time. As a result of our findings, SIPD encourages non-



surgical alternatives to addressing intersex conditions among infants.

It should be noted that there are many cases of medical mal-practice towards intersex children in Uganda, which remain undocumented and this is just because many parents hardly understand that early unnecessary surgeries constitute a violation of a child's right since it denies them to be part and parcel of a decision that determines their gender. We found out that this violation is driven by the enormous pressure from mostly family in-laws who need a concrete answer of whether the new born is male or female for celebrations to start. They mind less of the emotional and physical irreversible scars that are left on the child.

*Photograph showing a photo of a child who had unconsensual surgery/operation*



*Source: Field data*

In Uganda SIPD advocates for the “Best Guess Non-Surgical Strategy” as contrasted to the “Best Guess surgical strategy” because the non-surgical option gives room to the intersex child to be part and to participate actively in all or most of the decisions regarding his/her body. This option is also accompanied by counseling and

education for both the parents and the intersex person in order to better comprehend the social, cultural and legal issues related to intersexuality/disorders of sex development in Uganda.

**b) Violation of the right to non-discrimination at school**

Many children in Uganda have dropped out of schools due the mounting sense of shame and the increasing discrimination in schools as far as their sex is concerned.

SIPD has reports of 34 intersex school drop outs as a result of discrimination and stigma. Different intersex children experience different sexual development milestones as they grow up which don't correspond with the gender that they identify with. Therefore, due to the intense pressure in schools, these children find it hard staying in school.

For example a child in Kabale who had ovaries, a uterus and also experienced menses was raised as a girl for the first ten years of life; but as his body took on male gender attributes with the onset of adolescence he was abandoned by his family. In a bid to live in this hostile environment, he built himself a grass xatched house to live in and was able to pay for his upkeep and his school fees, but when menses begun, this child had to drop out of school as he was always bullied by fellow students as they had never seen a boy menstruating.



Source: Field data 2014

The teenager in the photograph above has faced discrimination at school and he has kept on changing schools due to the overwhelming questions regarding his identity by fellow students. In his own words, ***“I think I am not human, many times I feel like killing myself. I always ask myself why I was born like this. Many people have tried to explain to me why this could have happened but still I am mystified. I think I should die and get rid of these questions that keep on coming to my mind.*”**

c) **Violation to a child’s right to family (Abandonment)**

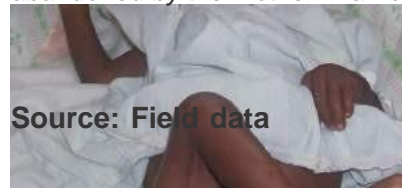
Intersex conditions are a health problem, which has a major impact on humanity and their wellbeing but has been given very little sensitisation. According to our reference doctors in Mulago National Referral Hospital) at least three children are born with a disorder of sex development condition every week. It should also be noted that these are the noticeable conditions but what of those that are born with these conditions that can not be seen shortly after birth? There are those ones whose conditions can be seen later in life i.e. sex development milestones may occur

and they compromise the gender that was assigned at birth. However, the shame and failure to find the right answers to the many questions parents ask after getting such a child has cost lives of many children.

We received 51 cases of abandonment. Some of these reports came from orphanages that are part of the Children at Risk Action Network, others from media review, and others from direct contact by traditional birth attendants, hospital staff, and community members. An example is a child born with a DSD condition known as Androgen Insensitivity Syndrome (AIS) in Kampala 1997 was abandoned by the father as he argued that this was a bad omen that was supposed to be away from the rest of the family. He also sent away the mother such that the evil spirit can follow them and live the family alone. This child because of her condition was raised as a girl but at 17 she felt was not a girl. Biologically, she had a male sex chromosome pattern and she always felt like a boy. She had surgery at one hospital in Kampala and by the time this report has been compiled he is living happily as a boy.

There are 42 reported cases of children who were killed in cleansing rituals owing to their intersex condition – because they were believed to be a curse. We also found out that the standard treatment of intersex infants is killing them shortly after birth. Families are breaking apart. We dealt with couples where the husband is not willing to accept the responsibility to father and intersex child.

*Photograph below showing a child who was abandoned by the mother in a hospital*



Source: Field data

It is critical that the MoH continues working with civil society organizations to come up with clear guidelines on how children and people with DSDs should be treated.

**d) Violation of the right to health (Prejudice and stigma when seeking health services)**

International Human Rights Law affirms the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and proscribes discrimination in access to health care on the grounds of sexual orientation and gender identity.

However, intersexphobic practices and attitudes on the part of health-care providers deter intersex persons in Uganda from seeking services out of concerns around breaches of confidentiality, stigma, and potentially violent reprisals. In fact to avoid possible prejudices from sections of communities, parents of intersex children have adopted a “Best Guess Surgical Strategy” in treating their children and this has left both physical and emotional scars. SIPD recorded 48 such cases. For example a child born in Masaka was cut badly during a surgical procedure to make his external genitalia “match” his presumed gender. The child’s family abandoned him claiming he is too expensive and that they cannot provide him with housing and food. Staff members at the hospital where the boy has been have said it in public that they are tired of this boy because of his endless problems.

**e) Family and community discrimination**

Many families in Uganda for children and people with differences of sex development

have tried to extend enormous support towards this population but they have also taken it upon themselves to determine sex of their children and thus therefore enforced gender norms and punished indiscretions. As a result many children with disorders of sex development find themselves excluded from family homes and this has accelerated intersex-phobia in Uganda where many of these violations have been caused by the immediate family members. In fact, instead of extending support to these families they end up ill advising the parents thus misleading them into harsh decisions to their children who have at times even killed them.

For many intersex persons in Uganda, social exclusion begins at birth, as exemplified by the story of a child who was born with ambiguous genitalia in Rakai district which is amongst the 50 districts where SIPD has put emphasis. The child’s mother was forced to leave the family home because family members thought the child was an omen and would bring bad luck to the family. Before telling the mother to take her child and leave, some relatives physically attacked her for giving birth to an intersex child. Having been forced from her home, the mother now has no land to grow food and has no financial means to afford food.

*Photograph of an intersex child who has been greatly discriminated by family and community*



*Source: Field data*

The above child has been greatly discriminated due to his/her confusing sex determination as she was raised as a girl but after several tests by medical doctors, she is said to be a boy. Intense discrimination emanated from here and some people in the community are seeing her as abnormal.

f) **Lack of legal protection**

The Ugandan constitution under the Registration of births and change of name/sex vis a - vis people with DSDs

The Births and Deaths Registration Act Cap 309 provides the framework for registration of births and deaths as well as change of names and sex. Births are supposed to be registered within three months of the date of birth of a live child. This condition provision requires all children to be registered and therefore, it doesn't leave out anyone including those children with DSDs.

It is also important to note that under this law, if a child after being registered either through an operation or otherwise, changes from a female to male or from a male to a female and the change is certified by a medical doctor, the Registrar of the Births and Deaths registration district in which the birth is registered shall, with the approval of the registrar general and on the application of the parent or guardian of that child alters the particulars of the child which appear on the birth register. This provision only applies to children and therefore it is also important to children who are intersex and whose sex was difficult to determine at birth.

For change of name, the parents or guardian of any child under the age of 21 years may apply in the prescribed form to the Registrar of the Births and Deaths Registration district in which the birth of a child is registered to change the name of

the child. We totally agree that this is a very important avenue for children with DSDs conditions/intersex to have their names legally changed when their sex changes.

The concern here is that this law does not give room to someone who is above twenty-one years of age to change their sex and this is a threat to many intersex people in Uganda. What will happen in case someone has been diagnosed with an intersex condition that needs sex-reassignment but this person is above twenty-one years of age? Policy advocacy is very much needed here such that these laws can be changed in order to favour all children and people in Uganda.

Conclusively, many children and people in Uganda particularly children are still being hidden by their parents with fear of being scorned by the community. In some cases children under go repeated surgeries/operations and others are taking hormonal treatments without even knowing why this is happening to their lives. This continuous secrecy surrounding intersex means that some people look at this as shameful. They may therefore find it difficult or impossible to talk to others about their condition and as a result may be fearful of forming intimate personal relationships. There is also fear of the way other people would respond if they knew about their intersex condition reason being intersex has been frequently confused with homosexuality in the public imagination.

Unless people with DSDs come out to talk about their lived realities and fight for their rights, violations of their rights and fundamental concerns in all spheres of life will not stop as religion, culture and moral fundamentalisms have been used by sections of societies to reproof intersex people and their existence.

# Recommendations

**D**ifferent stakeholders have different roles to play in the struggle to make sure those children and people in Uganda with DSDs are treated equally and that their rights are upheld. With Uganda's population now estimated at 35 million people, the government has to make sure that service delivery all in all sectors and for all people is improved for sustainable development of our country.

## To the Ministry of Health (MoH)

The government through the Ministry of Health (MoH) needs to do the following:

- a) Set up a central registry where these children can be registered once born to ease healthcare, social and legal support later on in their lives. This should include a policy to enable a gender neutral marker on their birth certificates, to ease change of sex, if necessary, when the child is old enough to be an active participant in this decision.
- b) This policy should apply whether children are born in hospitals or at the hands of traditional birth attendants. (*Respect for the views of the child (Article 12 of the UN*

*convention on the rights of the child: - "When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account")*

- c) Avail appropriate free health services – such as counseling services, accessibility of cytogenetic tests – particularly hormone and chromosomal tests – and endocrinology services for children and people who may need life-long hormone replacement treatment – should be accessible to all intersex children and people regardless of their gender identities or non-conformity. This will prevent random and best guess surgeries, which have resulted in irreversible and traumatic mutilations of children's genitals. (*UN Convention on the rights of the child, articles 2, 4, 24*).
- d) The Convention of the Rights of the Child as the first instrument to incorporate the complete range of international human rights including civil, cultural, economic, political and social rights and all aspects of humanitarian law. The convention on the rights of the

child sets out the rights that must be realized for children to develop their full potential, free from hunger and want, neglect and abuse. The convention offers a vision of the child as an individual and as a member of family and community with rights and responsibilities appropriate to his/her age and stage of development. It should also be noted that the Convention applies to all children, whatever their race, religion or abilities; whatever they think or say, whatever type of family they come from. It doesn't matter where children live, what language they speak, what their parents do, whether they are boys or girls, what their culture is, whether they have a disability or whether they are rich or poor. Therefore, no child should be treated unfairly on any basis.

- e) Improve the policy on antenatal clinic information packs. Parents are currently prepared for the possible birth of an HIV positive child and how to avoid this or to lessen the chances of such a birth through information and tests after birth to determine the status of a child. The MOH should work hand in hand with other actors, such as SIPD Uganda and others to develop information packs on the sex development and determination of a child born physiologically between male and female. (*UN Convention on the rights of the child, articles 3, 16, 17*)
- f) Incorporate training on sex development disorders manifested either at birth or at puberty in the

medical schools curricula. Children and adolescents born with these variations have been forced to drop out of school because of the immense stigma and discrimination caused by lack of a policy that protects the rights and mental health of such children in school. The ministry can collaborate with other countries to bring in experts to train Ugandan surgeons and other medical workers to appropriately handle cases from a rights-based approach (*UN Convention on the Rights of the Child, articles 19 and 23*).

- g) Strengthen the clinical evaluation system where all children are examined clearly after birth to detect any form of ambiguity of the children's genitals. For signs that manifest during puberty and adulthood, equip all health workers with knowledge and know-how to appropriately handle cases from a human and health rights based approach. This policy needs to include capacity building programming for traditional birth attendants – who can easily be identified by Village Health Teams (VHTs). This is critical because over 50% of women in Uganda continue to give birth at the hands of Traditional Birth Attendants (TBAs) despite government's efforts to erase them out of the system.

## To parents and caretakers of intersex persons

Parents should always thank God for what He has given them and that the birth of an intersex child should be equally celebrated.

## To religious leaders

- a) Religious leaders should start spreading a gospel that isn't based on discrimination and to inform their masses that God loves us (human beings) same way
- b) Use the different committees in parliament like Maternal and child health technical committee, its committee on human rights such that they can engage with advocates of children and people with DSDs to discuss the way forward and well-being of all these children and people.

## To Uganda Parliament

Amend the Ugandan constitution to favour all people including those with DSDs

## To the Ministry of Education and Sports (MoES)

- a) Create environment in all schools (both private and public) in Uganda that can allow children and people with DSDs stay and finish school like any other person
- b) Change the school curriculum to include issues to do with DSDs and to add this to the wider SRHR groups at schools

## To the Uganda Human Rights Commission (UHRC) and other Civil Society Organisations (CSOs)

The Uganda Human Rights Commission should work together with SIPD and other stakeholders to make sure that the rights of all people born with DSDs in Uganda are upheld and lifted since even the UHRC is constitutionally mandated to promote and protect human rights in the country. The UHRC should study well the policy concept note that was submitted to it by SIPD to see areas of intervention for further discussions. This can be done through reaching out to SIPD and all other stakeholders who refer cases to us/work with us.

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A PUBLICATION OF SUPPORT INITIATIVE  
FOR PEOPLE WITH CONGENITAL  
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## Table of Contents

### Contents

Glossary .....	2
List of acronyms.....	3
Introduction .....	4
Methodology.....	7
Data collection: Methods and process.....	7
a) Outreach campaign.....	7
b) Media campaign .....	7
c) Follow up strategies .....	7
Analysis: Human Rights Violations in Uganda of children and people with DSDs.....	8
a) Medical Malpractice.....	8
b) Discrimination and stigma at school.....	9
d) Prejudice and stigma when seeking health services .....	11
e) Family and community discrimination.....	11
f) Lack of legal protection .....	12