



Voices, visions and priorities: Key issues of young people living with and affected by HIV in Uganda

As part of a global consultation led by Link Up consortium members Global Youth Coalition on HIV/AIDS (GYCA) and the ATHENA Network, a consultation was held in 2013 in Uganda with young people living with and affected by HIV, to find out their views and experiences of accessing HIV and sexual and reproductive health (SRH) services.

Focus group discussions and community dialogues took place in and around Kampala with the help of the Girls-Awake Foundation, the International Community of Women Living with HIV and AIDS Eastern Africa (ICWEA), Uganda Health Science and Press Association, Uganda Harm Reduction Network (UHRN) and the Uganda Network of Young People Living with HIV.

Key issues and priorities that were identified by young people in Uganda highlighted the need for integration of HIV and SRH services for young people living with HIV, young sex workers, young people who use drugs, and young people from LGBTI communities.¹

These included:

Human rights, including sexual and reproductive rights

- **Lack of trust in services and in service providers, including HIV testing;** “Immediately after the test, I was actually satisfied but later, I developed doubt as almost a rough number of about a hundred people she had tested, none of us were positive, which made me not content about my results.”
- **Fear of stigma and discrimination, leading to reluctance to test for HIV and self-imposed isolation upon receiving an HIV positive result;** “The news about my positive status paralyzed me with shock. I had to run away from the village to hide somewhere I could get some peace, many miles away from home.”
- **Sex work is highly stigmatised and a criminal offence.**
- **Young persons suspected of doing sex work or belonging to LGBTI communities can be detained and imprisoned without charge, and forced to pay bribes for their release;** “We need our freedom. We need to walk freely with our partners.”

- **Lack of acceptance of sexuality by friends, family and community** – conditional on wealth, social status and other attributes; “My mother accepted me because I support her, but she warned me to be careful with my dad.”
- **Lack of confidentiality (perceived or actual) within health services, especially for young women.** “If I test positive they do not want to give me my results, they prefer to give them to my parents or guardians. It’s worse when they come to know that you are a sex worker, they may not even attend to you.”
- **Using condom-compatible lubricant and dental dams as incriminating evidence of same-sex activity by the police,** deters men who have sex with men (MSM) and women who have sex with women from accessing these commodities and practicing safer sex.
- **Discrimination against lesbians, sex workers and single mothers, who are expected to present with a male partner to access some services,** including couple counselling and testing in antenatal clinics, and condom provision. “There was a time where we had a condom crisis in the country and when health workers visited our brothels to do outreach they told us if we wanted to get condoms, we should first go for testing with our partners. But for us sex workers we do not have husbands, so we would go with *boda-boda* [motorbike taxi] men to pretend they are our husbands for us to get condoms.”

Comprehensive sexuality education

- **Myths and misinformation about SRH and HIV are rife,** including the belief that HIV is a death sentence.
- **Lack of information about sexually transmitted infections (STIs),** resulting in delay in accessing treatment; “I was dealing with many diseases that I had no idea about because, back at school, no one told us about STIs and I thought they were the wounds caused during rape”.
- **Lack of accurate information about contraceptive methods;** “Many women are being operated with fibroids caused by pills; I can’t risk taking those pills.”
- **Lack of accurate knowledge about the legal status of abortion in Uganda.**
- **Defeatist or fatalistic attitude about survival;** “We survive by the grace of God.”

1. Participants of community dialogues in Uganda were young women living with HIV who are mothers (65); young people who use drugs (15); young people who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI) (21); young people who engage in sex work (22); young people living with HIV (40 participants); and young people who chose not to identify with any one group (25). All quotes are from young people who took part in the community dialogues.

Access to safe and comprehensive services, and knowledgeable, ethical, supportive and qualified health service providers

- **Lack of youth-friendly SRH services and information;** “There is a need for youth desks and corners for young people in all health centres, to be able to access adequate information and be able to make smart decisions.”

- **Criminalisation of same-sex practices, leading to lack of access to HIV prevention supplies** such as lubricants and dental dams, or tailored sexual health services and commodities for MSM, women who have sex with women and transgender communities; “They think we are abnormal and senseless. They undermine us and ignore us and we do not receive any attention. I have gone to over three clinics so far but all they give me are painkillers.”

“You explain your problem and before you finish, the health worker has already switched his attention from you to someone else. They don’t want to know that am in pain, yet I am as normal and a human being just as they are.”

“Recently, we lost one of our friends ... because the doctors kept ignoring him and failed to pay attention to his condition. In one case, a transgender man was tossed around a private hospital when neither the male nor female waiting areas could accept him. Until a nurse exclaimed, ‘*Banange, mujje mulabe omusiyazi!*’ (people, come and see a homosexual!)”

- **Judgemental attitudes of service providers towards sex workers.**
- **Low and inconsistent uptake of family planning.**
- **Lack of family planning counselling among young women and mothers living with HIV.**
- **Lack of access to safe, affordable abortion services,** further hindered by traditional and religious leaders who condemn abortion as immoral.

- **Lack of access to affordable fertility treatment services** for MSM, transgender people, and lesbian and bisexual women who want to have children, leading to peer-group stigmatisation towards LGBTI persons who seek to have children; “If a lesbian decides to get a child and becomes pregnant, other LGBTI people will question her lesbianism. I know of lesbian friends of mine who have been touted about living a lie. There are transgender men who have hidden pregnancies from their LGBTI peers.”
- **Lack of availability and high price of female condoms,** and lack of knowledge on how to use them.
- **Lack of access and high price of clean syringes,** leading to sharing of needles.

Meaningful youth participation in all aspects of decision-making

- **Very limited access to decision-making among all groups.** For many participants, these dialogues were their first experiences of being invited to safe spaces to share their needs, priorities and visions.

Addressing gender-based violence

- **High levels of violence, including rape and sexual abuse from clients and police, reported among male and female sex workers and LGBTI people;** “Someone took me to his home; I thought he was one guy for the night. When I arrived, two more men came in as his friends ... [I ended up] being used by all three.”

“These four police officers raped me without even using a condom and they later left me on the street unconscious and took the money I had got that night and my phone. I did not report them because I felt I would not be helped since it was the police officers who had raped me.”

- **Intimate partner violence is common among women who learn their HIV positive status during pregnancy,** often leading to abandonment. This increases women’s vulnerability to financial hardship, institutional violence and abusive intimate relationships.



In 2013, Link Up consortium members Global Youth Coalition on HIV/AIDS (GYCA) and the ATHENA Network led a consultation with young people living with and affected by HIV. Nearly 800 people from every region of the world responded

to a **global online survey** that collected quantitative and qualitative data in five languages, and over 400 young people participated in a series of **community dialogues and focus groups** with national partners in Ethiopia, Uganda, Burundi, Bangladesh and Myanmar.

These face-to-face dialogues focused on and created a platform for key stakeholder groups, specifically young women living with HIV, young people engaged in sex work, young people who use drugs, and young LGBTI people. The consultation aimed to learn directly from young people living HIV and from key affected populations about their

lived experiences of accessing HIV and SRH services; participating in decision-making as young people most affected by HIV; and their vision for realising their sexual and reproductive rights.

KEY PRIORITIES EMERGING FROM THE CONSULTATIONS

- ✓ **Human rights, including sexual and reproductive rights**
- ✓ **Comprehensive sexuality education**
- ✓ **Access to safe and comprehensive services, and knowledgeable, ethical, supportive and qualified health service providers**
- ✓ **Meaningful youth participation in all aspects of decision-making**
- ✓ **Addressing gender-based violence**