

**BASELINE
SURVEY ON INTERSEX
REALITIES IN EAST
AFRICA - SPECIFIC FOCUS
ON UGANDA, KENYA,
AND RWANDA.**



A publication of **Support Initiative
for People with congenital
Disorders** – with support from the
Sigrid Rausing Trust

2015-2016

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LIST OF ACRONYMS

SIPD – Support Initiative for people with congenital disorders

DSDs – Differences of Sex Development

HRAPF – Human Rights Awareness and Promotion Forum

TBAs – Traditional Birth Attendants



EXECUTIVE SUMMARY

Understanding our journey: Background of the baseline survey

Support Initiative for People with Congenital Disorders (SIPD –Uganda), its clients, allies, and donors have had discussions around the possibility of conducting a Baseline Survey on intersex realities in Uganda and the East African region for a long time and it is our hope that this initial baseline survey focusing mainly on Uganda, Kenya, and Rwanda lived realities, will translate into other baseline surveys across sub-Saharan Africa.

Goal of the baseline survey

The purpose of the baseline survey is to “identify essential indicators to capture in describing the current context of the lives of intersex people and the state of organizing of intersex communities in Uganda, Kenya, and Rwanda.

- ✘ Monitor gains and losses and how they relate to changes in context or to actions taken by actors for and against intersex rights;
- ✘ Analyze strengths and weaknesses over time, as the basis for strengthening organizational capacities and strategies for individual organizations and a cohort of groups with similar goals;
- ✘ Assess and begin to minimize divergences between services provided and those that are needed by Intersex communities; and
- ✘ Build from the knowledge that if the technical assistance can be provided regionally, processes will be more horizontal and less hierarchical and activism as well as engagement will be more visible.

Objectives of the baseline survey

- ✘ To identify essential indicators against which to describe the current context of the lives of Intersex people and efforts to organize Intersex people in Uganda, Kenya, and Rwanda;
- ✘ To gather information in relation to each of these indicators and;
- ✘ To establish a framework for ongoing gathering of Baseline Information for the region.

SIPD Uganda is the leading team in this baseline survey. To achieve the above objectives, the team used both qualitative and quantitative data collection and analysis methods.

Thematic areas

- ✘ Legal and policy perceptions
- ✘ Landscape of Intersex organizing
- ✘ Lived realities
- ✘ Cultural, social and religious discourses
- ✘ Health discourse
- ✘ Sex determination, gender identity and sexual orientation discourses

Scope of the baseline survey

The survey looked generally at Uganda, Rwanda, and Kenya where SIPD operates and/or has alliances. The findings of this study were then juxtaposed with a few other Sub Saharan African countries, such as Zimbabwe, and Zambia as well as other international narratives.

Much of the literature on intersex children/people provided a perspective on gender and sex vis-à-vis intersexuality. These perspective show the socio-economic correlations, which further promote discrimination, torture, and even the threat of facing death for most intersex children and people in the region.

The baseline survey started in Kampala district where initial meetings with intersex people, their parents/guardians were held and later data collection was extended to 50 districts of Uganda where SIPD works as well as to 2 intersex people and 2 partners in Kenya and 1 partner in Rwanda. We hope that every three years a review will be done to update this baseline.



OBJECTIVES OF THE SURVEY

General objective

To contribute to broadening and deepening of understanding of the scale and implication of violence, abuse, neglect, exploitation and discrimination affecting intersex children, their special need of protection measures by amplifying their situation and the factors that contribute to their situation as a basis for planning programmatic interventions.

- ✘ To explore the social economic challenges faced by their intersex children and their parents
- ✘ To find out the existing legal framework backing the rights of intersex children and people.
- ✘ To show the relevance of social protection concerning the situation of children born with Differences of Sex Development.
- ✘ To identify essential indicators against which to describe the current context of the lives of Intersex people and efforts to organize Intersex people in Uganda;
- ✘ To gather information in relation to each of these indicators and;
- ✘ To establish a framework for ongoing gathering of Baseline Information.



METHODOLOGY AND PROCESSES

To achieve the mentioned objectives, SIPD used the following combination of methodologies:

Data Collection: This included primary and secondary data collection through desk reviews, personal interviews, and consultations, with a focus on understanding the views, attitudes and opinions of intersex people in Uganda, Kenya, and Rwanda and other stakeholders including but not limited to medical practitioners (Doctors and Traditional Birth Attendants), legal experts, counselors, psychologists, religious leaders, local leaders, educators among others. The intersex baseline survey started with a meeting in Kampala that brought together a total of 35 intersex people and their parents. This was followed by verification meetings in Kampala and Kigali to receive feedback from participants. Resources and sources of information, partners useful in the provision of information on focus areas, indicators that may have been left out were all discussed in these meetings.

The Data collection processes included:

- ✘ Focused group discussions – Sometimes discussions were held in groups since all of them had the same goal
- ✘ Review of literature – Literature was reviewed for a clear correlation to be established
- ✘ Home visits – Home visits were made to different intersex families in Uganda in order to have a clear picture that depicts an intersex ways of living in Uganda.
- ✘ Telephone calls – Telephone calls were carried out in seeking for clarity on different matters that were reported since some could have information gaps

Area of study: 30 districts of Uganda i.e. 120 participants across North, Western, Eastern and the Central regions respectively. As well as Kenya and Rwanda – i.e. two (2) intersex people and three (3) partners.

Data Analysis: The researcher(s) make analysis basing on lived realities of intersex people themselves (using a semi structured research interview), existing literature books on intersexuality, and interviews with medical practitioners, counselors, legal experts, local leaders, religious leaders among others.

Validation workshop

All participants attended a validation workshop in Kampala where the report was presented and discussed as well as planning for next steps for the draft baseline report presented and future actions for follow up by key partners, organizations and activists.

Final baseline report

There was integration of feedback from all meetings and this sustained in the production of the final baseline report that includes photos and videos that capture the findings.

Report dissemination

Communication of findings is planned through dissemination of the final baseline report to partners, activists, hospitals, schools organizations and all other relevant stakeholders.

Scope of follow up

It is envisioned that there will be follow up and review of key indicators every after three years.



CHALLENGES TO THE PROCESS

Information gaps – This was a challenge because respondents were sometimes unable to give all the information that the interviewer wanted since they had not yet come out.

Impact projection – Ensuring that the process and this report will reach the hands of those able to use it to benefit the intersex community in Uganda and the region.

Sustainability – The challenge of raising funds to ensure that there are follow up studies every after three years.



UNDERSTANDING THE CONTEXT AND THE ENVIRONMENT

In all three countries in this survey, namely, Uganda, Rwanda and Kenya when an intersex child is born, the family treats the birth with extreme secrecy – with intervention strategies limited to close family members. In all the responses we received, families will isolate the child from the general public. As standard treatment, the mother of such a child will be frowned upon, and most intersex infants will be killed shortly after birth. Those who are not killed face different forms of discrimination – for example, in Uganda intersex teenagers are forced to drop out of school and live a disempowered and secret life, often subjecting them to sexual violence in terms of curiosity rape and other forms of sexual and physical harassment. In Kenya, the family will send the intersex teenager away from home and from the village to find anywhere else to live and caution them never to return. In Rwanda, a few intersex young people have sought refuge in Nyamirambo camp for LGBTI destitute people but have been forced to leave for lack of safety and relevant services. Some have resorted to suicide. Usually superstition loom large as families consult witchdoctors, mediums and traditional healers for a solution. What would appear to be a positive story is for a scanty number of intersex people born into wealthy families, who avail them with medical information and where needed sex re-assignment surgeries. Even in these cases, the doctors were quick to note that no one is sure if the surgeries done are the right ones or if they will prove useful to the intersex child later on in their life.

Women who give birth to intersex children are often considered to be witches or victims of witchcraft, and the intersex children are considered a bad omen to the

family, which should be gotten rid of. The ridding takes the form of murders or abandonment. Many women are abandoned by their husbands and in-laws due to the news of such a birth. Most mothers of intersex children dump and abandon their intersex children for dead in pit latrines and lonely forest areas and run from their homes for fear of possible prejudice-driven crimes towards them by family or community members. It's so unfortunate that the general East African society has always responded with denial, hostility and at best, silence, on these matters pertaining to sexual development and related health and rights concerns.

In recent years, children's rights have developed into a major field of human rights, with children being recognized as critical priorities for legal focus, including those born with Differences of Sex Development. UNICEF has recognized the importance of children's rights thus the Convention on the rights of the child. An official from UNICEF during a national seminar on United Nations Convention on the rights of the child (UNCRC) said *"as important as needs of human rights, even more important is the need to recognize and protect the special rights of children, who are most vulnerable members of society."*

The critical question at the helm of this survey, which is echoed in most national findings is when will the various legal and human rights frameworks, which protect children's rights and other at risk populations at international, regional and local levels also specifically include Intersex children and people (those born with Differences of Sex Development).

The birth of a new baby is one of the greatest wonders of nature and one of the most exciting events known to man. The first question that is usually posed by the mother or father is "is it a boy or a girl", without this information the new parents cannot even formulate the second question which is usually "is he/she alright?". Magnus Danielson (2005, 3) alludes to this initial social construction of gender and says plenty has been written about how boys and girls are treated differently, about how something as common place as the tone of the voice towards a person differs depending on what sex that person is. This may seem ridiculous changing my voice just because I am talking to a person with a penis, may be not but how are children who can't be defined as neither boys nor girls be treated? What really happens when the midwife holds up the newly born baby and says, "congrats, it's a.....eh.... well...". Sadly the reality is too traumatic to joke about and yet it is a true scenario for thousands of parents whose children are born this way the world over – East Africa inclusive.

➤ DEFINING INTERSEX: WHAT THEN DOES IT MEAN TO BE INTERSEX?

Intersex can be looked at as a condition in which a person is born with a reproductive or sexual anatomy that doesn't seem to fit the typical definitions of female or male or a person born with genitals that lie between male and female. It therefore reflects a combination of differences in the development of a person's internal and external sexual and reproductive organs. For example a typical male is born with two complete testes and a penis that enables penetration during conventional sexual intercourse; passage of seminal fluids and urine. A typical female is born with two complete ovaries, a uterus, fallopian tubes, mammary glands that develop into breasts at puberty and a vagina that enables both menstruation and child birth. Being intersex is occupying the middle grounds between the typical male or female sexes.

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 which 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.

According to law students for reproductive justice in their article "Intersex rights and reproductive justice" (2013 , 1) they defined the term intersex as to people born with sexual or reproductive anatomy that does not fit within society's typical definitions of male or female and the intersex society of North Africa (www.isna.org) extends more on this definition and says being an intersex encompasses a variety of conditions, a person can be intersex in many ways and not all medical professionals agree on what constitutes an intersex condition, but people generally labeled as intersex include those who have;

- ✘ Internal and external reproductive organs of different sexes
- ✘ Internal reproductive organs that represent a combination of typically male and female organs (i.e. ovotestes)
- ✘ Genitals that do not appear typically male or female (e.g. a large clitoris and shallow or absent vagina, or a micro penis with an opening in the scrotum that looks like a vagina and
- ✘ Atypical chromosomal patterns, (such as XXY, XO or mosaic chromosomes) or a certain hormonal abnormalities such as Congenital Adrenal Hyperplasia or Androgen Insensitivity Syndrome.



Rainbow Health Ontario define intersex in their RHO fact sheet on intersex health as people whose bodies, reproductive systems, chromosomes and/or hormones are not easily characterized as male or female. This might include a woman with XY chromosomes or a man with ovaries instead of testes. Intersex characteristics occur in one out of every 1500 births (Handbook for parents, 2006). That means an intersex child is born every two days in Canada, five intersex children each day in the US and according to our reference doctors from Mulago hospital in Kampala, Dr. Laigong in Kenya, and Health Development Initiative (HDI) in Rwanda at least 2 children with intersex conditions are born every week. Estimates of the frequency of intersex status range widely, in part due to the cultural practice of concealment that ensures some individuals never know they were born intersex (Anne 2006, 59, 65) and in part to disagreements over the definition of what counts as an intersex configuration. Conservative figures place the frequency at 1 in every 2000 live births (www.plannedparenthood.org) while expanded definitions yield the estimate that about one in every 100 births is intersex (www.isna.org).

Dr. Thomas Muyunga, a sexual and health rights advocate (www.observer.ug), further supports this definition and explains that biologically, females have XX chromosomes and males have XY chromosomes, because in humans, the male gametes (sperms) contain X and Y while the female gametes (ova) contain X and X. So when the X from the sperm fuses with the X from the ova, the baby is XX and female. When the sperm releases Y chromosomes to fuse with the X chromosomes from the ova, the baby is XY and male. Yet, Muyunga says, some people may have an extra X or Y chromosome, sometimes the extra chromosome is hooked on the ordinary XY or XX chromosomes. Sometimes, intersex people have fewer chromosomes. They go on to say that within medical circles, the term “disorder of sex development” has replaced earlier terms such as sex reversal, hermaphrodite or pseudo hermaphrodite. (*Clinic Guidelines for the management of Disorders of sex Development in childhood. 2006*).

Intersex activist groups strongly disagree about the appropriateness of this pathological terminology (Koyama 2008) because people living with this range of conditions generally refer to themselves as “intersex”.

➤ IMPACT FORECAST OF THE BASELINE

The baseline will inform all relevant stakeholders who design or contribute to the designing of human rights protection and/or promotion policies – i.e. government, and non-government institutions, other policy makers and legislators, activists, development partners, parents, healthcare and legal practitioners to consider the vulnerability and human rights implications faced by intersex people.

The survey is expected to amplify the outstanding duty to recognize and protect the human rights and dignity of intersex children and people as part of the global commitment to respect for diversity.

This survey should pave way for future research and interventions in the areas of gender, sex, law, and organizing in the East African region and broader Sub Saharan Africa.

➤ KEY FINDINGS AND ANALYSIS

Legal and Human Rights Realities

Specific legal references to intersexuality

The law in Uganda, Kenya, and Rwanda is explicit and similar in regard to sex classification. Either one is born male with a penis – and constructed to live as a boy or female with a vagina and constructed to live as a girl. Since the law doesn't allow any variations, which nature abundantly allows nonetheless, a child that is born with atypical sex characteristics, i.e. conditions where the child's genitals, chromosomal or gonadal characteristics are not entirely female or male (Preves, 2003), parents and/or doctors will make a decision on behalf of the child to assign a sex out of the two sex classifications.

This is not just due to the law, which of course is unconditional, but also to the parents who want a normal child. Nonetheless, the literature reviewed proves that genes, hormones and genitals do not necessarily stick together (Dahlen 2006). A child with a penis can for instance have the XX chromosomes, (i.e. the female ones), and a child with a clitoris and/or a vagina can have the XY chromosomes (i.e. the



male ones). This can also be the case if the child has ambiguous genitalia where something ambiguous is always compared to something medially and/or socially to be “normal”. Technically speaking, the intersex condition signifies a variation in the reproductive and sexual system. And the real ambiguity lies in how the observers face the situation.

The simplified handbook on international and national laws, laws and policies on children (UNICEF and FIDA – Uganda) informs us that even at the regional level we have the African Charter on the rights and welfare of the African child and Uganda, Kenya, and Rwanda are signatory. This charter commits the country to protect ALL children – intersex children inclusive – against various forms of social, economic, cultural and political abuse and exploitation. As state parties, Uganda, Kenya, and Rwanda are obliged to undertake the necessary steps and adopt legislative and other measures to give effect to the provisions of this charter which spells out basic human rights that all children have.

Every child has the right to: live, survival and development; name, registration, education, leisure, recreation and cultural activities, health and health services, special judicial treatment in a manner consistent with the child’s sense of dignity and worth, parental care etc. the right to life, survival and development (Article 5). The right to be cared for, protected by his or her family and to reside with his or her parents (Article 19).

Protection against child abuse and all forms of torture, inhumane and degrading treatment, including physical or mental injury or abuse, neglect and sexual abuse (Article 16). That said, it is established that Intersex Genital Mutilation of intersex infants and forced mutilations of intersex adults are a form of torture and constitute a human rights violation.

The case of Uganda:

Law	Provision	Impact on intersex persons
The 1995 Constitution of the Republic of Uganda	Article 20: fundamental rights and freedoms are inherent and not granted by the state	Should include intersex persons rights and freedoms
	Article 21: The right to equality and freedom from discrimination	Intersex people have a right to equality and freedom from discrimination
	Article 27: The right to privacy	Intersex people have a right to privacy
	Article 30: Right to education	Intersex children have a right to education just like any other child
	Article 32: Affirmative action in favour of the marginalized groups	Intersex people are among the most marginalized groups in Uganda
Registration of Persons Act 2015	Change of name of an adult (Section 36)	Intersex persons should have the right to change their names. However, cross-sex names can be problematic both socially and legally even with this constitutional right.
	Registration of a child born a “hermaphrodite” (Section 38) and change of sex of such a child.	Intersex children can be registered and their sex changed at the recommendation of a medical practitioner.
	Registration as either male or female	Note: What of those that can’t really fit into the female or male boxes? And are no longer children? This makes them stateless.

The case of Kenya:

According to John Chigiti of Gender Minority Trust, in 2014, a Kenyan court ordered the Kenyan government to issue a birth certificate to a five-year-old child born with ambiguous genitalia. In Kenya a birth certificate is necessary for attending school, getting a national identity document, and voting. In the case of Baby “A” (Baby “A” Vs the Attorney General (AG) and others Petition number 266 of 2014) Justice Lenaola brought out the need to have a list of the Statutes that regulate the affairs of the intersex community. He further directed the AG to identify the state organ that is responsible for data collection around the issues of the intersex. We can

comfortably now say that Kenya is ready for the intersex.

The Persons Deprived of Liberty Act 2014 is a first in Kenya to define who an intersex person is. Section 2 of the Act defines an intersex as a person certified by a competent medical practitioner to have both male and female reproductive organs. Although this is an extremely shallow definition, it is fair to say that for Kenya, this is a first step in the right direction.

Going by legal documents, children in all the three East African countries under this survey generally have rights and freedoms entitlement under the terms of the Universal Declaration of Human Rights (UDHR 1948); International Covenant on Civil and Political rights (ICCPR 1966); International Covenant on Economic Social and Cultural Rights (ICESCR) and significantly the Convention on the Rights of the child (CRC 1989). Uganda has gone ahead and domesticated these Conventions into the 1995 constitution and other related legal reforms, chapter four of the Uganda constitution article 34 provides for the rights of children, also the children act was enacted to reform and consolidate the law relating to children. While Uganda's policy framework shows a strong commitment towards providing care, protection and maintenance of children, it forgets and excludes intersex children, it caters for only two categories of children male and female and provides no protection whatsoever for intersex children from fear of assault, abuse, inequality, exclusion and discrimination in the societies where they reside. SIPD works with 1402 intersex children and people in 50 districts of Uganda since 2008, and due to continued advocacy, the Uganda parliament in 2015 included some basic recognition clause of the right to citizenship of intersex children and people in the registration of persons Act of 2015. That said, the language used – of “hermaphrodites” instead of “intersex” in this recognition clause remains stigmatizing and de-humanizing.

In Rwanda, HDI reported that negligible attempts have been made to categorize intersex children among children with disabilities. HDI kept no specific numbers of intersex people they had interacted with reported that they had come in contact with at least twelve (12) intersex adults who had sought refuge in the LGBT camp but had to flee due to discrimination and lack of support.

In Kenya, the law does not explicitly recognize the existence of intersex children or people. However, the Kenyan law courts made a positive ruling in favor of “Baby A”'s right to citizenship through the issuance of a birth certificate in a ground breaking litigation suit by Gender Minority Trust (GMAT) in 2014. This has initiated a process of acknowledgement of the existence of intersex people in Kenya and hopefully will lead to more organized support. Apart from this legal milestone of baby “A”, SIPD was able to speak to six (6) intersex adults, only two (2) of whom were keen on initiating some rights organizing. The other four (4) just wanted to live a quiet and safe life.



CULTURAL, MORAL, SOCIAL AND RELIGIOUS DISCOURSES

The baseline looked at how the social, religious, and cultural fundamentalisms facilitate the discrimination of the intersex people in the different societies of East Africa.

People in the different communities in all the three countries Uganda, Kenya, and Rwanda the researcher interacted with have a view that you are either born a male or a female, and for the case of intersexuality some view it as myth, others a punishment leaving the child born with this condition to suffer in life even to the threat of being killed.

In Uganda if an intersex child is born in urban and rural areas of Uganda, it is considered to be a punishment for an offence the mother committed either in the present life or an earlier life. The child and the mother are expelled from the community, which is essential for survival. Therefore, many mothers kill their newborn baby, hoping that the child's intersex remains undetected at the funeral at the funeral, since other members of the community rarely touch the dead body during the funeral. And they continue to note that in Uganda we have failed to acknowledge that culture is not static it's dynamic. This leading to sections of the communities all over the country to reproof intersex children as a population haunted by witch craft and as result basic care needs and health become a problems to these children in case they survive death.

Discourse on the right to housing

Among the rights of the child, there is a right to housing, or shelter. In Kenya, the intersex child will usually be forced out with the mother but in many cases, the child is isolated and hidden in the house but when they reach early teens, they will be forced out of the house and homestead to go and fend for themselves, and warned never to return. One of the intersex young adults we interviewed had this experience, was chased from home and has not returned since.

In Uganda, the scenario is not that different from Kenya. Intersex children are denied this right to adequate standard of housing. In Northern Uganda for example, intersex children are denied housing. They are separated from their siblings and put in remote huts on the peripheral of the homestead, further than where animals are kept. They argue that if this child is left to stay with siblings it's very easy for this child to pass on the bad luck to other children in the family that are considered "normal". There

is another case in Rakai district where a child was moved from the main house and isolated in a small hut at the advice of the family's in-laws. This was a measure to control the continuity of what is considered a bad omen in the family.

The mother was quoted saying (translated from Luganda) *“I was ordered to take my child from the main house and abandon it in the outside hut because it was a “curse” and they didn’t want the “curse” to spread to other children and people in the main house... they also told me I was the cause of the evil happenings in their family”*

Photos1 & 2: Picture of a child who was isolated from the main house and photo 2 shows a typical homestead in Northern Uganda.



A typical homestead will have a main house and other sub houses. When an intersex child is born, they are removed from the main house and put into a small hut distanced from the main homestead to stop the bad omen affecting the entire family.

Discourse on the right to education

Every child is entitled to the right to education, but schools lack support and respect of a student's unambiguous sex or who lack a proper sex determination/gender identity as per societal norms. SIPD engaged 12 schools in Uganda, 1 school in Western Kenya, and consulted about school perceptions from HDI Rwanda and found out the following: Schools lack toilets, showers and change rooms which are specific to intersex children and youth. Coupled with the lack of appropriate facilities, they also face acute discrimination from their fellow students and teachers, making

them extremely vulnerable. It has been very difficult for some intersex children to choose toilets where to go as they don't seem to fit to either the boys side or the girls side i.e. it will be impossible for a boy who can't pass urine while standing to go to the girls toilet because girls will feel offended since they perceive him to be a boy yet fellow boys will not understand why he must squat to pass urine if he uses the boys' toilet. Whichever toilet he chooses to use, he must be in hiding. A situation like this is one of the several stories collected as causes for dropping out of school.

The baseline found out that in Uganda and other East African countries, 90% of the intersex youth interviewed reported that they were forced to drop out of school because of the immense stigma and discrimination associated with the non-binary development of their intersex body. An intersex teenager in Uganda was quoted saying "*Mukama bwakuyamba nomalako okusoma nga wazalibwa mweno embeera nga eyange obeera wa mukisa nnyo era Mukama osaana okukimwebaliza*". Meaning that in Uganda if you are in position to conclude school and you were born intersex, you are very lucky and you need to thank God.

The role and impact of religion

Culture, religion and morality are used by sections of communities to reproof intersex people as a population haunted by witchcraft, and whose redemption lies in the same. As a result access to education, health care, legal services and justice becomes a challenge. In all the three East African countries surveyed, religion encouraged various divine interventions and rituals, as well as overarching silence as a solution.

Socio-Economic Challenges

Concerning the socio-economic challenges, Gloria from Kampala district narrates that she lives with untold pain. Where she said a black cloud hang over her life when she discovered she was intersex. She said "*I lost both parents when I was two years old I was in taken up by my grandmother who lives in Bunyaruguru. When I was in P5, I discovered that urine passed out of a small hole on top of my genitals. However, I found out that I had no vaginal opening,*" she says, "*I wondered what had gone wrong with me and why grandmother and aunties had not told me about my condition. I became desperate. I wished my parents were alive to explain it to me. One day, one of my aunties told me that I was born with that condition and that my late knew about it, but had nothing to do,*" Gloria says. She further narrates that her parents thought she had been bewitched by her stepmother. But when the doctors examined her, they were advised to consider surgery at the age of seven or 10. Unfortunately, they died before she turned seven. "*I am now 29 years old, but*

I have never experienced menstruation and I have never developed breasts. People describe me as a man and others as a hermaphrodite; it hurts me and affects my self-esteem,” she said. According to a medical examination, the doctors confirmed that Gloria had a very small uterus and no vaginal opening. She has high levels of testosterone (a male hormone) which is responsible for her condition.

“ Maria, from Rakai district narrates “I cried myself to sleep” Her flat chest and male voice keeps one wondering whether Maria, is a man or a woman. Doctors say she has dominating male hormones in her body. What is more, she has ambiguous genital organs. Maria narrates that “I grew up with my grandmother in Kalisizo, Rakai district. While I was young, my grandmother never told me anything about my sex. When I turned 21, I realized I had a growing penis in my private parts.” “When I asked my grandmother about it, she gave me disquieting look. I got distressed and often cried myself to sleep. I kept pestering her for an answer, but in vain. One day, she explained that that’s how I was born. She told me to keep it a secret to avoid being stigmatized.” Maria said every time she wanted to consult her friends about her condition, she refrained as she feared being stigmatized. “It bothered me that I had this condition. I could not menstruate and I developed a male voice. I also had no breasts at all. Eventually, people began calling me names. Others laugh at me saying ancestral spirits cursed me. I feel worthless, as a result,” she lamented. Medical tests proved that Maria should have been a woman, although she has a masculine physique. However, the decision is hers to decide what sex she is. Nonetheless, if treatment is delayed, her condition might be irreversible by the age of 23.

“ William, from Jinja district also narrates in “Not a boy and not a girl” by Vique-Ocean Kahunju which goes by “Being born with ambiguous sex characteristics can be quite distressing. People call you names and you struggle to fit in society. Learning about his intersexuality tortured him deeply. The truth is that William, from Eastern Uganda, was a boy in a girl’s body. This upset him as arguments arose about him and some people considered him demonic. “I found out the “abnormality” when I started to menstruate at the age of 15. I nearly fainted, but opted to keep it a secret. I did not know how to explain this to any of my friends or relatives who had always known me as a boy,” says William. “My dilemma began when my parents died while I was a small boy. I was left under the care of a stepmother, who probably did not realize I

had a problem,” William adds. He says the fear of being stigmatized kept him tight-lipped about his condition. “I knew my life had hit a bumpy phase and thought I would die. As time went by, matters were not helped as I continued to menstruate. Though physically I looked like a boy, it did not stop me from experiencing every natural process a girl undergoes.”

“I developed breasts. My hips were pronounced and my voice was feminine. But with the biology knowledge I had, I knew it was only girls that menstruate, develop breasts and hips. I could not find justification as to why this was happening to me,” William laments. “Sometimes I desire to be in a relationship, but I am not sure whether I should get a female or male companion. I feel empty when people stare at me and call me names such as “hermaphrodite”. Sometimes I wish I was not born. Doctors also discovered that William has a vaginal opening under his penis instead of male testicles. Medical tests have further proved that he has a birth canal and a uterus. “Having breasts and a vagina under my penis freaked me out. And the worst part is that whoever I ran to for comfort made fun of it. Some fueled gossip about my sex ambiguity. It really worked my nerves. In fact, it forced me to drop out of school,” William narrates.



Sydney from Kenya also narrates “My family isolated me when I was young and I was not taken to school. In Kenya the parents will hide the child – if they are unable to kill it – and when one reaches teenage, they will ask you to leave the homestead and go far away. It is a scary time and one is left destitute. In some ways I think the intersex children in Uganda are now luckier that they have SIPD. My situation was worse and as a result, I have no skill I can use to earn a living.”

In responding to this gap, and as a pilot intervention, SIPD Uganda has trained eight (8) intersex teenagers in hair dressing, construction, and tailoring. In addition, three (3) intersex youth have been spent a week as SIPD interns to learn from the engagement and advocacy model SIPD uses in Uganda.

Healthcare Violations - Genital Mutilations

There are many children in Uganda who have had involuntary surgical procedures and it has been parents and doctors who have spearheaded this. A mother in Mukono district said



“Nze bwenazaala omwana wange, namuzaala nobusajja bwe nga butono nnyo mubutuufu nga tebulabika nakulabika. Kakati waliwo ekitongole ekyali kinyambako okulaba nti omwana wange afuna obujjanjabi obutuufu naye omusawo eyalongoosa omwana wange ngagezaako okutereza obusajja bwe teyambulira buzibu buyinza kukivamu wadde okusooka okungamba ekintu kyooona wabula ye yagenda bugenzi mu maaso nakulongoosa mwana wange era ebintu tebyatambula bulunji nakatono nokutuusa essawa ya leero era mu mutima gwange nejjusa lwaki netantala okutwala omwana ono mu ddwaliro..naye nange napapa okola kino kubanga nali ntaasa maka gange omwami wange aleme kundekawo kuba yali ayagala amaanye oba omwana gweyazaala mulenzi oba muwala ate nga ne nazaala wange nabenganda ze bandi bubu....nalowooza nti singa omwana ono aterera ebyange byali byakuba birunji naye munange byayongera kwononeka kuba ebyava ku dwaliro mukulongoosa tebyali birunji...kale munsabireko banange”.

The above statement means that when this mother gave birth, the child had a very tiny penis that couldn't be noticed. The husband wanted to know whether she gave birth to a boy or a girl and the in-laws were on her neck. There was an organization that helped her acquire medical help. It's very unfortunate that the doctor who did the surgery didn't tell her anything like implications and up today she is regretting why she made such a decision that her child should have a surgical procedure because what she was trying to protect, things just went worse as she was abandoned by the husband and the in-laws basing on all that happened since the surgery wasn't a success but rather left emotional and physical scars.

Photos 1 and 2 showing two intersex children who were born with penile agenesis and surgeries didn't go well





SIPD staff engaging a medical practitioner at a rural referral hospital

The baseline confirmed that indeed only 45% of women in Uganda for example, deliver at the hands of medical healthcare providers and close to 55% women deliver at the hands of the Traditional Birth Attendants (TBAs). Recently there was a plan by government to phase out TBAs and replace them with non-traditional health workers. TBAs don't have information concerning rights based care and management of babies born intersex but are closer to and more affordable for the people in the communities than medical facilities. The recommendation of SIPD to government is to train and equip them with enough information and tools rather than to ban them. This survey revealed that the Western medical approach to intersex is not dominant in East Africa, which is largely more rural than urban, and that the predominant approach is traditional riddance.

In association with the typical circumstances of giving birth in rural areas, such as communal attention and superstitious traditions, the lives of intersex babies are constantly at great risk of one or other form of discrimination. Uganda, Kenya, and Rwanda all don't have a statutory health insurance system, and only about 4-5% of the population is covered by a sickness insurance scheme. In the case of a diagnosis of DSD, health insurance companies do not assume the costs for medical measures, because they tend to be vast and prolonged. Some people pay for cosmetic genital surgery, the removal of the gonads or hormone therapy for themselves or for a relative. In rural areas, most of the births take place at home or in a birthing center. A traditional birth attendant and an experienced elder are present for most births. Every birth is traditionally a feast, and is celebrated in the presence of the entire village community. Soon after the birth, every single member of the community welcomes, holds, bathes, and celebrates the child. Hence, it is generally impossible to conceal the newborn's intersex characteristics if it is noticeable as early as at the time of birth.

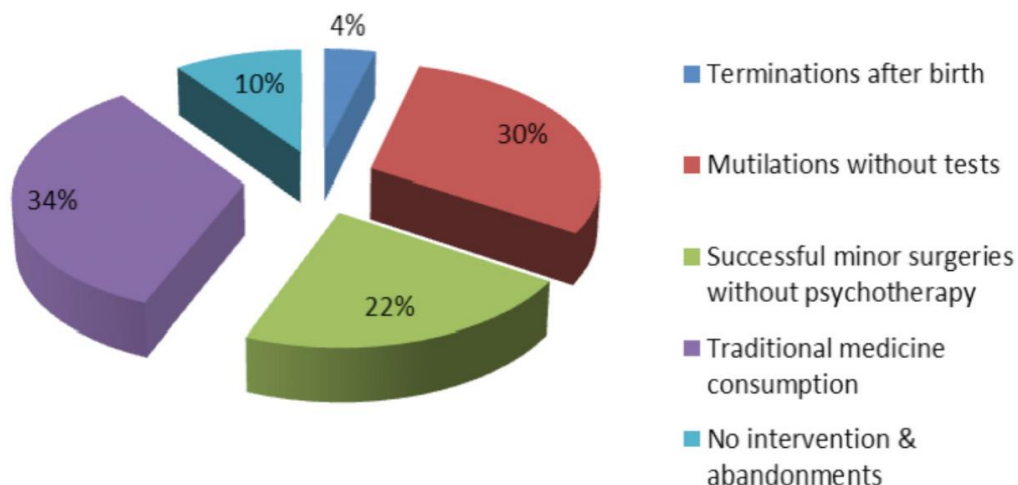
Mental Health implications

Lack of medical monitoring and access to appropriate healthcare can imply serious health risks for someone intersex. On the other hand, unnecessary, non-consensual surgery or cultural and social impositions on an infant and the mother leave life-long emotional and physical scars and also unattended health implications of opting for secretive corrective surgeries versus compromised immunity. (in the event of association with an individual's HIV status)

Interviews with intersex teenagers and young people in Uganda, Kenya, and Rwanda all revealed that there is a lot of stress. The majority of intersex people feel that they have no future, are scared all the time and succumb to substance abuse or criminal and suicidal tendencies.

Mental health challenges were also major among parents of intersex children, mostly mothers. This finding was primarily in Uganda and Kenya. SIPD did not get the opportunity to interview any parent of an intersex child in Rwanda.

GRAPHICAL REPRESENTATION OF COMMON APPROACHES TO INTERSEXUALITY – REPORTS FROM 200 RESPONDENTS FROM UGANDA, KENYA, AND RWANDA.



Major Misconceptions: Intersexuality Vis a Vis homosexuality

In most of East Africa, intersexuality has lately also been confused to be a form of sexual orientation, which is not the case. Intersex is sex determination and during adolescence, may or may not lead to gender identity and/or sexual orientation questions. Gender determination is the self-concept of being either male or female while sexual orientation is the romantic feelings and attractions towards a person of the same gender, different or both. Thus people who are intersex may take any gender identity and sexual orientation (Liao 2007, 399). However, they just have particular questions or worries about their sexuality. Many intersex consider that they are remarkable men or women who happen to have a medical condition which has caused some unusual physical features, which may disturb in their sex determination, and not gender identity or sexual orientation. One intersex person in Masaka district was quoted saying

“Kyangu nnyo omusajja ayagala basajja banne oba omukazi ayagala bakazi banne okuyitawo newataberawo amwogerako kuba kyaali kiba tekimwetimbye mu ffeesi naye nze eyazalibwa ngobutonde bwange tebutukanye, oluba okuyita kubantu ebiseera ebisinga ekiba kiddako kunjogerako ngabebuuza oba ndi mulenzi oba muwala ate tekikoma ku kino awo ebirowoozo byabwe biddukira mangu ku ani oba gwenjagala munsu muno olwo banguwa okakasa nti ndi omu ku abo abagala basajja oba bakazi banabwe kuba nomubiri gwange guba gubalemye okutegeera naye ngate mwana wattu okuzalibwa mu mbeera eno tekitegeeza nti ngenda kwebaka nabasajja oba bakazi banange....kale banange tulabye ennaku”.

The above statement translates thus:

“it’s very easy for a gay or lesbian person to pass and no one will even know that it’s a gay or lesbian that has just passed nor even asking if it’s a boy or a girl, but immediately an intersex person passes, people will start arguing whether it’s a boy or a girl and consequently start to discuss his/her orientation and naming the intersex person all sorts of names. In fact since they fail in most cases to understand our bodies, they will think we are the ones who are the homosexuals.”

The intersex individual also notes that

“It hasn’t been an easy journey living with my beloved wife as many people in the community thought I was a woman. I have been called all sorts of names and at some point I have been referred to as a lesbian. I have always defended myself by telling people that I am not a lesbian but a man who loves women. I am very sure many other intersex people are going through the same just that many of them are not bold enough to speak”.

He tells all this with his smiling face that gives hope to many other intersex teenagers knowing that they aren't alone.

Intersexuality Vis a Vis Gender/Sex

The notion of gender was introduced to indicate the social sex, i.e. something “socially and historically constructed” as noted by Magnus Danielson (intersexuality and its medical and social implications, 2005) in (Gamzoe, 2003, 23). The reason to introduce this concept was to separate biology from culture and this makes it easy to talk about masculinity and femininity “without the need to deduce this to biological differences” (Ambjornsson, 2004, 31): According to a poststructuralist position “gender and other dimensions of the identity do not exist beyond everyday action” (Ambjornsson, 2004, 32). In other words, there is nothing that predetermines our identities as women and men. “Gender is not a cause but rather an effect of certain actions”

(Ambjornsson, 2003, 32) or more aphoristically put, people do not act as they do due to who they are; people become who they are due to how they act. But for it to be more convincing, it requires continuous recreation. Thus, gender is not a static condition, but rather an infinite repetition of normalized behavioral patterns.

However, in this manner sex remains “a natural, unproblemitized and obvious representation for the biological sex” (Rosenberg in Butler, 2005, 22). Therefore, with the separation of culture and biology, the seemingly non-problematic status of the natural sex is reinforced. This might be one of the reasons why similar reasoning, as that regarding gender, is applied to the concept of sex.

According to Butler (1990) it is impossible to keep sex (biology) and gender (culture) detached. They are constructed in the same manner, i.e. through language and action. Femininity and masculinity are therefore an enforced quoting of a norm whose historicity is permanently united with relations shaped by discipline, regulation and punishment (Butler, 2005). It is with these codes of gender that the body is sexed. And if gender signifies the cultural part of the sexed body, then it follows that one gender simply can't be attached to one sex in an ambiguous way as for the case of an intersex child.

If we agree to the permanence in binary sex, it isn't given that the constructions of “men” will exclusively be placed to male bodies and that women exclusively describe female bodies (ibid). Consequently, masculinity and femininity can represent any body and even if sex would have been binary in its morphology, there is no reason to assume the existence of only two genders.

The conclusion from reviewed literature is that no one is by design man or woman.

“Man” and “Woman” are rather constructed. At the very first moment of life, when the midwife makes the sex of the child known, sex is being constructed via performativity. This announcement informs those around the child about how to behave towards it. “We fill up the genitals with meaning and decide that exactly those parts of the body should found the division of people in two groups” (Dahlen, 2006, 38).

In Uganda, Kenya, and Rwanda, interviews with 200 parents/guardians revealed that they worry that the child will not fit in at school and with peers. There is an urge for sexual normalization, generally justified with the noble ambition to preclude intense social stigma that may await a child who is identified and labeled as sexually deviant.

But while classifying others generally enables us to begin formulating social expectations as we engage in social encounters, it is not only confusing but a source of great social dilemma for a person born with ambiguous sex characteristics.



INTERSEX ORGANIZING

This section examines what has been done in the area of civic education, lobbying and policy advocacy for the rights of intersex children, with special emphasis on the achievements made, and the challenges that need to be addressed in order to improve and increase a better and safer quality of life. This section also looks on the philosophical underlying principles for the protection of intersex of children, which inform organizing in the East African region.

SIPD is at the forefront of intersex organizing in Uganda and it's the only exclusively intersex organization in Uganda and East Africa at large. Over the past eight years, it has networked around intersex organizing autonomously and in alliance with sexual minority rights organizing, as well as in alliance with children's rights organizing in other parts of the region. In 2014, SIPD organized the first ever regional intersex meeting where 20 intersex advocates and allies from Rwanda, Burundi, Kenya, Congo, Tanzania, and Uganda convened in Uganda to strategize and plan for the way forward. The key approach to organizing for SIPD is Public Education. This is done through community engagement, alliances building, mentorships, empowerment and learning interventions, policy advocacy, and media engagement. This is done nationally, regionally, and internationally. While these efforts have yielded more openness and visibility, there are a few concerns, which have been affecting intersex organizing in Uganda which included; Intersex being silenced within wider LGBT organizing. For the past decade of LGBT organizing in East Africa, intersex has

always been mentioned as part of the targeted sexual minorities but that's all it is – a mention and a very insignificant mention at that. Subsequently, the wrap up in the LGBTI acronym has been more of a disadvantage than an advantage in terms of visibility, support, funding, and security.

Interviews with all 30 field based focal persons SIPD is working with reveal that socialization has forced SIPD's organizing to operate along gender binaries of male and female body politics and gender identity. Intersex people who don't really conform to female or male identities are ostracized and forced to conform to the two normative and accepted sexes and genders.

This study also revealed that different strategies – though miniscule - are being implemented in the different East African countries – Kenya, and Rwanda and further down in Zimbabwe, South Africa, and Zambia and different organizations are seeking information and allies to augment their advocacy strategies for intersex rights. And there is a promise on the horizon of a vibrant intersex movement in the region. For example, in Kenya, the primary advocacy efforts by both GMAT and the Transgender Education and Advocacy organization have been in the area of ensuring registration of intersex children even with their indeterminate sex identities. No specific advocacy efforts were found in force in Rwanda.

The Registration of intersex children as citizens

Both SIPD Uganda and GMAT Kenya have successfully advocated and continue to advocate for amendments around the legal recognition of intersex children – even without a definite sex assignment – as citizens.

There is, however, a lot of work needed to shift social attitudes to meet with legal progression. In all the three East African countries under this study, there is still a huge sense of statelessness for intersex people. Addressing this need is still high on the radar of priorities for intersex advocates and allies in the region. SIPD called a regional meeting in Kampala to initiate this discussion.

Photographs from the SIPD regional Intersex convening



The regional meeting held in Kampala by SIPD Uganda to initiate a regional organizing agenda for intersex health and rights had five key critical aims; A). Amplifying advocacy voices around health and rights for intersex children and people in East Africa, technical support and facilitating knowledge transfer. B). Having a critical mass of intersex allies and stakeholders who are very confident in addressing issues surrounding the right to health, choice, life and dignity for intersex children and people. C). Documenting and disseminating best practices concerning intersex interventions from a regional focus. And D). Up lifting the support and advocacy networks for intersex health and rights in the East African region.

International advocacy tools specific to the rights of intersex people

The Yogyakarta Principles on the protection of intersex children's rights

As per the international organizations and our local organizations like SIPD are working to increase protections for children against medical abuse, including unnecessary surgeries performed on intersex infants (www.oiiinternational.com). Unfortunately International Human Rights instruments don't specifically address the protection of intersex children and people, the only mention of these protections are in 2006 Yogyakarta principles which essentially address gender identity and sexual orientation.

In 2006, a group of international human rights experts developed the Yogyakarta Principles to provide a universal guide for human rights regarding sexual orientation and gender identity (www.yogyakartaprinciples.org). Two relevant articles in this principle include:

“States shall “(t) take all necessary legislative, administration and other measures to ensure that no child’s body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration.” (Princ. 18(B))

“States shall “(e) establish child protection mechanisms whereby no child is at risk of, or subjected to, medical abuse.” (Princ. 18 (C))

The Yogyakarta principles come in force to protect infants born with DSD/congenital disorders because infants born visibly with intersex have historically been “treated” with surgery to “normalize their genitalia” (Tamar-Mattis, supra note 4, 60) most often by doctors following the “concealment method,” whereby they assign a gender, modify the genitals accordingly, and conceal the intersex condition from everyone, including the patient (Id.64-67). While this is still a common practice today, some doctors are changing the way they approach intersex infants in response to recommendations from advocacy groups like SIPD (Uganda), TEA in Kenya, Gender Minority Trust in Kenya, Health Development Initiative in Rwanda, other legislative allies, and the coming into force of The Yogyakarta principles (Id.64, 77-78).



CONCLUSION AND RECOMMENDATIONS

Conclusion

A.R. Byaruhanga wrote in *A Journal of Makerere University Convocation*:

“With regard to the bodily aspect, the human person’s basic needs have to be satisfied. These include food, shelter and protection. In the absence of any of these, social development is clearly unaffirmable. Regarding the spiritual aspect, the human person needs ideas of freedom, justice, honor, truth.....Lack of any of these implies lack of development.”

The baseline on sex development and gender non-conforming identity dilemmas among children in Uganda, Kenya, and Rwanda was made to investigate the lived realities of Intersex people in Uganda, Kenya, and Rwanda. The survey showed that in all the target East African countries of Uganda, Kenya, and Rwanda, intersex children and people continue to be pushed further to the extreme margins – even within the wider LGBT community, which makes some mention of this population. It also showed that intersex children and people are affected by cultural, moral, social and religious fundamentalisms which society uses to reproof the existence of intersex people in East Africa.

John Rawls (1971) John Rawls narrates that justice is not only impartiality but also treating people fairly and in proportion to their needs as well as their merits. There are inequalities of birth in this case of the children born with ambiguous sex characteristics or DSDs (what Rawls calls the ‘natural lottery’), all these create undeserved disadvantages for intersex people. Rawl argues us to change the social system so that it doesn’t permit injustices to occur. According to him, a socially just society is a product of a social contract founded on three major principles which include a) the principle of liberty b) the principle of difference and c) the principle of equality. The principle of equality requires public authorities to implement an atmosphere of equal opportunity where everyone has a reasonable chance of obtaining a decent life, especially and those with fewer native assets should be compensated. Intersex children and people have to be part of this focus and cannot continue to be mistreated and thrown to the extreme margins of society.



RECOMMENDATIONS

In order to protect the intersex children and people, we should make our domesticated laws on children in Uganda, Kenya, and Rwanda more practical and incorporate within them the provisions of children with ambiguous sex characteristics as it was done with children born with disability. The children's statutes and Acts which were enacted to in all three East countries in this survey.

Stop harmful unnecessary surgeries: Intersex Genital Surgery on intersex infants is unnecessary and a violation of bodily integrity. It causes a myriad of negative outcomes, including:

- ✗ Decreased or destroyed sexual sensation, including inability to orgasm
- ✗ Chronic pain and scar tissue
- ✗ Additional surgery arising from complications due to the first surgery
- ✗ Shame and depression from being made to feel that their bodies are inadequate
- ✗ Potential discordance with gender identity
- ✗ Sterilization – the denial of the fundamental right to reproduction (www.endocrinetoday.com)

Reform and introduce a specific law protecting intersex children and people, enabling access to care, and protection of intersex children and people. The children's act provides a legal and institutional framework for child care protection. It defines rights, which all children in Uganda have, accords specific rights for children with disabilities to ensure equal opportunities, and obliges the parents or any person in custody over the child to maintain the child ensuring education; guidance, immunization, adequate diet, shelter and medical care. Therefore as this is the case with other children also it should be the case with intersex children across East Africa and not just in Uganda.

Every intersex child has the right to: Stay and live with parents; Education and guidance; Immunization; Adequate diet; Shelter; Medical attention; Assistance and accommodation if in need; Leisure and participate in sports, and positive cultural and artistic activities;

Every intersex child should be protected from: Any form of discrimination, violence, abuse and neglect, and from social or customary practices such as

infanticide, and genital mutilations, which are harmful to the child's health, education, or mental, physical or moral development;

The findings in this study should be referenced in order to create awareness about the human rights and realities of intersex children and people in most of Eastern Africa.

Sex and gender based violence as pertains to intersex people should be continuously documented since most intersex people report human rights abuses such as the non –consensual, irrevocable surgical interventions to which they are subjected,

Include intersex people in health and social development education, service access, and employment policies which must be designed to prevent harassment, abuse, and discrimination.

Government and non-state institutions should work together to support intersex inclusion in health and human rights initiatives. Support intersex inclusion in relevant life supporting programs and promote the advancement of intersex children and people at large.

A central registry should be put in place where such births can be recorded to ease government planning and aiding policy change.



ABOUT SIPD – UGANDA

About SIPD Uganda

SIPD is a grass root, nonprofit human rights organization in Uganda, which through community outreach and engagement, provides reliable and objective information on atypical sex development issues and particularly addresses the need for organized medical, psychological support, public education as well as advocacy for human rights protection of intersex children and people. It was founded by a Ugandan born with an intersex condition backed by other advocates for the rights of children, women and other marginalized populations as a response to the needs of Ugandan children and people with intersex conditions/DSD in Uganda. SIPD provides support for and advocates for the human rights of children and people with DSDs throughout Uganda.

SIPD Vision

A supportive environment that allows intersex people to make informed and voluntary decisions regarding their gender and sexual identity.

Goal of SIPD

Ending stigma, discrimination, and secrecy surrounding children and people with intersex conditions/DSD by breaking through the current conservative thinking boundaries, which are closed to constructive dialogue on gender and sexuality issues by showcasing the reality and incidence of intersexuality /DSD in Uganda and the East African region.

Work towards a more compassionate, humane, open and tolerant society through innovative communication approaches such as educational and informative awareness drives aimed at challenging the exclusion of populations affected by intersexuality/DSD from social legal, economic and political frameworks.

Work with medical practitioners to increase the availability and clarity of information on DSD and to ensure that this information is appropriately interpreted at the

grassroots level where most of the socially orchestrated marginalization, hostility and ignorance originate.

SIPD Mission

To create awareness on intersex/DSD conditions and advocate for a more open, tolerant and supportive society towards children and people with intersex conditions and to advocate for protection, welfare and respect for the human rights of all such persons in Uganda.

Populations of concern

Children and people with intersex conditions/DSD and parents of children with DSDs, as well as Gender Variant People.

Main activities

- ✘ Awareness Raising
- ✘ Public education
- ✘ Capacity building
- ✘ Support (Counseling and information)
- ✘ Medical and psychosocial service referrals
- ✘ Advocacy and networking

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