



HIV and sexual and reproductive health and rights: **visions, voices, and priorities** of young people living with and most affected by HIV



ATHENA





## Link Up

Link Up is an ambitious five-country project to improve the sexual and reproductive health and rights (SRHR) of one million young people most affected by HIV in Bangladesh, Burundi, Ethiopia, Myanmar and Uganda. Launched in 2013 by a consortium of partners led by the International HIV/ AIDS Alliance, Link Up will strengthen the integration of HIV and SRHR programmes and service delivery. It will focus specifically on young men who have sex with men, sex workers, people who use drugs, transgender people, and young women and men living with HIV.

[www.link-up.org](http://www.link-up.org)

## ATHENA Network

ATHENA works with global partners to undertake policy work and movement-building that pushes a human rights and gender equity perspective. ATHENA creates physical spaces for advocacy, dialogue and networking at international and regional conferences and forums. In its virtual form, ATHENA enables knowledge-sharing and policy analysis via our list-serv and collaborative working style. Our work has been looked to and used by United Nations partners, global networks, non-governmental organizations, and community leaders and advocates.

[www.athenanetwork.org](http://www.athenanetwork.org)

## Global Youth Coalition on HIV/AIDS (GYCA)

GYCA is a youth-led global network of young leaders and adult allies working on youth and HIV/AIDS all over the world. GYCA was founded by youth attendees of the XV International AIDS Conference in Bangkok 2004 and XIV International AIDS Conference in Barcelona 2002. GYCA is a programme of the Public Health Institute.

[www.gyca.org](http://www.gyca.org)

[www.phi.org](http://www.phi.org)

**Cover:** Nahimana, 22, mother of two, meets peers at RNJ+'s new youth centre in Bujumbura, where services are offered to support vulnerable groups to get better education on HIV, sexual health and contraception. It is the first youth-led centre of its kind in Burundi. © International HIV/AIDS Alliance.

**This page:** A group of young women meet to talk about sexual and reproductive health in Dakar, Senegal. © Nell Freeman for International HIV/AIDS Alliance.

## Executive summary

As the global community defines a new post-2015 development agenda, including the voices and visions of young people must be a priority. In this report, young people from around the world living with and most affected by HIV champion their vision for realizing and claiming their sexual and reproductive health and rights (SRHR) and setting their priorities for HIV and SRHR integration.

The Link Up project, launched by a consortium of global and national partners in early 2013, is an ambitious three-year initiative that seeks to advance the SRHR of more than one million young people in five countries. Link Up distinctively works with young people most affected by HIV aged 10 to 24 years old, with a specific focus on young men who have sex with men, young people who do sex work, young people who use drugs, young transgender people, and young women and men living with HIV. It also seeks to amplify the voices of these young people through community mobilization and advocacy in national and global forums, particularly those informing the post-2015 development framework.

As partners in the consortium implementing Link Up, Global Youth Coalition on HIV/AIDS (GYCA) and ATHENA Network led a consultation with young people living with and most affected by HIV. Nearly 800 people from every region of the world responded to a global online survey<sup>1</sup> that collected quantitative and qualitative data in five languages, and over 400 young people<sup>2</sup> participated in a series of community dialogues and focus groups<sup>3</sup> with national partners in Ethiopia, Uganda, Burundi, Bangladesh, and Myanmar. These face-to-face dialogues created a platform for young people living with and most affected by HIV to share their lived experiences of and hope for: accessing HIV and SRH services, including family planning and contraceptives; participating

in decision-making both in their personal lives and in programming and policy; and, their vision for realizing their sexual and reproductive rights. In this document we share their voices directly, to inform clear and evidence-based advocacy messaging that can guide both global and national post-2015 negotiations, and national and regional-level programming.

Through this process, five clear vision areas for positive change and targeted recommendations emerged, which speak to young peoples' shared perspectives on what is needed to achieve real progress.

Link Up supports the integration of HIV and SRHR programming and policy, with the aim of providing comprehensive and accessible services. Supporting integration, ensuring that young people's sexual and reproductive rights are prioritized, and guaranteeing that young people are meaningfully engaged and their needs recognized are all essential elements of a post-2015 development framework that upholds the rights of young people living with and most affected by HIV. The recommendations and wider findings reported in this document provide a framework to achieve this.

First, the priorities and recommendations that emerged through the consultation are summarized. Then each is considered in detail, including the voices and visions of young people living with and most affected by HIV. For each vision area, we also include a case study of Link Up best practice profiling replicable efforts to implement the recommendations.

1. The online survey was administered in English, Spanish, French, Burmese, and Russian. 20% of participants identified primarily as lesbian, gay, bisexual, transgender, queer, or intersex (LGBTQI); 8.7% as people living with HIV; 6.8% as men who have sex with men, 0.5% as sex workers, and 0.1% as people who use drugs. Of all respondents who provided their age, ages ranged from 15 to 30 and above: 7% were 15–19 years old; 32% were 20–24 years old; 38% were 25–29 years old, and 23% were 30 or above.

2. All community dialogue and focus group participants were aged 28 and below.

3. Of participants who felt comfortable identifying with a particular group of young people most affected by HIV, 62.5% identified as young people living with HIV, 11.3% identified as young people who do sex work, 7.5% identified as LGBTQI, 7.1% identified as young people who use drugs, and 6.7% identified as transgender young people, 5% identified as young men who have sex with men. 33.9% of total participants chose not to identify themselves. While local facilitators' made their best efforts to provide a safe space for community dialogue, many factors (e.g., cultural and social context, the pervasive influence of stigma) may have led individuals to avoid identifying with a marginalized group.

## Priorities and recommendations



1

### **1. Provide quality sexual and reproductive health services from ethical and well-trained health service providers tailored to the needs, rights, and desires of young people—especially those living with and most affected by HIV**

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- Hold health service providers to high standards of ethical conduct, including confidentiality, respect, and the obligation to protect the SRHR of young people in all of their diversity.
- Train health service providers on sexual and reproductive rights and the importance of respecting the rights of all human beings, in particular those who often experience stigma such as young people living with HIV, affected by HIV and of diverse sexual orientations and gender identities.



2

### **2. Protect, respect, and promote young people's sexual and reproductive rights, including their right to love and be loved safely and freely**

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- Eliminate discriminatory laws and policies that criminalize or stigmatize HIV exposure and transmission, same-sex sexual activity and relationships, abortion, drug use and sex work.
- Clearly define sexual and reproductive rights (including the right to sexual and reproductive health) as human rights in national and international policy, as the international human rights community already has.
- Create, enact and enforce laws, policies and frameworks that specifically guarantee sexual and reproductive rights.



3

### **3. Ensure full access to age-appropriate information and education on HIV and sexual and reproductive health and rights, including on sexual orientation and gender identity**

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- Provide universal access to holistic, tailored, rights-based comprehensive sexuality education (including HIV, gender identity, sexual orientation, and sexual pleasure) to all young people, including and especially those living with and most affected by HIV.
- Eliminate restrictive laws and policies that prevent young people from accessing sexual and reproductive health, including HIV information, education, and training (such as parental consent laws and laws forbidding sexual material).
- Provide training to caregivers on parent-child communication; provide caregivers with resources for teaching young people about SRHR in the home.



Members of a youth group in the Malnicherra tea plantation in Sylhet, Bangladesh. The group raises awareness of sexual and reproductive health and rights. © International HIV/AIDS Alliance.

## 4

### 4. Promote gender equality and address gender-based violence, including sexual violence, in all its forms, including on the basis of sexual orientation and gender identity

- Eliminate laws and policies that contribute to gender-based violence and inhibit access to sexual and reproductive health services (such as the criminalization of: sex work, drug use, HIV exposure and transmission, and same-sex sexual activity and relationships).
- Clearly reiterate the definition of gender-based violence as including all forms of violence against women, violence against people who do sex work, violence against LGBTI people (including transphobia, “corrective rape” and other forms of violence against lesbian and bisexual women, and violence against men who have sex with men), and violence against any others who are persecuted because of their gender identity or sexual orientation.
- Implement and enforce laws against gender-based violence to protect women, people who do sex work, LGBTI people, men who have sex with men, and any others who are persecuted because of their gender identity or sexual orientation.
- Implement programming that works to transform gender norms that perpetuate violence and discrimination against young people most affected by HIV.

## 5


### 5. Meaningfully engage young people, in all their diversity, in all decision-making that affects their lives

- Ensure the full and active participation of young people living with and most affected by HIV in policy and programmes, at every stage of the process, from inception and design through implementation, monitoring, and evaluation.
- Create and expand concrete leadership spaces for young people that support participation in decision-making and policy fora, including support to ensure language and formal education levels are not barriers to participation.

# 1

**1. Provide quality sexual and reproductive health services from ethical and well-trained health service providers tailored to the needs, rights, and desires of young people—especially those living with and most affected by HIV**

Rashida, a transgender woman, attends an MSM group in Mymensingh, Bangladesh to receive HIV prevention and sexual and reproductive health information and support. Due to stigma and discrimination she prefers to conceal her identity and original name. © International HIV/AIDS Alliance.

 “Health services must be accessible, gender-sensitive, non-discriminatory, and uphold confidentiality. Services must be available for all young women, regardless of age, HIV status, sexual orientation, or socio economic status.”

YOUNG ACTIVIST WOMAN, UGANDA<sup>4</sup>

Sexual and reproductive health services are essential to supporting the realization of SRHR. Services include HIV testing, treatment, care and support; sexually transmitted infections (STI) testing and treatment; family planning and contraceptives; and safe abortion. Quality services are accessible, and are designed and able to meet the needs of the person accessing the services. Youth-friendly services are services that young people feel safe and supported to access and utilize.

In the consultation, many key issues emerged surrounding the challenges young people face in accessing sexual and reproductive health services. Not surprisingly, factors like high cost, inadequate supplies, and physical inaccessibility create barriers to accessing and utilizing health services. Participants in one focus group in Ethiopia identified that there was only one government health centre serving more than 30,000 people in their community, indicating a need for more service availability. In addition to these issues, young people most affected by HIV face a multi-layered set of additional constraints. Consultation participants consistently reported lack of confidentiality, ignorance of the unique issues young people most affected by HIV face, and inconsiderate, untrained, or outright abusive staff.

Gender norms and sexual taboos present challenges for young people in general, and these are exacerbated for young people living with and most affected by HIV. Stigma, discrimination, and violence at home and in the community (including while trying to access health services) are a huge problem for young women, young LGBTI people, young men who have sex with men, and young people who do sex work. Young women often lack the freedom to access family planning and contraceptives, for example, without parental or spousal consent, and young women living with HIV are often seen as people who are “not supposed” to

have sexual relationships, creating a double barrier to contraceptive access. Policies that place age limits on who can access family planning, HIV testing, and other sexual and reproductive health services underpin these barriers to access.


Reducing HIV acquisition in young people will require changes in laws and policies that exclude young people from services. In the *Political Declaration on HIV and AIDS* (2011) all UN Member States expressed “grave concern that young people aged 15 to 24 account for more than one third of all new HIV infections” and recognized that laws and policies often:

*exclude young people from accessing sexual healthcare and HIV-related services such as voluntary and confidential HIV-testing, counselling and age-appropriate sex and HIV prevention education.*

## Stigma and discrimination in health services and the wider community

The majority of participants in two community dialogues had never had an HIV test, and did not know their HIV status.<sup>5</sup> Many had not accessed SRH or HIV treatment services for fear of reactions from health providers on the basis of their age, sexual orientation, gender identity, engagement in sex work, drug use, or a combination of factors. One young man from Uganda who uses drugs said that he was afraid to go to the hospital for testing because most of his community considered him a *myuyaye* (an irresponsible person, unemployed and idle), and he preferred to trust in “the grace of God” rather than expose himself to the shame and embarrassment he might face from health workers at his local clinic.

When one young Burundian woman living with HIV became pregnant, she was made to feel so ashamed that she avoided seeking pre-natal care until she felt that her life was in danger.

 When I got pregnant, people from social service and sometimes the doctor were always asking me embarrassing questions like why I’m not ashamed or how will I feed my baby, and I decided not to go back again. Three months after, I gave up and I went back because I realized that my life and my baby were in danger.

Young people living with HIV in Myanmar, when attempting to receive treatment for STIs or other medical issues at private clinics, were often tested for HIV without their knowledge and then refused service if the test was positive.

4. Participants in the consultation provided their country, and selected from a list of descriptors to define how they identify. Options included “activist,” “feminist,” HIV status, gender identity, and sexual orientation.

5. 16 out of 20 young people in Uganda and 20 out of 20 young people in Bangladesh.

Although almost all the participants in one focus group in Burundi knew their HIV status, 12 out of 20 had not used any form of barrier or contraceptive protection the last time they had sex. Lack of access to services and lack of information were identified as causes. Sixteen out of 20 said they often needed a service and could not get it—either services were too expensive, too far away, or the people providing services were not knowledgeable and did not have proper equipment:

**I don't have somewhere or someone nearby me to help me with questions related to birth control, STIs, HIV/AIDS, or family planning. However, I heard by radio about National Programme for Prevention & Control of STI, HIV. The health centres are far from our village. [There is] no one to SMS for help. Sexual education is not available in Burundi.**

Young people living with HIV in Burundi also felt that their ability to access services was seriously limited by poor treatment from health providers, and that they were only seen as needing antiretrovirals (ARVs), rather than being offered a complete package of SRH services:

**Adherence to treatment is their [health providers] only concern.**

## Sexual orientation and gender identity

Young men who have sex with men, *hijras*<sup>6</sup>, and sex worker participants in Bangladesh only felt safe being tested for HIV and receiving other SRH services at drop-in centres specifically catering to them. Aside from HIV testing, they felt that services were lacking—specifically, mental health services:

**Actually our intervention area is only focused on preventing HIV and STIs, there are some counselling services, but there is no psychologist. ART [antiretroviral treatment] is provided by a people living with HIV (general) organization. Hijras do not feel comfortable going there.**

Young people from key populations routinely described experiencing difficulty in accessing services, even when they were already at a clinic, health post, or in some cases, a non-governmental organization (NGO). Young people from LGBTI communities frequently described being treated as lesser beings by uninformed health personnel, even to the extent of being refused treatment for STIs. In one case, a young transgender man seeking healthcare in Burundi, instead experienced moral judgment and sermonizing:

**The doctor, instead of conducting a normal consultation, began to give me moral advice, trying to make me understand that I am possessed by a demon and that I must approach a pastor. He said 'man is created to be a part of the woman and vice versa, you must understand that you are a man and not a woman.' Being angry, I quickly left his office without any time to get help.**

**43%** of e-consultation respondents said that the last time they had accessed HIV treatment (ART), the person helping them did not seem to care about their health.

**45%** of young women responded similarly when asked about accessing abortion services.

In general, health workers who are sensitive to the rights of young people from LGBTI and other key affected population communities are extremely few and far between. They are unlikely to be trained to address young peoples' sexual and reproductive health needs, much less those of young people from key affected populations. Often these services are provided by NGOs, and young people who participated in the consultation tended to avoid government clinics where possible. In some areas, young people from LGBTI communities and young people who do sex work feared arrest should their sexual orientation or identity be revealed during the visit.

In Uganda, it was also noted that transgender people are especially vulnerable because their identity is externally visible. In one particular case, a transgender man described how he was "tossed around a private hospital when neither the male nor female waiting areas would accept him and then a nurse exclaimed, '*Banange, mujje mulabe omusiyazi!*' ('People, come and see a homosexual!')."

Participants also reported being asked offensive questions about their sexuality by health workers who had very little knowledge of sexuality or of sexual and reproductive health.


**There is lube in [hospital name] but they [health workers] use it for their own work. If you go there to ask for it, they will ask you what you want it for. Their assumption is that lubricants are used by MSM for anal sex, and yet even straight people use lube both for vaginal and anal sex.**

### YOUNG TRANSGENDER MAN, UGANDA

Drop-in centres specifically for young people from key populations (whether it be LGBTI young people, young people who do sex work, or young people living with HIV, such as the Link Up-supported drop-in centre described in the case study on page 8) were reported as a safe source to access support.

6. *Hijra* is the Hindustani word used in South Asia to describe physiological males or intersex people who identify as female. Many *hijras* see themselves as a third gender, neither male nor female.




 Sexual and reproductive health and rights, which is in my mind but not in practice. In general hospital or clinic there is no possibility to talk about my sexual practice. So, it is only possible in an NGO or CBO-based office or clinic.

YOUNG MAN WHO HAS SEX WITH MEN, BANGLADESH


## Criminalization

Criminalization—of HIV transmission and exposure, of same sex practices, and of sex work—strongly discourages people living with HIV and from most affected populations from accessing SRH services. Fear of accessing services is made worse by community curiosity, gossip, and disapproval of young people exercising their right to have sex and access services. Frequent breaches of confidentiality at the health service level do nothing to calm people’s fears that health services may expose young people to humiliation and even arrest.

 I no longer trust people at the centre of care, I'd go elsewhere because once I had an STI, the day after the doctor had consulted me, everyone knew my situation, I had become a subject of discussion.

YOUNG PERSON LIVING WITH HIV, BURUNDI


Having condoms is often associated with sex work, to the extent that young people can be arrested and charged as sex workers on the “evidence” of carrying condoms alone. This discourages young people who both do and do not do sex work from carrying condoms.

 One day I left the doctor's office and I went to the front desk to take condoms and took only ten pieces, the receptionist told me, laughing, ‘you are a [sex] worker,’ and I was really shocked.


YOUNG WOMAN, ETHIOPIA

## Abortion

Young people in Burundi, Ethiopia, Myanmar, and Uganda all said that abortions were very expensive, and often done in secret and in unsanitary conditions by people with little to no medical training. Several had friends who had experienced illegal or “underground” abortions and been seriously injured or died.<sup>7</sup>

 A neighbour died because she aborted in an underground place. When we brought her to the hospital she lost water and blood.


YOUNG WOMAN IN BURUNDI

 The process of abortion wasn't professional. My girlfriend almost lost her life and it was God's grace that she recovered and I often told myself that this will never happen again.

YOUNG MAN IN UGANDA

Six out of nine young women who use drugs in one Ethiopian focus group had personal experience with abortion. They named an NGO as the only place to receive safe abortions, but added that it was unaffordable for most and inaccessible to young people (because they feared running into elders they knew). In addition, there are often “brokers” who work for illegal abortion providers loitering in the area around the NGO. They tell approaching young people that the NGO is closed, not offering services that day, etc. and then lead them to unsanitary facilities with untrained abortion providers. In a group of 24 young Ethiopian women, 19 had been pregnant and more than half had experiences with illegal abortion and abortion brokers.

One young woman in Ethiopia shared her experience as an adolescent (several years prior), which underscores the complexity and inter-connectedness of issues around unsafe abortion, rights violations within services, and gender-based violence, and the impact these have on young women’s agency and autonomy in relation to their SRHR:

 It wasn't a clinic, it was just a house. I didn't say anything about it. An old woman gave me something to drink and told me to exercise, a kind of push up. I did as she told me. After a while I felt serious pain, I cried and cried. No one helped me. I don't remember what came after that. I woke up covered in blood and lying on the floor. It took me 3 or 4 hours to speak a word, to ask for water to drink. They told me everything would be okay. Nothing followed, no drugs or follow-up. I had felt relief, not only from the pregnancy, but also from being worried about what to tell my husband.

This feeling however, only lasted a week. My husband had come to know everything that happened and what I had done. He was told by a man at the clinic that I had had a pregnancy test. He told him about my visit and my pregnancy.

I don't want to tell what he said and did. I was forced to leave our home immediately. I became homeless.

7. Even in countries where abortion is legal in some circumstances, young people tended to be unaware of the legal status of abortion, and found safe abortion extremely difficult to access.



Pacifique (right), 20, is optimistic about his future and directs a theatre group which raises awareness of HIV and related issues in Bujumbura, Burundi. © International HIV/AIDS Alliance.

## Case study

### Youth leadership in action: youth-led services in Burundi

In Burundi, Link Up support has enabled the establishment of a youth centre run by Burundi's national network of young people living with HIV, Réseau National des Jeunes Vivant avec le VIH/SIDA (RNJ+), which opened its doors in May 2014. The centre is utilized exclusively by young people living with and most affected by HIV. The centre is one of a kind in Bujumbura. Other youth centres exist, but not with the same philosophy of open-mindedness, safety, and non-judgment.

The centre offers information, training, HIV counselling and testing, contraceptives, advice and male and female condoms, a helpline, and community and school outreach. The services that RNJ+ provide equip young people with the information they need to make their own decisions. With more than half of Burundi's population under age 17, it's no surprise the youth centre is a popular place, and because of Burundi's young population, it is essential to reach adolescents to prevent HIV and unwanted pregnancies. Young people attending all have their own stories to share and connections to make—from being abused at home for their

sexual orientation, to having unplanned children at an early age because of lack of family planning advice. One RNJ+ member who visits the centre, Pacifique, was born with HIV, which he discovered at the age of 10.

*When I first found out I was HIV positive I thought I was someone who won't live for very long. I thought I was about to die so there was no need to seek out anything. I thought I couldn't even get married; I was just here waiting for my death.*

*I was very surprised when I first came to RNJ+ because I found very beautiful girls and handsome boys. The people shined, so I thought it must only be me who is living with HIV.*

When Pacifique realized he was among peers, he began to open up for the first time in his life.

*I felt I could share everything. RNJ+ is my second family. It's where I can meet young people who share the same views, who have the same way of seeing the world, and they're the ones who support me.*



### **Recommendation 1**

**Provide quality sexual and reproductive health services from ethical and well-trained health service providers tailored to the needs, rights, and desires of young people—especially those living with and most affected by HIV**

- Hold health service providers to high standards of ethical conduct, including confidentiality, respect, and the obligation to protect sexual and reproductive health and rights of young people in all of their diversity.
- Train health service providers on sexual and reproductive rights and the importance of respecting the rights of all human beings, in particular those who often experience stigma such as young people living with HIV, affected by HIV and of diverse sexual orientations and gender identities.


# 2

**2. Protect, respect, and promote young people's sexual and reproductive rights, including their right to love and be loved safely and freely**



'Protection' is a photograph taken during a PhotoVoice project with Alliance Myanmar and the Myanmar Youth Stars, a group of young people from key groups affected by HIV. © Mone Mann Htet 2014\International HIV/AIDS Alliance\PhotoVoice.



 “First, it is better for us to be accepted as human beings. You said sexual rights, good, what about our rights as humans?”

YOUNG WOMAN SEX WORKER, ETHIOPIA

Sexual and reproductive rights include a broad range of rights, as outlined in a working definition by the World Health Organization (WHO):

*Rights critical to the realization of sexual health include: the rights to equality and non-discrimination; the right to be free from torture or to cruel, inhumane or degrading treatment or punishment; the right to privacy; the rights to the highest attainable standard of health (including sexual health) and social security; the right to marry and to found a family and enter into marriage with the free and full consent of the intending spouses, and to equality in and at the dissolution of marriage; the right to decide the number and spacing of one's children; the rights to information, as well as education; the rights to freedom of opinion and expression; and the right to an effective remedy for violations of fundamental rights ... Sexual rights protect all people's rights to fulfill and express their sexuality and enjoy sexual health, with due regard for the rights of others and within a framework of protection against discrimination.*


WHO, 2002. *Defining sexual health: Report of a technical consultation on sexual health, 28–31 January 2002*. Geneva.

Despite national government support for the WHO definition of sexual rights, and more recent agreements, such as Resolution 17/19 on the intersection of human rights, sexual orientation and gender identity<sup>8</sup> adopted in 2011 by the Human Rights Council, many young people continued to have their sexual and reproductive rights violated.

## Sexual rights


Young women, especially young women living with HIV, young people who do sex work, young men who have sex with men, and young people from LGBTI communities are often not only at an economic disadvantage, but on the wrong side of a power imbalance that leaves it up to their partner to decide whether or not to have sex and whether to use a condom. Participants in focus groups in all five countries said the

decision about whether, when and where to have sex, as well as whether or not to use contraceptives, was up to the person paying for the hotel room, providing the space for sex, or providing some kind of incentive for the sex—almost all of the time, this person was older and male.

 ...a girl in Burundi is considered a child even if she is an adult. .... women or girls are poor, illiterate and financially unable to pay for costs related to personal leisure, including enjoying sex or a relationship.

YOUNG WOMAN, BURUNDI


Young men who have sex with men in Bangladesh also expressed difficulty in negotiating condom use and in having the freedom to decide whether, when, and where to have sex. All agreed that when having sex with an older man, it is up to the older man to make those decisions:

 Most of the time I cannot [decide whether, when, and where to have sex], due to societal power structure. Most of my partners are older and urban; they are not interested in arguing on sexual issues.

YOUNG MAN WHO HAS SEX WITH MEN AND DOES SEX WORK, BANGLADESH

Participants had often not thought about sexuality as a right before—rather, they perceived it as something inappropriate to talk about or shameful. In Ethiopia, the Amharic language has a pejorative word (*wesibawinet*) used to describe people who express sexual desire or speak about sexuality openly, reinforcing the skewed perception that sexual acts or behaviour are immoral. When asked to define sexual health and reproductive health, and sexual and reproductive rights, participants in one focus group in Bangladesh initially guessed that they were “rights exercised by the husband over the wife.”<sup>9</sup>

When asked what full realization of sexual and reproductive health and rights would be to her, one survey respondent clearly saw SRHR as an integral component of broader health and well-being:

 Being free and comfortable with your sexuality is sexual health; and you have an enjoyable life without worries and regret, and you live life to the fullest based on your rights.


YOUNG WOMAN, 20–24 YEARS OLD, ASIA AND THE PACIFIC

8. Resolution 17/19, introduced by South Africa and Brazil, was adopted in June 2011 at the Seventeenth Session of the Human Rights Council. As a result of Resolution 17/19, a high-level panel on sexual orientation and gender identity was held during the Nineteenth Session of the Human Rights Council. For a summary of the panel see <http://www.ohchr.org/EN/Issues/Discrimination/Pages/PanelSexualOrientation.aspx>

9. Made up of 20 people (aged below 24 years) including 8 who are studying and working, 5 married young women (3 of whom were pregnant or mothers), 2 drug users, and 5 transgender people.


## Young people living with HIV

Discrimination and ignorance surrounding HIV emerged as a major point of concern in the consultation.

 There is so much stigma around HIV/AIDS, even now in 2013. It is still this dark cloud in our lives. Our families do not talk about it. How conservative they are. And infected people are sometimes treated as “less”. Why is there so much shame? Why is sex not a topic of discussion with your children around the dinner table? Most parents only find out when their children become parents, that they are sexually active. Why?

20–24 YEAR OLD LGBT WOMAN, EASTERN AND SOUTHERN AFRICA

In several focus groups that included young people living with HIV, participants expressed that their communities do not see them as sexual, reproductive, or romantic beings. All participants had experienced some form of discrimination just for wanting to be in a romantic relationship, and the stigma around pregnancy while living with HIV was seen as very high:


 Perceiving HIV positive people as sexual beings is almost unthinkable by large number of population even today.

YOUNG WOMAN LIVING WITH HIV, ETHIOPIA

Participants in one Uganda focus group were afraid to discover their HIV status, fearing stigma and discrimination if others found out the result.

## Young people who do sex work

Young people who do sex work in Burundi expressed their lack of freedom to decide whether, when, and how to have children. Without access to contraception or the freedom to negotiate its use, they said they were often left with unwanted children:

 Being an orphan and the eldest of the family, I had to take care of my younger brothers and sisters, I left school and I became a sex worker, when I got pregnant, I could no longer give them what I used [to] and two months after giving birth to the child I left my baby home to go to work every night and they are the ones who had to deal with [it] and they were furious against me.


YOUNG WOMAN SEX WORKER, BURUNDI

When asked if she believed that sex was something positive to be enjoyed, one young woman in Burundi responded: “*For me it isn’t to enjoy, it’s a job like so many others.*”

## Young MSM and LGBT people

Focus group participants almost always said “no” when asked if others were accepting of their gender identities, sexuality, and sexual orientations.


A young *hijra* in Bangladesh shared her experience at home and in her community:

 I like a boy, want to marry him, this is my sexuality, but even my brother and sister do not accept my choice. For that reason I can’t stay in my family home.

# 20%

Nearly **20%** of e-consultation respondents said they never or rarely felt free to decide whether and when to have children without fear that anyone would get angry with them, discriminate against them, or act violently towards them.


A young LGBT man from Bangladesh wants to see all young people accessing equal rights and opportunities:

 Young LGBTQ people must be protected from discrimination and violence under the law. A nation cannot progress if it leaves out a significant portion of the young generation from enjoying equal rights and opportunity. Countries like Bangladesh where there are still draconian laws punishing homosexuality must repeal those laws and make sure to protect the minority population. There should be increased national and international pressure on the government to change these laws.

One Uganda focus group discussion, comprised of young LGBT people, identified the main legal barriers to SRH services as: the *Anti-Homosexuality Act* (which has since been declared invalid but is being re-introduced under a new name); the *HIV Prevention and Control Act*; the *Penal Code Act*; the *Marriage and Divorce Bill*; and the *Constitution*, among others. These policies, along with the more recent *Anti-Pornography Bill*, criminalize women’s bodies, LGBT people and men who have sex with men, and people living with HIV. The policy of demanding that women seeking antenatal care attend services with the expectant father was also noted as being a barrier to access to services by lesbian or bisexual women, unmarried women, female sex workers, those who are survivors of sexual assault, and transgender men.

Even when legal instruments such as those mentioned above are still Bills (not yet made law), participants reported that they are widely perceived to already be laws by not just the general public but also by the police, who cite them when disrupting LGBT meetings or gatherings and making arrests. It was also noted that there is need to monitor by-laws formulated at the local government level as they may be anti-LGBT.

One lesbian participant who had gone through a pregnancy and accessed antenatal services shared her experience with the antenatal care policy of conducting HIV testing for all expectant mothers and their partners:

 At the first visit it was like, “we want to see the father, to take some history.” Luckily, the father of our child is our friend, so he was willing to come with us and take some tests just for the sake of it.

## Case study

### Youth leadership in action: my journey from HIV activist to citizen journalist

When Brant Luswata was 15 he watched his elder brother die from AIDS-related illnesses. Now in his twenties, Brant is a passionate advocate for universal access to sexual and reproductive health services—including HIV prevention and treatment programmes.

In April 2014, Brant joined Key Correspondents—a network of citizen journalists around the world writing on HIV, health and human rights. The network helps get the voices of those most affected by HIV into global debates. It is working with Link Up partners to reach out to young people and ensure they have the skills and opportunities to tell their stories through the media, to influence HIV policy, programming and financing at a national and global level.

Here, Brant talks about his experience of being a Key Correspondent:

#### Why did you decide to become a Key Correspondent?

I work as a resource manager at Icebreakers Uganda, whose mission is to support and raise the awareness of all gay people in Uganda about their human rights aspects in health, with emphasis on HIV, and to speak out for those who are being bullied, abused or hated because of their sexual orientation. I've also been advocating for the rights of lesbian, gay, bisexual, transgender and intersex people (LGBTI) in Uganda since 2009 by volunteering with the Hate No More Campaign Committee, hosted by Freedom and Roam Uganda.

My motivation for joining the Key Correspondents network was my lived experiences and the fact that we need to do more to raise awareness of the issues that I see LGBTI people facing every day. I've lost many people to the HIV epidemic, including my older brother. We had bonded so well, he was my mentor, friend, role model, leader and the person taking care of my family, as my dad had died many years before while serving in the army.

I don't believe any one should die young because of HIV, and I became a Key Correspondent as another way to be an activist and speak out. I want my stories to highlight the concerns of the LGBTI communities where I live and to champion their sexual and reproductive health and rights.

#### What opportunity do you think Key Correspondents presents for young people?

For me the most outstanding opportunity is the ability it presents for young people to voice their concerns in the struggle against HIV and AIDS. Also, to be part of an international network and learn from other young people



Brant Luswata at the International AIDS Conference 2014 in Melbourne.

across the globe. Our articles are helping promote the health benefits of integrating sexual and reproductive health services and rights with HIV programmes for young people. Both by reporting other people's stories and sharing our own experiences we can help shape the discussions around health services and rights for young people in regards to HIV programming. The network is helping bring the real voices of young people in their respective constituencies to centre stage, which is particularly important as we go into 2015 and negotiations continue over the new sustainable development framework.

#### What have you achieved so far as a Key Correspondent?

I've written a number of articles on the issues I want to speak out on, including Uganda's anti-homosexuality legislation. The intense homophobia in Ugandan society means people are dying because they are afraid to seek health services. It's important that we keep raising awareness of this issue at both a national and international level. My stories have been published on the Key Correspondents website as well as other international media platforms including All Africa and the AIDS 2014 website.

As a Key Correspondent I was given the opportunity to attend the AIDS 2014 conference in Melbourne, including the youth pre-conference. It was a fantastic experience and I took part in several activities, including: speaking about involvement of key populations in the new funding model at the Global Fund Advocates Networking Zone; taking part in a panel about challenges in service delivery for young key populations at the Youth Pavilion; and speaking on behalf of the Link Up project at various meetings. I also gave an interview about being a gay man in Uganda to Joy FM.

Through these activities I've helped promote young people's sexual and reproductive rights, including their right to love and be loved safely and freely regardless of sexual orientation.

## **Recommendation 2**

**Protect, respect, and promote young people's sexual and reproductive rights, including their right to love and be loved safely and freely**

- Eliminate discriminatory laws and policies that criminalize or stigmatize HIV exposure and transmission, same-sex sexual activity and relationships, abortion, drug use and sex work.
- Clearly define sexual and reproductive rights (including the rights to sexual and reproductive health) as human rights in national and international policy, as the international human rights community already has.
- Create, enact and enforce laws, policies and frameworks that specifically guarantee sexual and reproductive rights.




# 3

3. Ensure full access to age-appropriate information and education on HIV and sexual and reproductive health and rights, including on sexuality and gender identity



The Addis Beza Anti-AIDS youth group in Addis Ababa, Ethiopia combine music and dance to get messages about HIV prevention to their peers. They hand out information leaflets and encourage people to get tested for HIV. © Sheikh Rajibul Islam\duckrabbit\International HIV/AIDS Alliance.

 “There should be an early engagement into sex education for young people. In my country, it is still taboo to talk about sex and sexuality with young people. They end up resorting to media to learn, when parents and extended family should be assuming this role.”

YOUNG WOMAN, 20–24 YEARS OLD, EAST AND SOUTHERN AFRICA

Comprehensive sexuality education and full information are an essential component of the HIV and SRHR integration agenda for young people. Information and education that includes sexuality and gender identity, as well as HIV and sexual and reproductive health, is a vital part of ensuring young people have the information they need to secure their sexual and reproductive health and choices.

The ICPD Programme of Action (1994) states that:

*As part of their commitment, full attention should be given to the promotion of mutually respectful and equitable gender relations and particularly to meeting the educational and service needs of adolescents to enable them to deal in a positive and responsible way with their sexuality. ... Adolescents are particularly vulnerable because of their lack of information and access to relevant services in most countries.<sup>10</sup>*

The consultation found that a young person could more easily access HIV testing and reproductive health services than comprehensive sexuality education and full information about their bodies, health, and rights. Furthermore, speaking about sex, sexuality, the changes that occur during puberty, and about sexual violence, is often completely off-limits at home, leaving young people only their peers (who are equally uninformed) to seek advice from.

### Lack of information


Participants in the consultation described the impact of a lack of information and education in their lives, and in their ability to protect their sexual health. Thirty-two percent of e-consultation participants said SRH education was not accessible in their communities. Among those living with HIV, that number rose to 44%.

10. Report of the International Conference on Population and Development, para 7.3 (A/CONF.171/13/Rev.1). 1995. UNFPA: New York.

In 26 of 31 surveyed countries with generalized epidemics, less than


**50%** of young women have comprehensive and correct knowledge about HIV.

UNAIDS Report on the Global AIDS Epidemic, 2012

 Because sexuality or issues related to sex is taboo, I don't know if they accept it [my sexuality] or if they do not. The cause is that in Burundi, we don't have sex education and we cannot talk about sex publicly.


YOUNG WOMAN UNDER 24, BURUNDI

Young people who do sex work in Burundi lacked basic information about how to effectively prevent pregnancy:

 Whenever I do not protect myself and when I do not have a pill, I take two paracetamol and a coca cola lemonade, so I am sure I cannot get pregnant."

A lack of comprehensive sexuality education and accurate information about sexual orientation can have tangible, and harmful, effects. In Ethiopia, young people in one focus group<sup>12</sup> believed that “we don't have such kind of things [gay people] in our village and even if we see one we will go after him/her.” They erroneously believed that “addiction to *khat* [stimulant drug], cigars, and alcohol; the negative impact of movies; same-sex schools, prison, and boarding schools” were the cause of homosexuality (rather than the explanation, accepted by the international scientific community, that we are born with our sexual orientation and gender identity), and exhibited alarming and hostile attitudes towards LGBTI people. These beliefs illustrate a sociocultural environment of serious, and worrisome, ignorance about sexuality and sexual orientation.

Speaking about the sexual violence that led to her becoming HIV positive, a young woman in Uganda expressed the shame and powerlessness in lack of information:

 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.... I smelled awfully, but personally, I did not know what the problem was .... I discovered I had all types of STIs including syphilis, genital warts, candida, and others that I couldn't read and understand, etc. At least if we were taught in school the signs of STIs, I would have figured out how to get treatment before this embarrassment.

11. Focus group made up of 6 young women who do sex work in Burundi.

12. Made up of 20 young people between the ages of 18 and 24 living in Addis Ababa. It is important to note here that this group was not desegregated for LGBT status; it was comprised of a random mix of young people from two youth development organizations.

Knowledge on HIV prevention and treatment is also lacking. Young people who use drugs participating in a community dialogue in Uganda<sup>13</sup> reported that they had heard of TASO (The AIDS Support Organisation) “*but for us translated it as tasobola kuwona, meaning ‘you can’t get cured.’ So I don’t see the reason why I have to go for testing and treatment when I can’t get cured.*”

## Young people call for comprehensive sexuality education

Against this backdrop of need and expressed desire for comprehensive sexuality education (CSE), young people voiced their visions for positive change.

13. 27 young people aged 15–28 who either use drugs and/or do sex work took part in a community dialogue hosted by the Uganda Harm Reduction Network.

Improve SRHR education in schools. My suggestions are: 1) to introduce dedicated healthcare staff into schools to serve the needs of pupils age 10 plus with confidential advice, counselling and testing, and 2) to integrate SRHR issues into the humanities curriculum (where appropriate) to erode stigma and taboo surrounding discussing sexuality in particular, as well as STIs, contraception, and consent.

YOUNG FEMINIST WOMAN, 25–29 YEARS OLD, WESTERN EUROPE

My government [should be] putting SRHR at the heart of the fight against HIV/AIDS; realising that making the young people more aware of their sexuality by giving them access to SRHR information and services does not make them promiscuous but rather more informed and more likely to make the right decisions, stay in school and have less children.

YOUNG FEMINIST WOMAN, 25–29 YEARS OLD, EAST AND SOUTHERN AFRICA

## Case study

### Youth leadership in action: making female condoms available to young women in Burundi

“When I was up-country [in Burundi], I saw a man wearing a female condom as a bracelet—he did not know what it was. I thought ‘why is it that do people not know what female condoms are?’” says Nadia Ndayikeza, a 29-year-old activist. This was one of the moments that helped inspire a local female condom project, an initiative conceived by Nadia with support from the Link Up programme.

Nadia’s aim is to give women the “power to choose”. The first step is to carry out research with health centres. Nadia is exploring the availability of female condoms compared to male condoms, and then comparing availability to the demand. The hypothesis is that the demand is not being met. This presumption is coming from the fact that female sex workers are proactively asking for female condoms and not receiving them. Because of this, they will be one of the first two groups the project will reach. “Female condoms are important because of double-protection,” says Nadia. In other words, they prevent both pregnancy and STIs. “According to sex workers, you can agree with someone to use a condom but they may take it off during sex,” explains Nadia. “In this case when a client agrees to use a condom they would choose to wear a female condom instead of a male one so they [the sex workers] have more control to make sure it stays in place.”

The second group that the project will initially target is women living with HIV. This group is easy to access, as they regularly visit the health centre for check-ups. Nadia explains that these visits also address women’s sexual and reproductive health needs. She will start work in five provinces and hopes the project will then extend into other areas, eventually going nationwide and reaching all women. “I want to see female condoms available like male condoms, to give women more choice.”

Nadia has initiated a female condom project in Burundi, to give more choices to women, in particular women living with HIV and sex workers. © International HIV/AIDS Alliance.



### **Recommendation 3**

**Ensure full access to age-appropriate information and education on HIV and sexual and reproductive health and rights, including on sexuality and gender identity**

- Provide universal access to holistic, tailored, rights-based comprehensive sexuality education (including HIV, gender identity, sexual orientation, and sexual pleasure) to all young people, including and especially those living with and most affected by HIV.
- Eliminate restrictive laws and policies that prevent young people from accessing sexual and reproductive health, including HIV information, education, and training (such as parental consent laws and laws forbidding sexual material).
- Provide training to caregivers on parent-child communication; provide caregivers with resources for teaching young people about sexual and reproductive health and rights in the home.

## 4

4. Promote gender equality and address gender-based violence, including sexual violence, in all its forms, including on the basis of sexual orientation and gender identity



The Addis Beza Anti-AIDS youth group in Addis Ababa, Ethiopia combine music and dance to get messages about HIV prevention to their peers. They hand out information leaflets and encourage people to get tested for HIV. © Sheikh Rajibul Islam / duckrabbii / International HIV/AIDS Alliance.

“Make society safe for women, young women specifically, to socialise and move about freely at any time of the day. Teach young women how to protect themselves and teach our young men how to handle themselves: a woman’s body is not a war zone.”

YOUNG FEMINIST WOMAN, EAST AND SOUTHERN AFRICA

Gender inequality has long been recognized as a key driver of the HIV pandemic, making women and girls more vulnerable to HIV acquisition and less able to mitigate its impacts. This inequality manifests itself in many ways, including unequal rights and legal protections, economic opportunities, and decision-making power in all realms (from an individual’s sexual experiences to the broader economic position of women worldwide). People from sexual and gender minorities are also negatively affected by inequality founded on fixed or heteronormative gender norms and expectations, particularly through unequal and discriminatory laws and policies.

*Gender-based discrimination—including the denial of the rights of women and girls and their disempowerment to take control of their lives and bodies—remains the single most widespread driver of inequalities in today’s world.*

The World We Want Global Thematic Consultation on the Post-2015 Development Agenda, *Addressing Inequalities: Overview and Key Messages*

Gender-based violence on the basis of gender, sexual orientation and gender identity affects women, girls, and people from sexual and gender minorities, and particularly impacts on people from key populations most affected by HIV.

## Gender norms

Gender-based violence is fuelled by gender norms that define the expectations and accepted behaviours of everyone in society. These constraints are particularly limiting for women and girls:

For girls, it is not easy to talk about sexual matters with their boyfriends. There is less chance of refusing sex if boys ask explicitly.

YOUNG WOMAN, ASIA AND THE PACIFIC

94%

In Bangladesh, 94% of people who do sex work have experienced violence from clients, gatekeepers, police, intimate partners or neighbors.

*Addressing Violence against Women and HIV/AIDS: What Works?*  
World Health Organization (WHO) and United Nations Programme on AIDS (UNAIDS), 2010

Gender-based violence is one of the most harmful manifestations of gender inequality, and often leads to unwanted and teen pregnancy, STIs and HIV, unsafe abortion, denial of SRH services, exclusion and discrimination in the community and the family, and psychological trauma and suicide, among other sexual and reproductive health and rights-threatening repercussions. It can also occur as a consequence of HIV disclosure. It is impossible to disconnect gender-based violence from HIV and sexual and reproductive health and rights.

Pressure to conform to patriarchal and heterosexual norms creates secrecy and double lives among men who have sex with men, placing both men and their female partners at greater risk of HIV and other sexual health issues. Young men who have sex with men in Burundi, Bangladesh, Myanmar, and Uganda all spoke of the pressure to marry and have children with women despite their wishes to be with romantic partners of the same gender and/or to adopt children:

My aunt always told me she understands me, but according to her, I have to make a girl pregnant in order to cover my family. I always reply that it may be possible but it is unfortunately not a solution.

YOUNG MAN WHO HAS SEX WITH MEN, BURUNDI

I am not going to follow tradition and marry a woman. I will go out of Bangladesh and will marry a man. So I will not get baby naturally, but I can adopt a baby.

YOUNG MAN WHO HAS SEX WITH MEN, BANGLADESH

## Sexual and physical violence


It is well-known that women and girls face a disproportionate level of sexual and physical violence, and that both female and male young people most affected by HIV face further and amplified risk factors related to gender-based violence.<sup>14</sup> Of 24 young women in one Ethiopian focus group, 19 had experienced one or more forms of gender-based violence including sexual violence at some point in their lives.

Causal pathways between gender-based violence, sexual and reproductive rights violations, and HIV can be direct, for example when HIV transmission occurs as a result of rape or forced sex. They can also be indirect, as when violence or the threat of violence leads to a particular course of action or set

14. Please see *Technical Paper: Review of Training and Programming Resources on Gender-Based Violence against Key Populations*, submitted to USAID by Management Sciences for Health on September 30, 2013 for more information.

of circumstances which heighten vulnerability. For example, in a group of young Ethiopian women who do sex work, five of 13 had been married before they were 16 years old, and three others had left home because of impending forced marriages.


One woman from Central Africa noted the relationship between sexual violence and HIV:

 Stop rape and early marriage. Here sexual violence is the major cause of the spread of HIV among girls. We believe that putting an end to these criminal practices, the girls will be saved from HIV and sexual rights will be promoted.

In a series of community dialogues among young mothers living with HIV in Uganda, all the participants had received their HIV diagnosis during pregnancy, and most had experienced violence as a result, including abandonment by their partners.

People of all sexual orientations and gender identities who do sex work routinely experience physical and sexual violence at the hands of clients, members of the public, police, and even


health providers. In fact, a growing body of evidence suggests that most violence against sex workers does not come from clients or intimate partners, but from state actors like police and health care providers (as also clearly demonstrated through this consultation).

 As I took off my pants so he could examine me, I turned around and saw that he was about to take off his pants. I told him that if he dared to penetrate me I would scream and all the world would know what was happening.

YOUNG WOMAN SEX WORKER, COMMUNITY DIALOGUE, BURUNDI

 Last month I was raped by three policemen. They took my money after they raped me.

YOUNG TRANSGENDER MAN SEX WORKER, BANGLADESH

 I wish there was a law to protect the human and sexual rights of people who do sex work, and a law that encouraged people who do sex work to report any sexual abuse or sexual violence whenever it happens.

YOUNG WOMAN SEX WORKER, ETHIOPIA

## Case study

### Youth leadership in action: The Young Women's Leadership Initiative

Link Up partner ATHENA is an international network campaigning for gender equity in the HIV response. As part of this work, ATHENA has developed the Young Women's Leadership Initiative (YWLI), a mentoring and leadership development programme enabling young women and girls to meaningfully engage and lead the HIV response. ATHENA launched the YWLI with the Global Coalition on Women and AIDS in 2011 and has continued this through Link Up – bringing gender expertise and previous work in building a cadre of young women living with HIV leaders to the project.

Through Link Up, ATHENA brought a YWLI to the Research 4 Prevention conference in Cape Town in 2014. Young women engaged in HIV research were identified by Link Up partners, and supported to attend and engage in the conference. Wraparound support including clear objectives, regular briefings and structured mentoring were provided to ensure that the young women were able to benefit from and meaningfully contribute to advocacy at the conference. The young women participants led a panel discussion on young women, HIV prevention and new prevention technologies, ensuring that a gendered understanding of the impact of prevention research was given a platform at the conference.



#### **Recommendation 4**

##### **Promote gender equality and address gender-based violence, including sexual violence, in all its forms, including on the basis of sexual orientation and gender identity**

- Eliminate laws and policies that contribute to gender-based violence and inhibit access to sexual and reproductive health services (such as the criminalization of: sex work, drug use, HIV exposure and transmission, and same-sex sexual activity and relationships).
- Clearly reiterate the definition of gender-based violence as including all forms of violence against women, violence against people who do sex work, violence against LGBT people (including transphobia, “corrective rape” and other forms of violence against lesbian and bisexual women, and violence against men who have sex with men), and violence against any others who are persecuted because of their gender identity or sexual orientation.
- Implement and enforce laws against gender-based violence to protect women, people who do sex work, LGBT people, men who have sex with men, and any others who are persecuted because of their gender identity or sexual orientation.
- Implement programming that works to transform gender norms that perpetuate violence and discrimination against young people most affected by HIV.




## 5

**5. Meaningfully engage young people, in all their diversity, in the decision-making that affects their lives**

'Positive Contribution. This transgender lady is living with HIV and is volunteering for my organization to help care for others living with HIV.'

A photograph taken during a PhotoVoice project with Alliance Myanmar and the Myanmar Youth Stars, a group of young people from key groups affected by HIV.  
© Arkar 2014\International HIV/AIDS Alliance\PhotoVoice.

**72%** of e-consultation participants were not members of an advocacy network or organization that supports youth or other groups affected by HIV.

 “Nobody can have a better voice than youth [themselves]. They are the ones who know their issues and ways to deal with them.”

YOUNG WOMAN, ASIA AND THE PACIFIC

The number of adolescents and young people today is at an all-time high—there are more than 1.8 billion young people in the world, 90 percent of whom live in developing countries, where they tend to make up a large proportion of the population.<sup>15</sup> For example, in Uganda, 69.9 percent of the population is below 25.<sup>16</sup> It is estimated that five million young people aged 15–24 and two million adolescents aged 10–19 are living with HIV worldwide.<sup>17</sup> Yet young people and young people affected by HIV are often excluded from programme design, policy deliberation, and decision-making about youth HIV and SRHR policy. The critical steps to policy design and implementation, including monitoring and evaluation, research, and governance must also be taken by young people—not only by older adults on their behalf.


Meaningful participation of young people is included in international commitments:

*“Youth should be actively involved in the planning, implementation and evaluation of development activities that have a direct impact on their daily lives...”*

International Conference on Population and Development, 1994, para 6.14

## Participation in community dialogues

Young mothers living with HIV involved in community dialogues in Uganda had never met before as a group, and found the very experience of exchanging experiences – and more importantly, finding that their individual stories were not unique – extremely empowering. Similarly, in a dialogue among young women who use drugs and do sex work in Uganda, participants felt that:

 Sharing personal experiences is powerful and renewing. Our stories show how human we are, they show that we laugh, we cry and have responsibilities just like any other human being especially the adults who despise us.


Meeting in safe spaces allows young people to make sense of personal experiences and to transform them into collective stories that can be used to engage in political processes and decision-making. These spaces provide a vital starting point for advocacy and political engagement, and nurture a new sense of agency.

## Participation in policy-making

Many visions for positive change in the consultation voiced a need for actively including young people in policy-making, and allowing youth to take control of all aspects of decision-making in their own lives, especially related to their sexual and reproductive health and rights.

Young women living with HIV in Ethiopia had never been involved or asked to be involved in policy dialogue. Young participants in the Link Up project have commented that breaking into high-level policy dialogues (such as the UANIDS Programme Coordinating Board and the Global Fund Country Coordinating Mechanisms) is extremely difficult if one is not highly educated, proficient in English, and well-connected to organizers.

One young Ethiopian woman living with HIV commented, “We need to be engaged, participate as productive citizens, and not [only] as people who use ARVs, and wait for death.” Likewise, young people who do sex work felt that they were “targeted” by campaigns for HIV testing and contraceptives, where they might be blamed for failing to utilize services, but were not offered family planning or reproductive health services, or involved in the design of services or consulted on their needs. For young people, being truly engaged means more than being involved in existing processes—rather, it requires changing existing processes to include a specific and equal decision-making space for young people. This does not mean removing older people from their positions, but that young people can work together with older allies as equals, or in mentee-mentor roles.<sup>18</sup>

 More funds [are needed] for HIV/AIDS, adolescent sexual and reproductive health, and policy influence. These funds should have limited or no restrictions that make youth led organizations able to access it. In Uganda, the youth fund was established but then the majority of the youth were kicked out because of the requirements like the level of education, running enterprise, etc.

YOUNG MAN ACTIVIST, UGANDA

15. *Adolescents and Youth Demographics: A Brief Overview*. UNFPA, 2012.

16. CIA World Factbook, 2014

17. *Opportunity in crisis: preventing HIV from early adolescence to young adulthood*. 2011, UNICEF.

18. For more information on meaningful youth participation, please see the Youth Coalition for Sexual and Reproductive Rights’ publication, *Meaningful Youth Participation: what it actually means for you, your work and your organization*.

Youth want to be involved in community campaigns and caring for people in the local community. The community should also actively communicate with and involve in youth-led activities such as rights-based campaigns and approaches to challenges in the future.

#### MYANMAR FOCUS GROUP STATEMENT

Participants in the consultation repeatedly called on policy and programme makers (both local and global) to ensure their full and active participation at every stage of the process, from inception and design through implementation, monitoring, and evaluation.

Meaningfully and effectively involving young people in programming and decision-making. All players/stakeholders in health should prioritize this. Imposing programmes on young people without their say in designing them is old fashioned. It is very important to have the young people's say in the initial stages of any programme you would love to have them be part in implementation. This gives us confidence and more information on the programme and it creates ownership of the project.

20-24 YEAR OLD MALE ACTIVIST, UGANDA

## Case study

### Young people defining their priorities for the Global Fund in Uganda

Link Up supports young people living with and most affected by HIV to participate in advocacy forums, planning processes, and strategy in national, regional and international fora. One such opportunity arose around the Global Fund's New Funding Model, which provides an opportunity for civil society to influence the HIV response in participating countries, and a platform for the issues of key populations to be prioritized. To achieve these opportunities requires effective participation and active support for broad and meaningful involvement.

Recognising this, in Uganda, a broad civil society group that included young people living with and most affected by HIV (supported by the Link Up programme) came together to develop the Young Key Populations Priorities Charter. The development of the charter included the active participation of: young people living with HIV, young people who use drugs, young people who do sex work, young transgender people, and men who have sex with men. National and international partners provided support to the process. A broad and comprehensive range of priorities were identified.

By bringing together young people from key populations and living with HIV, the Charter development process created a platform for meaningful and active youth leadership, identifying the issues prioritized by young people and taking a gender and human rights approach. Priorities identified through the process provide a template for action and, if reflected in the Uganda concept note as planned, have the potential to catalyze real change for young people.

### Young activists using photography to target stigma

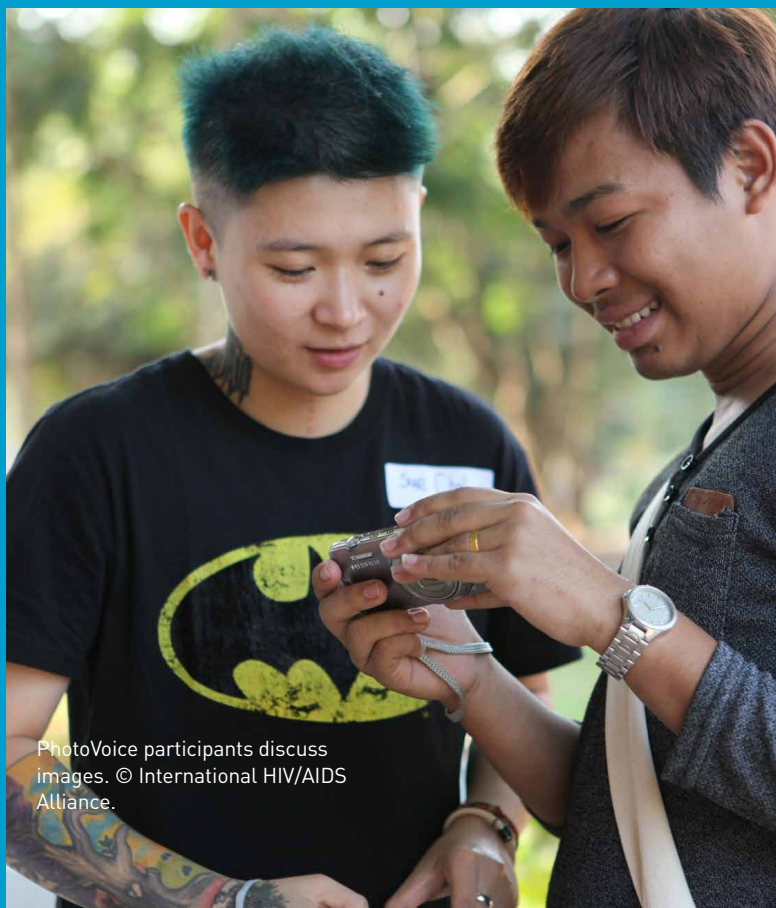
In Myanmar, young people living with and most affected by HIV reported high levels of stigma and discrimination and a lack of opportunities to discuss sex and sexuality. Myanmar Youth Stars, a youth-led organization, collaborated with Alliance Myanmar, PhotoVoice and the Link Up programme to lead a photography project providing a platform for young people most affected by HIV to challenge discrimination.

The Mysterious Youth Eyes project wanted to increase visibility of key groups including sex workers, LGBT people

and people living with HIV. The project trained young people from these groups in photography and then held a public exhibition of their photos. A participant said, *"The main thing I want to get from the exhibition is that when the general public see my photos it might change their minds. I'm looking forward to reducing stigma and discrimination towards young stigmatised people. I am very happy and also proud of myself for taking part in this process."*

The project also built young people's skills so that they can be effective advocates and peer educators in the future. "At the PhotoVoice project we have a chance to provide training in photography and how to take photographs in a meaningful way to express feelings, and to advocate to people about the needs and issues of the key populations," says Thiha Nyi Nyi, from the Alliance Myanmar.

The photos were also used to support a Loud and Proud event in Yangon and exhibited at the International AIDS Conference in Melbourne in July 2014.



PhotoVoice participants discuss images. © International HIV/AIDS Alliance.

### **Recommendation 5**

**Meaningfully engage young people, in all their diversity, in all decision-making that affects their lives**

- Ensure the full and active participation of young people living with and most affected by HIV in policy and programmes, at every stage of the process, from inception and design through implementation, monitoring, and evaluation.
- Create and expand concrete leadership spaces for young people that support participation in decision-making and policy fora, including support to ensure language and formal education levels are not barriers to participation.

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### Lead author team

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This page: Pacifique, a member of RNJ+, at home with his family in Bujumbura, Burundi. © Cédric Nininahazwe/RNJ+

Back cover: The receptionist puts up anti-homophobic posters around the ISHTAR Wellness Centre, Nairobi, Kenya. © Corrie Wingate for International HIV/AIDS Alliance.

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# LINKUP

Link Up aims to improve the sexual and reproductive health and rights (SRHR) of one million young people affected by HIV across five countries in Africa and Asia. The project is being implemented by a consortium of partners led by the International HIV/AIDS Alliance. For more information, visit [www.link-up.org](http://www.link-up.org)



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