



SIPD Uganda

HEALTH NEEDS AND ACCESS TO HEALTHCARE FOR INTERSEX PEOPLE IN UGANDA



**SUPPORT INITIATIVE FOR PEOPLE
WITH CONGENITAL DISORDER
(SIPD UGANDA)**

**WITH SUPPORT FROM WELLSPRING
PHILANTHROPIC FUND**

APRIL, 2024

ACKNOWLEDGEMENT

SIPD extends its appreciation to the various individuals that were involved in this study, particularly the various respondents including intersex persons and parents, health workers and all the Key Informants from the districts, Ministry of Health and Parliament.

SIPD also applauds the Wellsprings Philanthropic Fund for providing the financial support that enabled the conduction of this study.

LIST OF ACRONYMS

DHO	District Health Officer
DSFP	District Surveillance Focal Person
FGD	Focus Group Discussions
IRB	Institutional Review Board
MOH	Ministry of Health
REC	Research Ethics Committee
SIPD	Support Initiative for People with Congenital Disorders
SRH	Sexual and Reproductive Health
SRHR	Sexual, Reproductive Health and Rights
WHO	World Health Organisation
RHU	Reproductive Health Uganda
HRAFP	Human Rights Awareness and Promotion Forum
DSD	Disorders of Sex Development
STIs	Sexually Transmitted Infections
STDs	Sexually Transmitted Diseases

EXECUTIVE SUMMARY

Introduction

Intersex individuals grapple with multifaceted hardships in accessing health services. Societal stigmatization and discrimination cause severe psychosocial repercussions, including anxiety, depression, and exclusion. These challenges compound when accessing healthcare, leading to delayed diagnoses, inappropriate medical interventions, and enduring physical health issues. Ethical concerns arise as many medical procedures are conducted without the full understanding and consent of the individuals involved, resulting in lasting physical and emotional consequences. The limited awareness and sensitivity of healthcare professionals adds to the predicament, often leading to misdiagnoses, inadequate treatments, and a lack of psychological support. Although studies elsewhere have documented the healthcare need of intersex persons as well as their experiences with healthcare, there is scanty information on the health needs and access to healthcare for intersex persons in Uganda.

SIPD conducted this study to gather initial baseline data regarding the different healthcare needs of intersex persons and children in Uganda and the quality of healthcare services as well as the accessibility of health facilities to intersex persons with a view of making recommendations for improving access to healthcare for intersex persons.

Methodology

The study adopted a descriptive cross-sectional design using both quantitative and qualitative approaches. It was conducted in six districts in Uganda (Tororo, Mbale, Gulu, Mbarara, Mukono, and Kampala) where SIPD implements activities. A total of 101 respondents were reached. These included 24 intersex persons and 12 parents who responded to questionnaires from Gulu in Northern Uganda; Tororo and Mbale in Eastern Uganda; Kampala and Mukono in Central Uganda and Mbarara in Western Uganda. Questionnaires were also completed by 29 health workers from health centres in the different districts of the four regions. A total of 6 Focus Group Discussions were conducted in each of the six districts across the four regions. These reached 20 intersex persons and 10 parents of intersex persons. A total of 20 Key Informant Interviews were held with 3 District Health Officers of Gulu, Mbale and Tororo, 12 in charge of different health centres from the six districts, 2 officials from the Ministry of Health, 2 officials from SIPD and the chairperson of the Health Committee of Parliament.

Findings

The findings of this study revealed that intersex persons have unique health needs that are different from those of the general population. All (100%) intersex respondents needed access to hormones, 40% of the respondents needed access to enhanced mental health support, expanded infrastructure and access to quality medical professionals and 30% needed access to surgical services and some of these were for treatment of effects of surgical operations gone wrong. They also mentioned the need for sexual reproductive health services as most of them worried about their sexual and reproductive life.

The study further indicated that 100% of the intersex individuals emphasized that they also needed general health services, similar to the general population, including family planning, counselling, antenatal care, treatment for STIs and STDs, and HIV services, which are typically available at nearby health centres.

In addition, the study found that healthcare services meeting the unique healthcare services are only available in health centres in Kampala and Wakiso districts. These services are non-existent in health centres upcountry.

The study also documented numerous barriers to access to healthcare services for intersex persons in Uganda including: the high cost of healthcare services to address the unique healthcare needs of intersex persons; the conflation of intersex issues with homosexuality which causes intersex persons to suffer homophobic effects and eventually constrain their access to healthcare; the lack of clear and adequate confidentiality mechanisms in healthcare facilities leading to the discrimination of intersex persons as 47% of intersex persons reported that they had been discriminated against in healthcare settings because the information was leaked by health workers. Other barriers also included limited technical competencies of healthcare providers in addressing the unique healthcare requirements of intersex children and people; the lack of Policies and guidelines for enhancing health service provision for intersex persons and as well as stigma and discrimination in society and healthcare settings against intersex persons.

Recommendations

To Parliament of Uganda

- Parliament should use its legislative powers to pass laws that increase the protection of intersex persons and strengthen the provision of healthcare to intersex persons.

The ongoing effort by civil society organisations and the chairperson of the health committee of parliament should be supported to fruition.

To the Ministry of Health

The Ministry of Health should:

- Develop and implement comprehensive training programs for health workers to enhance their understanding of intersex issues.
 - Develop a comprehensive policy to address Sexual and Reproductive Health and Rights (SRHR) issues for intersex individuals to promote inclusivity, respect, and equal access to healthcare for intersex persons.
 - Develop standardized guidelines and protocols for the care and treatment of intersex individuals, incorporating inclusive policies, cultural sensitivity, informed consent, holistic healthcare approaches, regular review, and ongoing education to ensure equitable and respectful medical practices.
 - Ensure the provision of specialized services in government healthcare facilities including those upcountry, encompassing hormonal therapy, counselling, and necessary surgeries, to adequately equip health facilities for comprehensive care in support of individuals with diverse healthcare needs.
 - Establish health facilities, support networks and counselling services specifically tailored for intersex individuals and their families.

To the Ministry of Education and Sports

- Integrate accurate information on intersex variations into the school curriculum and sex education programs.

To SIPD and human rights organizations advocating for the rights of intersex persons

- Proactively engage with the Ministry of Health to advocate for the incorporation of specific Sexual and Reproductive Health and Rights (SRHR) policies and services tailored to the unique healthcare needs of intersex persons.
- Conduct public awareness campaigns to dispel myths and reduce societal stigma surrounding intersexuality.
- Continue to advance efforts for a law to promote the rights and access to healthcare for intersex persons in Uganda.

To intersex persons and parents

- Seek support and information from reputable intersex advocacy groups,
- Engage in open and informed conversations with healthcare professionals to understand all available options, prioritize informed decision-making, and
- Actively participate in shaping policies and guidelines related to intersex care and rights to ensure their voices are heard and respected.
- Report and document all forms of violations, stigma and discrimination

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SECTION I:

INTRODUCTION, BACKGROUND AND METHODOLOGY

1.1. Introduction

Intersex denotes differences in sex characteristics that do not necessarily conform to the predictably binary idea of male or female. Intersex people may have a diverse range of innate physical variations in sex characteristics that differ from medical and social norms for female or male bodies. As a result of these instinctive variations, intersex persons often experience erratic degrees of stigmatization, discrimination and violence in several settings.¹ Intersex characteristics can manifest in a very broad variety of ways ranging from physical, hormonal or genetic features. While some intersex traits may be visible at birth, others may not appear until the person reaches puberty.

The differences in sex development experienced by intersex persons therefore expose them to varying health needs and experiences. They are exposed to biomedical interventions, including hormonal treatment or surgery on minors to align their bodies with typical male/female sex characteristics, with complex challenges around the provision of informed consent. In the end, these interventions may have lifelong consequences due to surgical scarring, the continuation of surgery into adulthood or the effects of trauma linked to surgery that combines with the emotional impact of discrimination and stigma.²

SIPD therefore commissioned a study to shed light on the healthcare needs and accessibility issues facing intersex persons in Uganda and make recommendations for improving access to healthcare services that meet the needs of intersex persons in Uganda.

¹ Carpenter, M. (2020). The OHCHR background note on human rights violations against intersex people. Sexual and reproductive health matters, 28(1), 1731298.

² See Zeeman L, Aranda K. A Systematic Review of the Health and Healthcare Inequalities for People with Intersex Variance. Int J Environ Res Public Health. 2020 Sep 8;17(18):6533. doi: 10.3390/ijerph17186533. PMID: 32911732; PMCID: PMC7559554.

1.2. Background

There is no definite answer on the exact number of intersex persons in the world. However, it has been estimated that intersex persons are approximately between 0.05% and 1.7%³ and sometimes about 4% of the total population.⁴ The United Nations estimates that there are around 70 million intersex people worldwide.⁵ In Africa, data on the population of intersex persons has been compiled only in Kenya, and according to the Census conducted in 2019, there are over 1,524 intersex persons in Kenya out of a total enumerated population of 47,564,296.⁶

Going by the estimated percentage of intersex persons to be between 0.05% and 1.7%⁷ and sometimes about 4%, Uganda may have between 17,300 (0.05%) and 588,200 (1.7%) or 1,384,000(4%) intersex persons using Uganda’s total population of 34.6 million (as at 2014 Population and Housing Census Report).⁸ According to information from SIPD, Sabano (2021) reported that “at least three children are born with an intersex condition at Mulago Hospital every week”⁹ and that between 2018 and 2020, SIPD had “worked with 1,402 intersex persons in the country”.¹⁰ This group faces unique healthcare challenges, including the potential for unnecessary medical interventions and the psychological impact of stigmatization. On an international scale, intersex people have gained visibility through organizations like the Intersex Society of North America¹¹ and the Intersex Human Rights Fund¹², advocating for intersex rights and healthcare worldwide. In Uganda, SIPD is the only intersex-led

³ See Human Rights Awareness and Promotion Forum on the Impact of The Legal aid Policy Framework on The Human Rights of Intersex Persons in Uganda (2016) <https://hrapf.org/index.php/resources/research-reports/168-the-impact-of-the-legal-and-policy-framework-on-the-human-rights-of-intersex-persons-in-uganda/file> (accessed on 05th February 2024).

⁴ A Akre ‘Hanging in the balance: the intersex child, the parent and the state’ 5 Tennessee Journal of Race, Gender & Social Justice 39.

⁵ <https://www.ohchr.org/en/sexual-orientation-and-gender-identity/intersex-people>

⁶ Kenya National Bureau of statistics <https://www.knbs.or.ke/2019-kenya-population-and-housing-census-results/>. (accessed 05 February 2024).

⁷ As in 3 above

⁸ Uganda Bureau of Statistics 2016, The National Population and Housing Census 2014 – Main Report, Kampala, Uganda

⁹ Sabano, J (2021). Intersex surgeries raising concerns among Ugandans. https://www.monitor.co.ug/uganda/magazines/healthy-living/intersex-surgeries-raising-concerns-among-ugandans-3334884?view=htmlamp&_twitter_impression=true. Accessed on 05/02/2024.

¹⁰ Segawa, N (2020). Intersex Children in Uganda Face Rejection, Violence. <https://globalpressjournal.com/africa/uganda/intersex-children-uganda-face-rejection-violence/>. Accessed 05/02/2024

¹¹ <https://isna.org>

¹² <https://www.astraeafoundation.org/apply/intersex-human-rights-fund/>

organisation advocating for their rights and access to a range of services including healthcare.¹³ The World Health Organization (WHO) acknowledges the importance of equitable healthcare access for all individuals, including those with intersex variations. The International Commission of Jurists, in its 2019 publication titled "The Yogyakarta Principles plus 10," emphasized the need for inclusive healthcare systems that respect and protect the rights of intersex people. The Lancet series on gender equality, norms, and health has also highlighted the urgent need to address gender-based disparities in healthcare, including those experienced by intersex individuals. However, access to competent healthcare remains a concern even in more developed regions.

Across African nations, the healthcare landscape for intersex individuals varies considerably, and accessing appropriate care can be a significant challenge, as reported by Meer, T. et al (2017) and Vestlie, A. W. (2021). It's worth noting that there's limited data available on this issue, but existing studies do reveal that intersex individuals encounter discrimination and stigmatization in diverse regions. Historically, intersex issues have been largely overlooked and marginalized in East Africa. This is exacerbated by societal norms that often rigidly adhere to binary gender identities and conventional male or female physical characteristics. Consequently, intersex individuals are often left vulnerable to discrimination, misunderstanding, and the burden of secrecy. The region has witnessed instances of harmful medical interventions on intersex children occurring without informed consent.¹⁴ Such interventions can result in severe and enduring physical and psychological consequences. These practices are driven by societal pressures and a lack of awareness regarding intersex conditions.

These issues affect the ability of intersex persons to access healthcare services and create a hostile environment for seeking care. Healthcare services that specifically address the unique needs of intersex individuals are often inadequate or non-existent. Comprehensive sexual and reproductive healthcare tailored to intersex persons is rarely available. Legal frameworks across East African countries often do not explicitly protect the rights and well-being of intersex individuals. However, most recently Kenya's parliament introduced the intersex bill, to provide for the recognition, protection and safeguarding of intersex persons 'human rights

¹³ <https://sipdug.org/> SIPD is however in the process of building the capacity of other intersex persons to start new initiatives aimed at supplementing the existing effort.

¹⁴ As in 6 above

in Kenya; to provide for the equalization of opportunities, affirmative action and non-discrimination of intersex persons, and connected purposes. According to Mutua, M (2013) this legal gap perpetuates discrimination and violation of their rights in other countries in Africa and East Africa in general.

Intersex individuals in Uganda experience significant stigma and discrimination. They often face rejection from their families and communities, which can lead to mental health challenges and social isolation. Studies elsewhere have also documented that intersex persons experience a lot of self-stigma due to low self-esteem¹⁵ and anxiety due to their physical appearance.¹⁶ Uganda does not have explicit legal protections for intersex individuals and the Ministry of Health does not have policies or guidelines in place to guide healthcare provision for intersex persons.¹⁷ This legal and policy gap can result in human rights violations and discrimination in various aspects of life, including healthcare access. Uganda's approach to intersex issues is influenced by both global and regional trends, with advocacy and best practices emerging from international human rights and intersex movements. While Uganda faces significant challenges in addressing the SRHR needs of intersex individuals, there is also a growing movement within the country raising awareness, advocating for change, and providing support. To obtain, more insights into health needs and access to health care by intersex persons in Uganda, additional research and data collection are essential, which this study sought to do.

1.3 Problem statement

Intersex individuals, whose sex characteristics don't conform to the traditional male/female binary, grapple with multifaceted hardships according to Sudai, M. (2018). Societal stigmatization and discrimination cause severe psychosocial repercussions, including anxiety, depression, and exclusion. These challenges compound when accessing healthcare, leading to delayed diagnoses, inappropriate medical interventions, and enduring physical health issues.

¹⁵ See Close, S., Fennoy, I., Smaldone, A., & Reame, N. K. (2015). Phenotype and Adverse Quality of Life in Boys with Klinefelter Syndrome. *The Journal of Pediatrics*, 167(3), 650–657. <https://doi.org/10.1016/j.jpeds.2015.06.037>

¹⁶ See Van Rijn, S., Stockmann, L., Borghgraef, M., Bruining, H., Van Ravenswaaij-Arts, C. M. A., Govaerts, L., Hansson, K., & Swaab, H. (2013). The Social Behavioral Phenotype in Boys and Girls with an Extra X Chromosome (Klinefelter Syndrome and Trisomy X): A Comparison with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 44(2), 310–320. <https://doi.org/10.1007/s10803-013-1860-5>

¹⁷ See HRAPF and SIPD, 2019: The impact of the legal and policy framework on the human rights of intersex persons in Uganda. <https://sipdug.org/wp-content/uploads/2020/03/Impact-of-Legal-and-Policy-Framework-on-Human-Rights-of-Intersex-Persons-in-Uganda.pdf>

Ethical concerns arise as many medical procedures are conducted without the full understanding and consent of the individuals involved, resulting in lasting physical and emotional consequences according to Hill, M. (2005). The limited awareness and sensitivity of healthcare professionals adds to the predicament, often leading to misdiagnoses, inadequate treatments, and a lack of psychological support. Central to this problem is the violation of human rights and dignity, as intersex individuals deserve healthcare services that respect their rights and well-being.

During the review of literature related to this study findings indicated there are a few studies related to the broader topic of intersex healthcare and rights like Carpenter, M. (2016), but the specific focus on the health needs and access to healthcare for intersex persons in Uganda have limited existing research. This is due to the relatively understudied and marginalized nature of intersex issues, particularly in specific contexts like Uganda. The current study was designed to address this gap to guide the design and implementation of interventions to meet the healthcare needs of intersex persons in Uganda.

1.4 General objective

The main objective of this research was to gather initial baseline data regarding the unique healthcare needs of intersex persons and children in Uganda and access to healthcare services for intersex persons.

1.4.1 Specific objectives

- a) To establish the healthcare needs of intersex persons in Uganda
- b) To assess whether healthcare services are available to meet the unique health needs of intersex persons in Uganda.
- c) To appraise the bottlenecks to access to healthcare services for intersex persons to meet their unique health needs
- d) To gauge the level of satisfaction of intersex persons and parents with existing healthcare services and identify areas for improvement.

1.5 Literature review

Access to health care and the healthcare needs of intersex persons is an area that has not been so much focused on by researchers across the world (Zeeman & Aranda, 2020). Although some research has been conducted on the issue of access to health care by intersex persons as well as the healthcare needs, it suffices to note that most of this research has been conducted outside of Uganda and in most cases outside of the East African region.

Globally research has established that intersex persons are exposed to pervasive mental health challenges because of the prevalent stigma and discrimination that they face. Zeeman & Aranda (2020), conducted a thematic review to synthesize the health and healthcare inequalities for people with intersex variance. Searching systematically in five electronic databases (Medline, Web of Science, Cochrane, PsycINFO and CINAHL) the two authors, considering 16 published articles in the period 2012 to 2019 discovered that people with intersex variance experience a higher incidence of anxiety, depression and psychological distress compared to the general population linked to stigma and discrimination. The synthesis also revealed that even progressive healthcare treatment, including support to question normative binaries of sex and gender, aids understanding of somatic intersex variance and non-binary gender identity, especially when invasive treatment options are avoided or delayed until individuals can self-identify or provide consent to treatment. The study suggests the rethinking of sex and gender to reflect greater diversity within a more nuanced sex-gender spectrum. However, they noted that there were gaps in research around the general health profile and the healthcare experiences of people with intersex variance.

The synthesis also revealed a range of healthcare-related concerns for intersex persons ranging from problematic sexual experiences after medical intervention, dissatisfaction with treatment and surgery, combined with sexual desire problems and an absence of patient or service user consultation regarding their health needs. Results from different studies have challenged the notion that early surgery to feminize or masculinize the bodies of intersex persons is in the best interest of intersex persons. For example, a study in Europe with intersex persons (n = 57) who had undergone genital surgery, revealed that 47% were unhappy with the outcome of surgery, 70% had problems with sexual desire and 56% had experienced symptoms of dyspareunia while 44% XY males feared sexual contact compared to 81% XY females. Overall

dissatisfaction with the sex life of XY females was 42% compared to 11% for the general female population (Köhler et al., 2012).

A study published by the United Nations Development Programme profiled the most common and cross-cutting human rights challenges which intersex persons face in Eastern Europe, particularly Albania, Bosnia, Herzegovina, the former Yugoslav Republic of Macedonia and Serbia.¹⁸ The study revealed that the major human rights concerns of intersex persons in the countries under consideration are the performance of medically unnecessary ‘gender affirming’ surgeries; a lack of legal recognition and discrimination in education and healthcare. In the same measure, Human Rights Watch and InterAct published a study which found that medically unnecessary surgeries are carried out on infants and young children without their informed consent and called for the suspension of such surgeries pending the development of clear guidelines for clinicians.¹⁹

In many parts of the world the treatment protocol for intersexed persons often includes early surgical intervention and an environment of secrecy according to Bishop, E. A. (2007). It should also be noted that minor consent statutes represent a limited departure from the principle that parents are empowered to make decisions on behalf of their children. Bishop, E. A. (2007) proposes that confidentiality requirement in the early stages should be absolute: When the minor has only consulted with a psychiatrist or psychologist about his or her preliminary feelings about the transition, the care provider should be prohibited from disclosing the fact or content of these discussions to the parents without the child’s consent. Intersex individuals often face unique health challenges and may require specialized healthcare and research attention. To ensure the well-being and rights of intersex persons, it is imperative to establish robust confidentiality mechanisms throughout the research and healthcare process. Getting informed consent is a core ethical guideline that applies to both research settings and healthcare settings according to Marshall, P. A. (2006). People must understand the reason for data collection, how it will be used, and any possible dangers or advantages of participating to give their informed permission. This procedure gives intersex people the power to decide for

¹⁸ UNDP ‘Intersex research study: Albania, Bosnia and Herzegovina, the former Yugoslav Republic of Macedonia and Serbia’ (2017).

¹⁹ Human Rights Watch and InterACT ‘I want to be like nature made me: Medically unnecessary surgeries on children in the US’ (2017).

themselves whether to share their personal and health-related data. In many studies, only parental consent is sought when determining surgery solutions for intersex children.

Limited research has been conducted in Uganda on access to health care for Intersex persons. The closest one is the baseline study conducted by the Support Initiative for People with Congenital Disorders (SIPD) in 2016. This baseline provides a broader scope of the lived realities of intersex people in East African countries. It endeavoured to document the status of intersex persons' realities revealing the legal and human rights realities by comparing Uganda's situation to that of Kenya, further profiling the cultural, moral, social and religious discourses, and disrobing conversations on the right to housing, the right to education, the role and impact of religion, socio-economic challenges, healthcare violations and mental health implications. Unfortunately, this broader scope means that the study did not explore the health needs and access to health care of Intersex persons in depth. Nevertheless, it does provide valuable information on the most prevalent concerns of intersex persons living in Uganda, yet access to health is not also a concern in the baseline. This study aims to further build on these findings.

Although Intersex children in Uganda receive sex realignment surgeries, these surgeries are often unsuccessful.²⁰ According to the Ministry of Health, only those surgeries that are in line with medical ethics are performed. Nevertheless, human rights organisations argue that performing these surgeries on young children is a violation of rights as most of the children are simply forced (SIPD, 2016). Moreover, there is prevalent stigma and discrimination in society that intersex persons go through. SIPD established a medical clinic to provide emergency medical services to intersex persons to try and bridge this gap, however, this clinic has majorly focused on diagnosis with challenges in providing real health care (SIPD consolidated Annual reports, 2021).

The legal and human rights framework does not also provide the required guidance to intersex persons on access to health care. Human Rights Awareness and Promotion Forum (HRAPF) and SIPD conducted a study on the impact of the legal and policy framework on the human rights of intersex persons in Uganda in October 2019. In their study, HRAPF and SIPD discuss the various laws and policy frameworks and their implications on the human rights of intersex

²⁰ <https://www.monitor.co.ug/uganda/magazines/healthy-living/intersex-surgeries-raising-concerns-among-ugandans-3334884>

persons. Notably, the report vehemently notes that there is limited protection of intersex persons under the law in Uganda with only the Registration of Persons Act 2015, specifically mentioning intersex persons concerning the change of particulars on birth certificates, albeit referring to them as a hermaphrodite, which is a derogatory term. This study further stresses a violation of the right to health of intersex persons in Uganda as many of them are subjected to surgeries that have not been consented to as these surgeries often occur when they are too young and consent is given by their parents, and yet it is them to live with the impact of the surgeries for the rest of their lives. It is however worth noting that this study looked at the issue from a human rights perspective, negating the health needs and health perspective of intersex persons. It was therefore important to explore in depth the health needs and experiences of intersex persons, which this study sought to navigate.

1.6 Methodology

The study adopted a descriptive cross-sectional design using both quantitative and qualitative approaches to obtain as much information as possible on the health needs and access to healthcare for intersex persons in Uganda.

Primary data was collected through questionnaires, key informant interviews and focus group discussions with intersex persons, parents of intersex persons, health workers, DHOs, officials from the Ministry of Health and officials from SIPD. Through these methods, the study collected primary information on the health needs of intersex persons, accessibility to healthcare that meets these needs and the knowledge and attitudes of health workers in the provision of health services to intersex persons. A total of 24 intersex persons and 12 parents responded to questionnaires from Gulu in Northern Uganda; Tororo and Mbale in Eastern Uganda; Kampala and Mukono in Central Uganda and Mbarara in Western Uganda. These questionnaires collected quantitative information on the health needs of intersex persons, the availability of healthcare that meets their needs and the ease of access to these healthcare services. Questionnaires were also completed by 29 health workers from health centres in the different districts of the four regions as in the table below.

Table 1: Showing the health centres selected for the study

No	District/Region	Health Center
1.	Mbarara/Western region	Ruharo Mission Hospital
		Nyamitanga Health center II
		Kakoba health center III
		Kamukuzi health center
		Mbarara health centre II
2	Gulu/Northern Region	St Peter health center II
		Layibi health center
		Opit health centre III
		St Luke Health center II
		Agonga Karin Community health center II
3	Mbale & Tororo/ Eastern region	Lwaso HC II
		Joy health center III
		Nyondo Health center III
		Magale Health center
		Bungokho Mutoto health center III
		Ligingi health center
		Kayoro health center II
		Panyangasi health center III
		Atangi health center III
		Kasoli health center II
4	Kampala & Mukono/ Central Region	Mulago, Rubaga, Nsambya, CoRSU, Mukono health center IV, Bukerere HC II, Kasawo Health center II

The questionnaires for health workers collected information on the technical competence of health workers to provide health services that address the unique needs of intersex persons, the existence of facilities and equipment that suit the provision of these services as well as

confidential mechanisms in place for intersex persons. They also collected information about the attitudes of health workers towards intersex persons generally.

A total of 6 Focus Group Discussions were conducted in each of the six districts across the four regions. These reached 20 intersex persons and 10 parents of intersex persons. These were aimed at gathering opinions and experiences of intersex persons and parents on the health needs of intersex persons and their access to healthcare that meets these needs. A total of 20 Key Informant Interviews were held with 3 District Health Officers of Gulu, Mbale and Tororo, 12 in charge of different health centres from the six districts, 2 officials from the Ministry of Health, 2 officials from SIPD and the chairperson of the Health committee of Parliament. These interviews sought to obtain information on the health needs of intersex persons, the availability of healthcare services to address the unique healthcare needs of intersex persons, the technical competence of health workers to provide services that address the unique health needs of intersex persons and the experiences of intersex persons in accessing these services. Respondents also made recommendations for improving access to healthcare services for intersex persons in Uganda.

1.7 Data management and analysis

During data collection, the study utilized the Kobo collect application to automate questionnaires and hence created data entry screens that sent the completed data automatically to the central computer controlled by the co-investigator. The research team then carried out data cleaning, organization, and transformation to make it ready for analysis. This involved ensuring data quality, including aspects such as completeness, accuracy and reliability. The raw data sets were exported, and stored, in Excel format. Data from KIIs and FGD were audio-recorded and transcribed into Word documents by the research team making it ready for analysis. All KII interviews were conducted in English except for the Focus group discussions that were conducted in the different dominant local languages in the different regions. These were translated to English at transcription. Qualitative data was analysed using Stata v15, a statistical software for analysis. The study made use of descriptive statistics, including mean, median, and mode, to summarize the relevant data points. The findings were visualized and presented through charts like bar graphs and tables, accompanied by in-depth interpretations to enhance the comprehension of the results. Qualitative data was analysed thematically following a step-by-step framework analysis of qualitative data.

1.8 Ethical considerations

1.8.1 Informed consent

The researcher explained the purpose of the research very well to all participants and sought their consent to participate in the study. Participants were asked to either sign forms confirming their informed consent or recordings were made of their verbal consent. They were given time to think through their response, and, with the participants, a convenient place and time were selected to conduct the interviews in consultation with them. They were all informed of the freedom to participate or not participate in the study. They were also informed that they had a right to withdraw from the study at any time of data collection, if they so wished, without having to give a reason and without affecting any of their rights.

1.8.2 Anonymity and Confidentiality

The study observed strict confidentiality. It does not list the real names of respondents. The information obtained was not shared with other people apart from those working directly on the study and SIPD. The data was kept on a password-protected computer and documents were locked with security passwords as well.

1.8.3 Privacy

To observe this, the researchers discussed with the participants the study's aims, instruments, and methodology and sought their consent and advice on the appropriate time, place, and extent of the interviews. Apart from the group discussions, the rest of the interviews were held in private with just the respondent and the researchers.

1.8.4 Ethical review

Ethical review and approval for the study was undertaken by the Makerere University School of Public Health Research and Ethics Committee reference number SPH-2023-515.

SECTION II:

HEALTHCARE NEEDS OF INTERSEX PERSONS

2.1. Introduction

The findings of this study revealed that intersex persons have unique healthcare needs that are different from those of the general population. However, they also have general health needs like the rest of society. This section presents a comprehensive exploration of the unique health needs as well as the general health needs of intersex persons in Uganda.

2.2. Unique health needs of intersex persons

Because of their variations in sex development, intersex people experience unique health needs compared with the rest of the population.²¹ They may experience the need for hormonal therapy, customized surgeries, and psychosocial support as a result of mental health challenges, unique sexual reproductive health needs and unique health care information.²² This study discovered that all (100%) intersex respondents needed access to hormones, 40% of the respondents needed access to enhanced mental health support, expanded infrastructure and access to quality medical professionals and 30% needed access to surgical services and for some of these were for treatment of effects of surgical operations gone wrong. They also mentioned the need for sexual reproductive health services as most of them worried about their sexual and reproductive life. These are discussed further in detail below.

2.2.1. Hormonal therapy

Hormonal therapy is integral to the treatment of all intersex conditions. In certain cases, like salt-wasting congenital adrenal hyperplasia, hormonal replacement therapy is crucial for

²¹ See Zeeman, L., & Aranda, K. (2020b). A Systematic Review of the Health and Healthcare Inequalities for People with Intersex Variance. *International Journal of Environmental Research and Public Health*, 17(18), 6533. <https://doi.org/10.3390/ijerph17186533>

²² As above

survival as it replenishes essential hormones (such as cortisol and aldosterone).²³ Another study, conducted by Sharma S and Gupta DK, underscores the importance of prudent hormonal supplementation tailored to the specific type of Disorder in Sex Development (DSD) and assigned gender, which can offer psychological and cosmetic advantages to patients with DSD.²⁴ Conversely, in conditions like congenital adrenal hyperplasia where there's an enzyme imbalance leading to excessive secretion of androgens or mineralocorticoids, hormonal therapy aims to regulate hormone levels by employing negative feedback mechanisms to suppress the unwanted hormone excess. However, there are heated debates about the moral implications of current medical practices about intersex disorders and treatments like hormone therapy.

This study found that hormone therapy was necessary for each of the intersex participants in the study. Some intersex persons needed to access hormones to strengthen the development of particular body parts for the sex they felt belonged. However, the cost of these hormones often affected their decision to enroll on those hormones as one of the intersex persons noted below.

"My breast development was delayed despite being a woman, so I needed to take estrogen hormones to ensure they develop. I feel depressed as a woman because women have to have breasts. However, the hormones that I was supposed to take are costly, around 100,000 Ugandan shillings per month yet I was told that this would be continuous." (FGD with intersex persons in Gulu).

This meant that intersex persons would have to postpone the desire to access these services creating mental health challenges including depression and stress. The situation was even worse for intersex persons living out of Kampala and surrounding areas because the study revealed that assessment for hormones and treatment would on be obtained from Mulago Hospital (National Referral Hospital), Nsambya Hospital, Victoria Hospital and Comprehensive Rehabilitation Services in Uganda (CoRSU) Hospital were equipped to provide such specialized treatment due to their trained doctors and specialized equipment.

²³ Warne GL, Grover S, Zajac JD. Hormonal therapies for individuals with intersex conditions: protocol for use. *Treat Endocrinol.* 2005;4(1):19-29.

²⁴ Sharma S, Gupta DK. Gender assignment and hormonal treatment for disorders of sexual differentiation. *Pediatr Surg Int.* 2008 Oct;24(10):1131-5.

However, patients are still required to purchase these medicines from pharmacies, which can be expensive.

"I am required to receive injections daily for the remainder of my life, and I can only obtain this medication from Frieca pharmacy in Wandegeya. Additionally, I must visit Nsambya family clinic for the injections to be administered. This incurs significant costs as each injection costs approximately 200,000/= Ugandan shillings without transport costs." (Focus Group Discussion with Intersex persons in Mukono district).

This underscores the evident absence of specialized health services for intersex individuals at health facilities, including crucial treatments like hormonal therapy, which is integral to the care of every intersex child or person. But these services cannot be found in any of the 23 health facilities that were visited during the study in Mbarara, Gulu, Tororo, Mbale, Mukono and some facilities in Kampala where intersex persons usually go to seek healthcare.

2.2.2. Counselling and psychosocial support services

It was also discovered that Intersex persons needed access to tailored counselling and psychosocial support services. While 85% had sought counselling, especially on issues related to intersexuality it was noted that most health workers in the health centres did not have any idea about their issues so in most cases they were referred to bigger health facilities which was also a big challenge to them. These services are also needed for them to stick to some treatments as some of the treatments are lifetime.²⁵ Studies elsewhere have concluded that lack of counselling and support for parents and genetic counselling for intersex persons has a significant impact on their health.²⁶ They therefore frequently seek counselling, trauma-based care and psychological support with intricate life stories.²⁷ Intersex persons participating in this study revealed that counselling and psychosocial services are required since they face a lot of challenges related to stigma and discrimination in the general society and their general internal

²⁵ Interview with a health worker at CoRSU

²⁶ <https://www.health.vic.gov.au/populations/health-of-people-with-intersex-variations>

²⁷ Ginicola, M. M. (2017). Counseling intersex clients. In M. M. Ginicola, C. Smith, & J. M. Filmore (Eds.), *Affirmative counseling with LGBTQI+ people* (pp. 241–250). American Counseling Association. <https://doi.org/10.1002/9781119375517.ch17>

conflict of who they are. They encounter stigma, prejudice, and oppression for challenging the conventional gender binary both physically and mentally. The shame associated with their bodies can be profound, with prevailing societal messages being rigidly binary and monosexist.

“I ask myself a lot of questions that in most cases I cannot answer and yet when I try to confide in family members, friends and even health workers, I feel resentment still. I don’t feel they are even willing to understand my situation. Sometimes I feel like I should not even have been born.” (Focus Group Discussion with intersex persons in Tororo)

This revelation also points to suicidal intentions underscoring the urgent need for psychosocial services.

All the respondents (intersex persons and parents) that participated in the Focus group discussions (FGDs) in Mbarara, Gulu, Kampala, Tororo and Mbale and intersex persons and parents of intersex persons that filled the questionnaires indicated that no facility especially the health centres had counselling services specialised for them because most of them have no idea of intersexuality.

“We require specialized counselling tailored for the intersex community, yet no health worker is currently equipped to offer it due to their lack of understanding about intersexuality and our unique experiences. They can only provide general counselling services available at any health facility. It does not help at all” (FGD with intersex persons and parents in Gulu)

The only facilities that were cited that would be able to provide adequate counselling services for intersex persons in Uganda are Mulago and CoRSU which have specialised health workers dealing with intersex issues and children born with congenital disorders.

2.2.3. Surgeries

Although not all intersex variations may require surgeries some intersex persons and parents (40%) that participated in the study revealed that intersex persons need surgeries to align their specific body parts to their gender. This same information was also confirmed during Key

Informant interviews.²⁸ Although doctors usually advise parents of intersex children to opt for surgeries or other interventions to make their bodies appear to be gender-conforming, such interventions are often medically unnecessary and have the potential to adversely affect the intersex person later in life.²⁹ Some of these medical interventions are categorized as “gender assignment” or “reassignment”, “normalization” surgeries, genital “enhancement”, clitoral recessions, vaginoplasties, phalloplasties and hypospadias repairs, gonadectomies and associated genital examinations, genital sensitivity testing and medical photography.³⁰ A study done by Fenway Institute in 2020 clearly indicated that there is no evidence demonstrating the benefits of cosmetic genital surgery to a child’s long-term mental or physical health, nor is there evidence of any risk to delaying the procedures until the individual can decide if they wish to have the surgery. However, some intersex variations with congenital disorders may require surgeries which at times lead to post-surgical complications including scarring, chronic pain, loss of sensation, urinary and sexual dysfunction, and other complications that require repeated follow-up surgeries. For instance, in Tororo, an intersex child underwent a similar surgery and the mother had no money to keep taking the child for further surgery so the child currently drips with urine.³¹

Nevertheless, intersex persons continue to express the desire for surgeries. During a Focus Group Discussion in Mbarara, an intersex person expressed the burning desire to undergo surgery to remove breasts.

“I have wanted for a long term to undergo surgery to remove my breasts because as a man the appearance of breasts on my chest terrorises me. It is something that I do not want but there is no clear information here. Health workers have continuously discouraged me which is also not helping at all. If I had money, I would have gone for more specialised assessment and treatment.” (Focus Group discussion with Intersex persons in Mbarara)

²⁸ Interview with official from SIPD and an official from Ministry of Health.

²⁹ DC Ghattas ‘Standing up for the rights of intersex people – how you can help’ ILGA Europe (2015). Accessed from chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://ilga-europe.org/files/uploads/2022/04/Standing-up-human-rights-intersex-people.pdf

³⁰ Carpenter, M. (2020). The OHCHR background note on human rights violations against intersex people. Sexual and reproductive health matters, 28(1), 1731298.

³¹ Focus Group Discussion with Intersex persons and parents in Tororo

While some intersex persons require surgeries, they remain so expensive that intersex persons cannot afford these surgeries as noted by the person above. Another intersex person in Mukono recounted that their surgery would not be completed because they failed to obtain money to travel to India where it would be completed,

"I underwent genital surgery because I would menstruate despite being biologically male. This necessitated corrective surgeries, of which I've had two. However, I have been unable to undergo the third and final surgery, which requires travelling to India and costs no less than 7 million Ugandan shillings." (FGD with intersex persons in Mukono district)

The study indicates that out of the 23 health facilities that included major health centres visited in Mbarara, Gulu, Mbale, Tororo, and Mukono and observations made, none of them had the equipment to conduct these surgeries. Some of the facilities in Kampala like Mulago, Rubaga, and Nsambya also don't have standard equipment to conduct some surgeries so the patients are referred to facilities abroad like in South Africa and India as noted by one of the respondents which are even more expensive for them.³² These same facilities in Kampala including CorSU are the only facilities that can provide hormonal therapy which includes cortisol, androgens mineralocorticoids and aldosterone but they are expensive for intersex persons in Uganda. While these treatments may be used for treating intersex, conditions pose challenges since they may inherently disrupt various elements of an individual's gender identity, gender-role behaviour, sexual orientation, sexual functioning, and psychological adjustment.³³ Additionally, determinations made by doctors and parents about an infant's gender may not consistently align with the individual's actual gender identity as they grow older.³⁴ This can lead to feelings of uncertainty or, worse, resentment towards their life experiences and treatment. When the time for hormonal therapy approaches, individuals with such experiences will likely have strong opinions, emphasizing the need for adept counselling.

³² Key Informant Interview with an official from SIPD

³³ Warne, G.L., Grover, S. & Zajac, J.D. Hormonal Therapies for Individuals with Intersex Conditions. *Mol Diag Ther* 4, 19–30 (2005).

³⁴ Interview with an official from SIPD

2.2.4. Unique Sexual Reproductive Health (SRH) needs

Sexual Reproductive Health (SRH) comprises maternal and newborn care, services for family planning, abortion services, and addressing sexually transmitted infections.³⁵ Sexual and reproductive health and rights concerns include; unplanned pregnancies, an increase in STIs and HIV, abortion care including preventing unsafe abortions and providing post-abortion care; and an increase in sexual gender-based violence, cervical cancer, and family planning among others.³⁶ SRH are “centred around individual autonomy and the ability to make choices regarding individuals’ reproduction and sexuality to enjoy the highest attainable standard of health”.³⁷ Therefore, critical aspects of sexual health rights are about rights to express one’s sexuality; receive sexuality education and services and also the right to freedom from exploitation and violence including sexual and gender-based violence.³⁸ Conversely, despite the strong support for SRHR among many governments, civil society and the general population, there is not much information available on the SRHR for intersex persons. Even in most policy documents, intersex persons are hardly mentioned as a category of concern.

This study, however, revealed a range of SRH needs that are unique for intersex persons. These unique needs are related to concerns about fertility, reproduction and raising a family as well as sex education and the general access to information on SRH. For example, Intersex persons had concerns about how, when and with whom they would have children.

“I feel like I want to test my sperms to know if I will be able to impregnate someone and get a child. I am 32 years old. I am now too old to continue to go through several surgeries. So, I would like to know if I can be able to impregnate someone and if I am not able, I need to know and get over it for good.” That’s my biggest need now (FGD with Intersex Persons)

³⁵ WHO Sexual and Reproductive Health Factsheet <https://www.afro.who.int/fr/node/12795>

³⁶ <https://www.afro.who.int/sites/default/files/2020-06/Sexual%20and%20reproductive%20health-%20Fact%20sheet%2028-05-2020.pdf>

³⁷ Sundewall, J., & Kaiser, H. (2019). Sexual and Reproductive Health and Rights: An Essential Element of Universal Health Coverage. Background document for the Nairobi Summit on ICPD25-Accelerating the promise.

³⁸ As above.

While this is not a concern among the rest of the public, this concerned intersex persons so much to the extent that they wanted to test their sperms. Indeed, some intersex parents also expressed worry about whether their children would ever give birth.

“I don’t know if it will be possible for my child to give birth because of their condition. I would have desired for them to give birth so that I could also get to see grandchildren. I don’t know if there are even services that help them out with this issue so that they can also live a normal life like the rest of the people and be able to give birth and raise their children.” (FGD with intersex persons and parents).

Some intersex persons expressed anxiety as to how and whether they can have sex given their conditions. To some, the size of their sexual organs makes them fear having sex.³⁹

2.3. General health services

The study indicates that 100% of the intersex individuals emphasized that they also needed general health services, similar to the general population, including family planning, counselling, antenatal care, treatment for STIs and STDs, and HIV services, which are typically available at nearby health centres. For instance, 80% of the respondents noted that they had accessed medical assistance when ill with malaria, STI and HIV services. During a focus group discussion in Tororo, one respondent mentioned,

“Health centres can offer essential primary health care services such as family planning, condom distribution, counselling, referrals, and treatment for common illnesses like malaria.” (FGD with intersex persons in Tororo)

These services are crucial for their overall well-being and health management. However, despite the availability of these services at nearby health centers, intersex individuals face several barriers that hinder their access and utilization. One notable barrier highlighted in the study is the lack of awareness and understanding of intersexuality among healthcare providers.

³⁹ Focus Group Discussion with intersex persons in Tororo

As a result, many intersex individuals encounter difficulties when seeking care even the usual general services, as healthcare workers may not be equipped to address their unique needs and concerns.

“One time I went to a health centre in my area to seek for treatment an STI but because of my condition, the health worker failed to diagnose the issue and referred me to Mbarara Referral Hospital.” (FGD with intersex persons in Mbarara)

This lack of awareness can lead to misdiagnosis, inappropriate treatment, and inadequate support, exacerbating the physical and psychological challenges already faced by intersex individuals.

Moreover, the study indicates that while some intersex individuals are able to access healthcare services, they often experience stigma and discrimination within healthcare settings. This discrimination can manifest in various forms, including judgmental attitudes, disrespectful treatment, and even denial of care. For instance, one of the respondents in Gulu noted

“I recall visiting a healthcare facility when I had an infection, but instead of receiving assistance, the doctor hastily summoned other healthcare workers to examine my organs.” (FGD with intersex persons in Gulu)

Such experiences not only undermine the trust between intersex individuals and healthcare providers but also deter them from seeking necessary care, leading to further health complications and disparities.

The issue of medicine shortages which is generally faced by the other persons in the general public was also raised by intersex persons. For instance, one respondent in Tororo noted

“At times when you go to the health facility, you may find not drugs so you are requested to go a pharmacy to get them yet you even don’t have money.” (FGD with intersex persons and parents in Tororo)

This study indicates that measures should be taken to address medication shortages and improve access to affordable healthcare services for intersex individuals. This may involve expanding healthcare infrastructure, increasing funding for essential medications, and implementing policies to reduce out-of-pocket expenses for healthcare services. Additionally, there is a need for greater collaboration between healthcare providers, policymakers, and intersex advocacy groups to develop and implement comprehensive strategies to improve healthcare access and outcomes for intersex individuals. This approach requires addressing these challenges requires a multifaceted approach that addresses systemic barriers, promotes awareness and understanding, and ensures inclusive and equitable healthcare for all individuals, regardless of their intersex status. Prioritizing the needs and rights of intersex individuals, could lead to building a healthcare system that truly meets the needs of all members of society.

SECTION THREE

ACCESSIBILITY TO HEALTHCARE SERVICES FOR INTERSEX PERSONS

3.1. Introduction

Access to healthcare services for intersex individuals is a multifaceted issue that encompasses numerous challenges and considerations. The ability of intersex persons to obtain and utilize healthcare services effectively is influenced by a range of factors, including physical proximity to healthcare facilities, affordability, availability of necessary resources, quality of health services and the presence or absence of stigma and discrimination. Understanding and addressing these complexities are essential for ensuring equitable and inclusive healthcare provision for intersex individuals. In this section, we explore the various dimensions of access to healthcare services for intersex persons in Uganda.

3.2. Availability of the healthcare services

Availability of health services refers to the adequate supply and accessibility of health services by the individuals who need them.⁴⁰

Table showing a summary of responses from health workers, intersex persons and parents on questions regarding availability of health services

No	Variable studied	% of Responses	Nature of respondent
1	Intersex persons medical approaches like surgeries	100%(agree)	Health workers
2	Average distance required to access health services	230kms	Intersex persons and parents

⁴⁰ Mary, O, Onoja-Alexander., S.H., Idris., Chinedu, John-Camillus, Igboanusi., A.D, Onoja., A.J., Istifanus., O.A., Olawepo. (2017). Assessment of the Availability and Accessibility of Emergency Obstetric Care Services in Murtala

3	Health facilities with specific services tailored for intersex persons like hormonal therapy, counselling	0%	Health worker and intersex persons
4	Intersex persons discriminated in the health care system	83%	Intersex persons and parents

The study found that 100% of the health workers agreed that intersex persons required medical approaches like surgeries which may not be the case since most health facilities do have the services in place. According to intersex persons and parents, the average distance required to access health services that address their unique health needs is 230 kilometres. This is because most of them had to travel from their districts to Kampala where some health centers could offer these services. This indicates that availability of healthcare services for intersex persons is constrained in Uganda. All intersex persons, parents of intersex and health workers (0%) agreed that there were no health centres upcountry providing services that addressed the unique health needs of intersex persons. This suggests a lack of specialized healthcare services catering to the needs of intersex individuals which greatly constrains access to services.

This study indicated that only Mulago National Referral Hospital and CoRSU (Kampala and Wakiso) are the health facilities that can provide these specialised services though they are inadequate. For instance, one respondent from the focus group discussion in Kampala noted;

“While CoRSU and Mulago have services like hormone therapy, counselling and surgeries specific for intersex persons, all the health facilities/centres near us don’t have these services”. (FGD with intersex persons and parents in Kampala)

However, the study indicated still that some of these facilities don't have standard equipment to conduct some surgeries so the patients are referred to facilities abroad like in South African and India in case of surgeries⁴¹ which are even more expensive for them.

Although some health facilities could provide some of these services, most of them can only provide hormone therapy. Intersex persons and parents have found themselves in a dilemma when they are referred to South Africa or India for specialised treatment. You pity them, because you need a lot of money to access services from those countries. (KII with an official from SIPD).

These same facilities in Kampala including CoRSU are the only facilities that can provide hormonal therapy which includes cortisol, androgens, mineralocorticoids and aldosterone but they are expensive for intersex persons in Uganda. None of the other 23 health centers where intersex individuals had sought services, offered these specific provisions. Nonetheless, they mentioned that they could access general services such as family planning, HIV treatment, malaria treatment, referrals and others at these facilities.

3.3. Affordability of the health care services

Affordability of health care services encompasses a function of income, spending and judgement of the health services provided.⁴² It relates to the economic capacity of individuals to access health services, and the ability to pay for the services determines whether the services are affordable.⁴³

The study revealed that although intersex persons have an urgent need to access services to address their unique health needs, the cost of these treatments prohibits them from accessing these services. Notably, 94% of the respondents reported earning less than 500,000/= Ugandan shillings, with a significant portion lacking any source of income. Furthermore, despite only 6% of the parents and intersex individuals earning an income exceeding 500,000/= per month,

⁴¹ Key informant interview with official from SIPD

⁴²https://ldi.upenn.edu/wpcontent/uploads/archive/pdf/Penn%20LDI%20and%20USofC%20Affordability%20Issue%20Brief_Final.pdf

⁴³ Levesque, J., Harris, M. F., & Russell, G. (2013). Patient-centred access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*, 12(1), 18. doi.10.1186/1475-9276-12-18

they still encountered considerable difficulties in accessing medical care, particularly for expensive treatments like hormonal therapy and necessary medications available at specialized clinics and facilities.

They expressed that their capacity to secure only basic treatments for their children is hindered by the exorbitant costs, exemplified by a respondent in Mukono who disclosed being unable to afford their final surgery, necessitating travel to the South for the procedure. A different participant from Kampala mentioned,

"I have to purchase hormones to facilitate breast development because I identify as a woman. However, they are quite costly, requiring approximately 80,000/= to 150,000/= Ug shillings per month." (FGD with intersex persons and parents in Kampala)

This highlights how costly it is for intersex persons to afford services like hormonal therapy, psychosocial services and surgeries when required.

As earlier indicated medical surgeries can only be obtained from specific facilities like CoRSU and Mulago. However, these medical procedures are expensive and they may not provide all the levels of treatment required by an intersex person. The situation becomes very difficult if someone is even referred to outside of the country.

"I have undergone three surgeries; however, I have failed to get the last surgery that doctors in CoRSU referred me to because it requires me to travel to India for the surgery at 7 million shillings." (FGD with intersex persons in Mukono district)

The study discovered that counselling is the only service that intersex persons could easily afford because no costs are requested from them by the health workers. However, given the stigma and discrimination that they face, they require specialised counselling services which may also not be offered at CoRSU, Nsambya and Mulago.⁴⁴

⁴⁴ Lampalzer, U., Briken, P. & Schweizer, K. Psychosocial care and support in the field of intersex/diverse sex development (dsd): counselling experiences, localisation and needed improvements. *Int J Impot Res* **33**, 228–242 (2021). <https://doi.org/10.1038/s41443-021-00422-x>

3.4. Appropriateness of the healthcare services

Appropriateness is about whether the available services fit the needs of those who seek the services. It relates to the adequacy and quality of services provided, including providers' professional experience.⁴⁵ This study examined the quality and effectiveness of the healthcare services provided to intersex persons in Uganda by determining whether the available healthcare services are sufficient in quantity and quality to meet the diverse needs of intersex persons. This study adopted the World Health Organization's definition of quality of health care as being the degree of health services to which intersex persons increase the likelihood of desired health outcomes. So, this study inquired about the level of satisfaction while accessing health services at the different facilities.

Among the health facilities we visited during the study only Mulago and CoRSU could offer healthcare services specific to intersex persons although these were also still inadequate as hypothesized by an officer working with SIPD.

“I appreciate the services rendered by Mulago and CoRSU, though they are still inadequate to serve all the intersex persons in Uganda.” (KII with an official working with SIPD).

The reason why they appreciated the services from Mulago and CoRSU is that they received services from specialized facilities as compared to the services acquired from health centres where the health service providers didn't know much about intersexuality and their health needs.

While intersex persons require unique health services there is a need to ensure that health workers are knowledgeable about their issues and health needs to avoid further stigma and discrimination that they are already facing.⁴⁶ To further stress this point, 47% of the respondents (intersex persons and parents of intersex persons) noted that the quality of health services they received were poor while 22% indicated that services were good and only 2 out of 36 (6%) noted that they were excellent. Only 6% indicated that most of the health needs and

⁴⁵ See no 42 above

⁴⁶ Lee, D. S., & Chopak-Foss, J. (2023). Improving Healthcare Experiences for Transgender and Intersex Populations. *Journal of the Georgia Public Health Association*, 9(1), 4.

services were acquired once while accessing them from the facilities while 69% noted that only a few of their needs were met at the health facilities. 38% of the intersex persons and parents of intersex persons were not satisfied with the amount of help and services from the health facilities they accessed because they did not have the drugs for hormonal treatments and they had to travel to far hospitals like Mulago and CoRSU if they were to acquire the medication and treatment.

3.5. Other factors associated with access to health care for intersex persons

Beyond the above, access to healthcare for intersex persons was constrained by some other factors. These are expounded below:

3.5.1 The conflation of intersex issues with homosexuality.

In Uganda, sex education and experience have excluded intersex bodies and this has raised misconceptions where people think biological sex is either “female” or “male yet it can be more complicated than that. In some cases, intersex persons have suffered homophobia directed towards homosexuals constraining access to healthcare services. One of the in charges in one of the facilities in Tororo, clearly said that there was a slim chance that intersex persons would be homosexuals yet that may not be the case. This highlights the lack of knowledge of intersex issues.

“I think and I might be right, intersex issues are linked to homosexuality. You see there are a lot of issues we have to deal with right in a very careful way. There is a law already and these are things we need to be careful about as leaders.” (KII with a health facility in charge in Tororo district)

This lack of knowledge about intersex persons by even health service providers has left them exposed as 83% of the respondents noted that they were discriminated against because people don’t clearly know about them and the issues they were facing. Whereas parents of intersex persons have raised their children knowing them, the other community members may not know about them but the ones who are known are subjected to stigma and discrimination.

3.5.2. Confidentiality mechanisms within health facilities for collecting feedback from intersex children

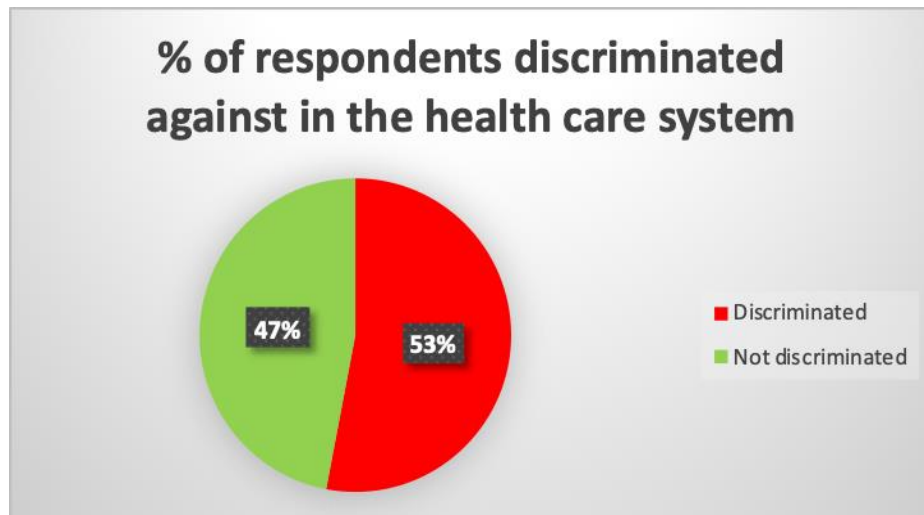
According to the study conducted by Orishaba, G& Serunjogi, D (2022), emphasised that patients are always required to share information with their doctors to facilitate correct diagnosis and determination of the treatment.⁴⁷ However, this comes with issues of privacy and confidentiality which remain a major concern at health facilities. Ugandan policies, guidelines and patients advocate for confidentiality as regards information on all patients at health facilities. This is meant to protect the patient's rights to privacy, give the patient the right to refuse being examined, treated or observed by learners, and access to medical records to be told about their intersex status or any medical history. This implies that all patients have the right to informed consent and bodily autonomy.

However, this study indicates that 3 in 6 (50%) of the intersex persons and parents have faced an incidence where a health worker does not request for formal consent to tell another doctor about the child's sexuality and hence causing a lot of lack of privacy where one respondent noted that a lot of health workers kept storming into the room to see the born child without any assistance as requested. For instance, one of the health workers working in a health centre in Tororo noted that she would just call the in charge in case she a kid with ambiguous genitalia. Thus;

“since I do not know much about intersex persons I just go immediately a call the in-charge to intervene.”

This is done with the knowledge and consent of the mother of the intersex child. While 78% of the health facilities visited have written guidelines on patient confidentiality some cases these guidelines are gone against by the same health workers who now days use social media to post some of these pictures of intersex persons like one the health workers in Mbale noted.

⁴⁷ Orishaba , G. ., & Serunjogi, D. (2022). What Privacy and Confidentiality Mechanisms are used in the Electronic Health Records (Clinical Master and ICT4 M-Power systems)? A design Science Research Approach. *Student's Journal of Health Research Africa*, 3(9), 8.



This study also highlighted that confidentiality concerns accompany stigma and discrimination when left unattended since there is a belief that information flow can facilitate this according to an article published by the Canadian Public Health Association in 2017.⁴⁸ According to the current study 76% of the health workers noted that informed consent protocols are always enforced in the health centres implying that there are incidents where informed consent protocols may not be enforced as explained by the response of 25% of the health workers. Without consent protocols established within the health facilities, intersex persons are prone to face incidents where their privacy is encroached on. For instance, one of the respondents in Gulu during the focus group discussion noted that:

“while I went to the health facility to check for an infection instead the health worker went ahead to tell all the fellow health workers without consent and I was not happy.”

3.5.3. Technical competencies of healthcare providers in addressing the unique healthcare requirements of intersex children and people.

A study conducted by Obedin-M, J et al. (2011)⁴⁹ indicates that since intersex persons experience barriers to equitable health care there is a need to train health workers on issues concerning the intersex persons so that they can help them. Cosmetic, irreversible and harmful

⁴⁸ Canadian, H. I. V., Network, A. L., & Canadian Public Health Association. (2017). Reducing stigma and discrimination through the protection of privacy and confidentiality. *Ottawa (ON): Canadian Public Health Association.*

⁴⁹ Obedin-Maliver J, Goldsmith ES, Stewart L, et al.: Lesbian, gay, bisexual, and transgender-related content in undergraduate medical education. *JAMA* 2011;306:971–977. [Crossref](#), [Medline](#)

medical and clinical procedures infants and children born with intersex variations have been subject to include unconsented and medically unnecessary surgeries, mutilation and sterilization that cause irreversible physical and psychological harm.⁵⁰ Despite these natural variations in sex presentation, the medical community has historically embraced a harmful and inaccurate model for providing care to intersex individuals, including performing irreversible surgeries on intersex infants. Research has shown that such “gender normalizing surgeries” can impose long-term physical and psychological harm with little research documenting the supposed benefits of such procedures.⁵¹

While medical interventions are generally discouraged during a child's early years, it remains crucial for health workers dealing with intersex individuals to possess the necessary technical knowledge to provide adequate care. Lack of such knowledge may expose intersex persons to heightened levels of stigma and discrimination within society and healthcare setting. With the exception of medical professionals providing information during key informant interviews like doctors from CoRSU and Mulago, most health workers demonstrated limited or no understanding of intersex persons. The study reveals that 66% of health workers that responded to the questionnaires acknowledged never having received any training on intersexuality. Moreover, all respondents worked in maternity or antenatal sections of the health facilities approached, suggesting that they may have insufficient knowledge on how to address intersex variations in children. All the health workers (100%) that responded to the questionnaire believe that intersexuality is a problem that requires a medical approach like surgeries to treating intersex infants and children aimed to prevent the possibility of a child growing up to have non-heterosexual relationships and are seen as medical curiosities. This is often due to healthcare providers lacking a clear understanding of the condition, and a few health facilities could have these conditions making it difficult to determine the child's gender for parents.⁵²

⁵⁰https://www.researchgate.net/publication/374543307_Intersexuality_What_Primary_and_Specialized_Healthcare_Providers_Should_Know_and_Do_to_End_Cosmetic_and_Harmful_Medical_Practices_on_Infants_and_Children_Born_with_Intersex_Variations_in_Tanzania

⁵¹ <https://howardbrown.org/supporting-intersex-identities-in-healthcare/>

⁵² <https://fenwayhealth.org/improving-health-care-for-intersex-people/>

Table showing responses of health workers on knowledge about health care on intersex persons

Question	Response	Frequency	Percentage
Corrective surgeries and other medical, hormonal and psychological treatments for intersex people are	Always necessary, as having both male and female sex characteristics leads to medical problems, but they have to be put in place in infancy in order to be followed by a normal life	15	51.72
	Always necessary, as having both male and female sex characteristics leads to medical problems, but they should be introduced in adulthood so that patients can choose the sex they feel more comfortable	13	44.83
	Not always necessary, as in many cases an intersex body is a perfectly healthy body	1	3.45

Source: Primary data for the study.

The study also indicates only 50% of the health workers from Mbarara, Tororo, Mbale, Mukono, Kampala and Gulu who filled out the questionnaires have been trained on principles of confidentiality and patient’s privacy. Only 24% of the health workers have been trained on the principles and procedures of extending health care to persons with intersex characteristics and informed consent. The observations also made during the study indicate, that intersex patients and their families with specialist care needs don’t have access to an integrated multidisciplinary team of intersex-affirming medical and behavioral health clinicians who do not condone medically unnecessary surgeries on infants. Because some intersex patients have experienced medical trauma, they may have a high level of anxiety and distrust when visiting a health care provider and the fact fear the health workers in Uganda know intersex issues there are increased incidents of avoidance of accessing health care services due to stigma and discrimination.

The study findings indicated that 74% of the intersex persons trying to access health services have avoided visiting healthcare providers even when they were feeling unwell. All 46(100%)

of the health workers that answered the questionnaires noted that they could be able to counsel any patient that comes to the facilities however, the fact that they do not know intersex issues they can counsel them specifically on issues that affect them hence they always face further stigma, medical trauma for patients that have undergone surgeries and discrimination that may affect their mental, interpersonal, PTSD and physical health. While many intersex people do not need any specialized medical care, some require care at specific developmental junctures, and others have lifelong needs related to their variation. Primary care providers should be able to help intersex persons/individuals and families find trusted referrals and navigate specialized care.

All the 23 health centres visited did not have health personnel who were well versed and knowledgeable about intersex persons and their health needs and yet 80% of the health workers that filled out the questionnaires indicated that all intersex persons needed to undergo medical surgeries to correct their sex to avoid confusion in the future. All the health centres in Mbarara, Gulu, Tororo, Mbale and Mukono did not have the appropriate equipment to conduct surgeries if needed. One of the respondents noted they have only seen standard surgery equipment that would help persons in Mulago for detecting intersex variations (prenatal ultrasound). While 50% of the health workers were confident in supporting and providing health care to intersex persons and 39% were very confident of supporting and providing healthcare to intersex persons, it should be noted all the 23 health centres visited are not able to provide psychological health services including interpersonal distress and PTSD, gynecologic care, and hormone replace therapy because they don't have specialised health workers and equipment to do that and 96% of the health workers in the facilities indicated that they believe that services like corrective surgeries, other medical services, hormonal treatment and psychosocial services should be available at the facilities.

While 23% of the health workers do not that the health centres have standard operating procedures for the care and treatment of intersex, there was no evidence of the SOPs in place and this confirms that most of the health centres in Uganda do not have SOPs for care and treatment of an intersex person as seen that majority 77% of the health workers agreed that the health facilities don't have specialized standard operating procedures for intersex persons. However, it is key to note that 76% of the health facilities visited by the research team have informed consent protocols enforced when screening or providing health care for the general community including intersex persons. The study also found out that while most health workers

are able to provide counselling to any patient that comes to the facilities that no one of the health workers can provided specialized counselling services to the intersex persons because their barely know their issues and conditions yet compared to the general population, intersex people have greater rates of anxiety, depression, and psychological distress symptoms associated with discrimination and stigma.⁵³

3.5.4. Lack of Policies and guidelines for enhancing health service provision for intersex persons

The study indicates that Uganda does not have specific policies and guidelines specifically tailored to healthcare for intersex persons. The healthcare system in Uganda generally addresses broader issues related to reproductive health, HIV/AIDS, and other health concerns, but there are no specific provisions addressing the unique needs of intersex individuals. One of the respondents from the parliament that was championing the introduction of the bill that would help cater for intersex issues noted that

“.....we currently don’t have policies and guidelines that would even help to fight the stigma and discrimination the intersex persons face in society especially in the health care system.” (KII with a Member of Parliament)

The absence of specific policies and guidelines on healthcare for intersex persons in Uganda poses several disadvantages. Firstly, it has led to inadequate and inconsistent healthcare provision for intersex individuals, as healthcare providers lack proper training and awareness regarding their unique medical needs. This has in most cases resulted in misdiagnosis like for instance as one respondent noted.

“I grew up thinking that I was female due to misdiagnosis and I have to deal with that I am male with the discrimination out there”,

This means that intersex persons undergo inappropriate treatment, and unnecessary medical interventions, leading to physical and psychological harm. Additionally, without clear guidelines, intersex individuals have faced discrimination and stigma within healthcare

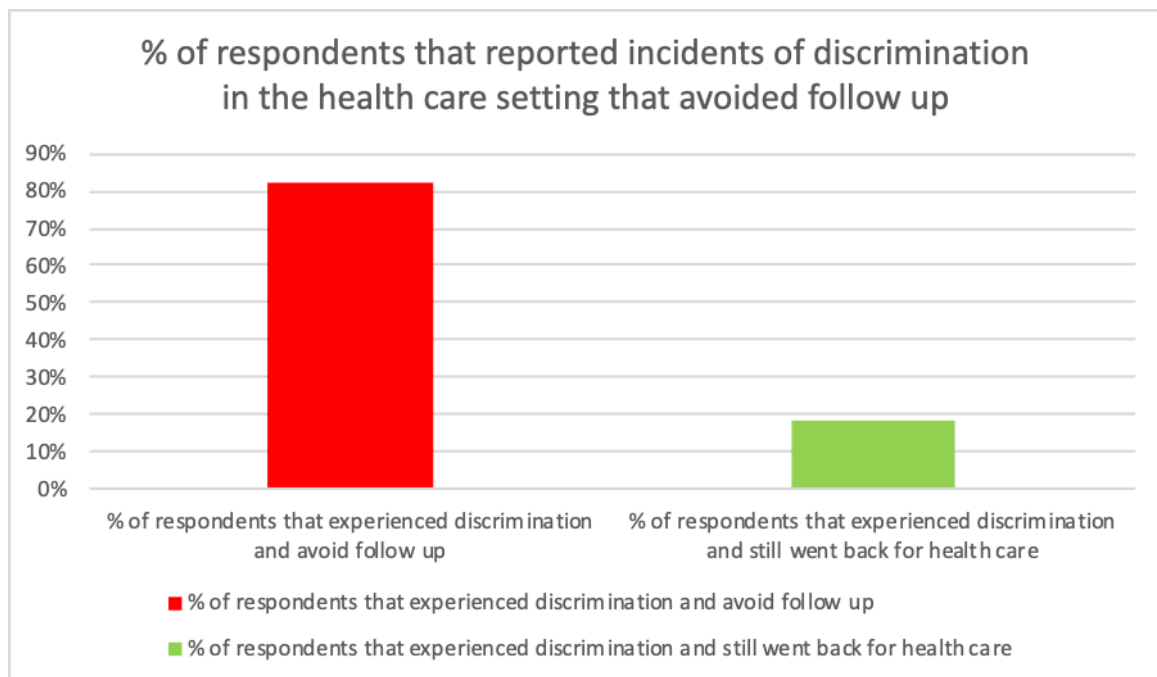
⁵³ <https://howardbrown.org/supporting-intersex-identities-in-healthcare/>

settings, hindering their access to essential services and deterring them from seeking necessary care. Furthermore, the lack of policies has exacerbated existing disparities in healthcare access and outcomes, disproportionately impacting intersex individuals who are already facing marginalization and social exclusion. Overall, the absence of policies and guidelines on healthcare for intersex persons in Uganda perpetuates systemic barriers to their well-being and underscores the urgent need for inclusive and equitable healthcare policies that prioritize their rights and dignity.

3.5.5. Stigma and discrimination

According to the questionnaires of intersex persons and parents, 83% of intersex persons reported experiencing discrimination within the healthcare system. This indicates that a significant proportion of intersex individuals encounter discrimination when accessing healthcare services, highlighting a concerning issue within the healthcare system. For instance, in Tororo in village called Ligingi, most community members believe that families with intersex children are cursed.

This highlight some of the confidentiality issues that are faced by intersex persons while trying to access health services.



The study also indicated that 65% of the health workers noted that health care records are stored in secure places for privacy reasons of patient's information. This percentage leaves a gap that some records may not be stored in secure places for privacy as indicated by the 35% of the responses from the health workers because some health facilities don't have proper storage facilities.

The study also discovered only 47% of the health workers noted if a health worker or provider discriminates against a patient, especially intersex persons have had an issue addressed by the administration like reporting the health worker to the disciplinary committee, and punishments, among others. This implies that many incidents of discrimination may occur in the health care system but they go on unnoticed or addressed by the authorities since the patients see them as their saviours say noted by one of the respondents. Even in big health care facilities, health workers are still struggling to provide services to intersex persons due to stigma and discrimination. Thus;

“.....but here in Mulago its different but still there challenges dealing with intersex variations. We strive to provide compassionate and confidential care to all individuals, including those with intersex variations. We have protocols in place to ensure that patients' privacy and dignity are respected, and we make efforts to create a welcoming and inclusive environment. Our staff are trained to communicate sensitively and effectively with intersex patients, and we have referral mechanisms in place to connect patients with specialized care when needed.” (KII with a doctor at Mulago).

3.6 Conclusion

This study revealed constricted access to healthcare services especially those aimed at addressing their unique healthcare services. As discussed above, only very few health facilities can provide these services. However, these also lack clear guidelines and policies to guide these treatments. Access is also restricted by the various barriers to care including the limited knowledge of health workers of intersex issues, stigma and discrimination, lack of policies and

guidelines, limited confidentiality mechanisms and the conflation of intersex issues with homosexuality.

SECTION FOUR:

CONCLUSIONS AND RECOMMENDATIONS

4.1. Conclusion

The study emphasizes the diverse health needs of intersex individuals in Uganda, spanning issues from access to medical treatment, disclosure challenges, and lack of support for parents. Cultural beliefs and ignorance contribute to the rejection and stigmatization of intersex individuals, impacting their freedom and right to health. The study reveals the inadequacy of

healthcare services, with health workers lacking awareness and facilities not equipped for specialized intersex care.

Intersex variations in Uganda present a spectrum of genetic features, with potential consequences of coercive medical interventions. Lack of proper diagnostic equipment, limited access to essential surgeries, and financial barriers exacerbate challenges. Discrimination, both in societal and within healthcare settings, compounds psychological distress. Limited knowledge among health professionals underscores the need for improved education and awareness regarding intersex issues.

The study further finds a significant gap in the quality of healthcare services for intersex individuals in Uganda. Health centres lack essential specialized services, leading to dissatisfaction among intersex persons seeking health care services. Limited knowledge and training among health workers contribute to further stigmatization and discrimination. Adequate counselling services, mental health support, and specific surgeries are notably absent, emphasizing the need for comprehensive improvements in healthcare infrastructure and personnel training.

The study reveals a lack of technical knowledge among healthcare providers, with most health workers having little or no training on intersexuality. Inadequate awareness results in potential harm to intersex infants and children through harmful medical procedures. The absence of multidisciplinary teams and specialized care exacerbates the challenges faced by intersex individuals. The study advocates for enhanced training on intersex issues and the development of integrated care teams to improve patient outcomes.

While Ugandan policies emphasize patient confidentiality, the study exposes instances where privacy is compromised. Violations, including unauthorized disclosure of intersex status, highlight the need for improved adherence to guidelines. Health facilities must enforce informed consent protocols and maintain secure patient records. The study recommends strengthened disciplinary measures for healthcare workers who discriminate against or violate the privacy of intersex individuals.

4.2. Recommendations

To improve access to services for intersex persons, the study makes the following recommendations:

To Parliament of Uganda

- Parliament should use its legislative powers to pass a law that increase the protection of intersex persons and strengthens the provision of healthcare among. The ongoing effort by civil society organisations and the chairperson of the health committee of parliament should be supported to fruition.

To the Ministry of Health

The Ministry of Health should;

- Develop and implement comprehensive training programs for health workers to enhance their understanding of intersex issues. Key takeaways include the importance of sensitivity training for healthcare professionals, ensuring the provision of inclusive and non-discriminatory services, and actively involving intersex individuals in the policy development process to guarantee that their perspectives and experiences are appropriately represented and prioritized.
- Develop a comprehensive policy to address Sexual and Reproductive Health and Rights (SRHR) issues for intersex individuals is crucial for promoting inclusivity, respect, and equal access to healthcare. This initiative will not only foster a supportive environment for intersex persons but also enhance overall healthcare equity by recognizing and addressing their unique needs.
- Develop standardized guidelines and protocols for the care and treatment of intersex individuals, incorporating inclusive policies, cultural sensitivity, informed consent, holistic healthcare approaches, regular review, and ongoing education to ensure equitable and respectful medical practices.
- Ensure the provision of specialized services in government healthcare facilities upcountry, encompassing hormonal therapy, counselling, and necessary surgeries, to adequately equip health facilities for comprehensive care in support of individuals with diverse healthcare needs.

- Establish in health facilities, support networks and counselling services specifically tailored for intersex individuals and their families.

To the Ministry of Education and Sports

- Integrate accurate information on intersex variations into the school curriculum and sex education programs.

To SIPD and human rights organizations advocating for the rights of intersex persons

- Proactively engage with the Ministry of Health through collaborative consultations, workshops, and inclusive policy dialogues to advocate for the incorporation of specific Sexual and Reproductive Health and Rights (SRHR) policies and services tailored to the unique needs of intersex persons, fostering a supportive healthcare environment that prioritizes inclusivity, education, and sensitivity training for healthcare professionals.
- Conduct public awareness campaigns to dispel myths and reduce societal stigma surrounding intersexuality.
- Continue to advance efforts for a law to promote the rights and access to healthcare for intersex persons in Uganda.

To intersex persons and parents

- Seek support and information from reputable intersex advocacy groups,
- Engage in open and informed conversations with healthcare professionals to understand all available options, prioritize informed decision-making, and
- Actively participate in shaping policies and guidelines related to intersex care and rights to ensure their voices are heard and respected.
- Report and document all forms of violations, stigma and discrimination

REFERENCES

Ard, K. L., & Keuroghlian, A. S. (2018). Training in sexual and gender minority health-expanding education to reach all clinicians. *The New England journal of medicine*, 379(25), 2388-2391.

Bishop, E. A. (2007). A child's expertise: establishing statutory protection for intersexed children who reject their gender of assignment. *NYUL Rev.*, 82, 531.

Canadian, H. I. V., Network, A. L., & Canadian Public Health Association. (2017). Reducing stigma and discrimination through the protection of privacy and confidentiality. Ottawa (ON): Canadian Public Health Association.

Carpenter, M. (2016). The human rights of intersex people: addressing harmful practices and rhetoric of change. *Reproductive Health Matters*, 24(47), 74-84.

Dreger, A. D. (2004). Ambiguous sex—or ambivalent medicine.

Haghighat, D., Berro, T., Sosa, L. T., Horowitz, K., Brown-King, B., & Zayhowski, K. (2023). Intersex People's perspectives on affirming healthcare practices: A qualitative study. *Social Science & Medicine*, 116047.

Hill, M. (2005). Ethical considerations in researching children's experiences. *Researching children's experience*, 61-86.

Jones, T. (2018). Intersex studies: A systematic review of international health literature. *Sage Open*, 8(2), 2158244017745577

Karkazis, K., & Rossi, W. C. (2010). Ethics for the pediatrician: disorders of sex development: optimizing care. *Pediatrics in Review*, 31(11), e82-e85.

Koe, G. K. (2018). An Analysis of the legal rights of intersex people in Kenya.

Lampalzer, U., Briken, P. & Schweizer, K. Psychosocial care and support in the field of intersex/diverse sex development (dsd): counselling experiences, localisation and needed improvements. *Int J Impot Res* 33, 228–242 (2021). <https://doi.org/10.1038/s41443-021-00422-x>

Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., ... & Global DSD Update Consortium. (2016). Global disorders of sex development update since 2006: perceptions, approach and care. *Hormone research in paediatrics*, 85(3), 158-180.

Mary, O, Onoja-Alexander., S.H., Idris., Chinedu, John-Camillus, Igboanusi., A.D, Onoja., A.J., Istifanus., O.A., Olawepo. (2017). Assessment of the Availability and Accessibility of

Emergency Obstetric Care Services in Murtala Mohammed Specialist Hospital, Kano, Nigeria. *Journal of Community Medicine and Primary Health Care*, doi: 10.4314/JCMPHC.V29I1

Marshall, P. A. (2006). Informed consent in international health research. *Journal of Empirical Research on Human Research Ethics*, 1(1), 25-41.

Orr, C. E. (2022). *Crippling Intersex*. UBC Press.

Orishaba , G. ., & Serunjogi, D. (2022). What Privacy and Confidentiality Mechanisms are used in the Electronic Health Records (Clinical Master and ICT4 M-Power systems)? A design Science Research Approach. *Student's Journal of Health Research Africa*, 3(9), 8.

Sudai, M. (2018). Revisiting the Limits of Professional Autonomy: The Intersex Rights Movement's Path to De-Medicalization. *Harv. Women's LJ*, 41, 1.

Sundewall, J., & Kaiser, H. (2019). Sexual and Reproductive Health and Rights: An Essential Element of Universal Health Coverage. Background document for the Nairobi Summit on ICPD25-Accelerating the promise.

Spector, P. E. (2019). Do not cross me: Optimizing the use of cross-sectional designs. *Journal of Business and Psychology*, 34(2), 125-137.

Levesque, J., Harris, M. F., & Russell, G. (2013). Patient-centered access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*, 12(1), 18. doi.10.1186/1475-9276-12-18

Logie, C. H., Khoshnood, K., Okumu, M., Rashid, S. F., Senova, F., Meghari, H., & Kipenda, C. U. (2019). Self care interventions could advance sexual and reproductive health in humanitarian settings. *bmj*, 365.

Obedin-Maliver J, Goldsmith ES, Stewart L, et al.: Lesbian, gay, bisexual, and transgender-related content in undergraduate medical education. *JAMA* 2011;306:971–977. Crossref, Medline

