



Visions, voices, and priorities*

ADOLESCENTS TALK ABOUT ACCESS TO HIV TREATMENT & CARE

1

Young people want quality sexual and reproductive health services, from ethical and well-trained health service providers, with services tailored to their needs, rights and desires – especially as young people living with and most affected by HIV.

HIV-related stigma and discrimination continue to be experienced by young people and adolescents at the family, community and service level, and must be eradicated. Stigma and discrimination, fear of involuntary disclosure and negative attitudes among service providers present a real threat to adolescents' retention in care and adherence to treatment.

2

Young people want to enjoy their sexual and reproductive health and rights (SRHR), including the freedom to love and be loved safely.

Adolescents and young people often lack the independence and autonomy to access services without practical support or permission from adults. Policy and legal barriers pose additional obstacles to accessing services. Age of consent laws to HIV testing and SRHR services should be lowered or removed. Adolescents tested and diagnosed with HIV should have immediate and on-going access to psycho-social care and counselling, including peer counselling and support, and treatment for side effects. Adolescent girls and young women living with HIV need access to equitable SRHR services including counselling for family planning and information about pregnancy and childbirth

3

Young people want full access to information and education on HIV and SRHR, including on sexual orientation and gender identity.

Adolescents need comprehensive sexuality education including information and awareness on HIV. Lack of or inaccurate information about HIV put young people's lives at risk. Adolescents living with HIV need accurate and up to date information, counselling and support around expressing and exploring their sexuality safely, including support and counselling on pregnancy and STI prevention, and realising fertility desires.

4

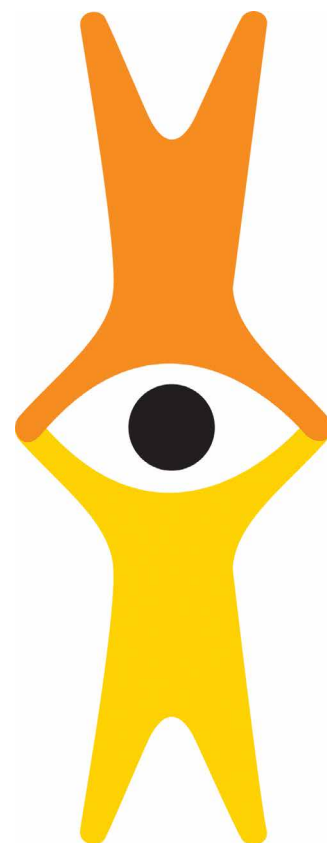
Young people seek gender equality and to see an end to gender-based violence. This includes sexual violence, in all its forms, including because of sexual orientation or gender identity.

Gender-based and intimate partner violence, or fear of the same, can delay treatment initiation and jeopardise retention in care. Adolescent girls and young women need support with disclosure and access to information, counselling and support services for intimate partner violence. All young people should be sensitised to identify and name different forms of gender-based violence, and be made aware of their rights.

5

Young people, in all their diversity, want to be a meaningful part of the solution, and participate in the decision-making that affects their lives.

Young people, including adolescents, living with HIV should be seen as more than beneficiaries of treatment, but rather as participants in their own healthcare, and that of their community. Young people living with HIV have an important role to play as community educators and service-providers as peer counsellors and navigators. They should be involved in all decision-making that affects their lives – helping to shape policy and programmes that respond to the needs, aspirations and realities of young people in all of their diversity.



* The Link Up *Visions, Voices, and Priorities* consultation created a five-point framework for programming and advocacy designed by and for young people living with and most affected by HIV. This issue brief applies the framework to adolescent access to HIV care and treatment services. See www.aidsalliance.org/resources/510-report-visions-voices-and-priorities-of-young-people



Background and introduction

The original *Visions, Voices, and Priorities* report¹ shares the findings of a global consultation carried out by the ATHENA Network and the Global Youth Coalition on HIV and AIDS (GYCA) in partnership with local community-based organisations as part of the Link Up project in 2013. The consultation explored access to and priorities for SRHR for young people living with and most affected by HIV,² through an on-line survey and community dialogues involving over 1,200 young people. Near the end of the Link Up project in 2016, three new areas of focus within the HIV and SRHR spheres were identified for further consultation:

- Access to HIV treatment and care among adolescents living with HIV – with attention to adherence and staying in care
- Attitudes toward and perceptions about pre-exposure prophylaxis (PrEP)
- Attitudes toward and perceived benefits and challenges of self-testing for HIV among different key populations and age groups.

Despite advances in HIV treatment and care, access to treatment and retention in care continues to pose challenges for adolescent young people (aged 10–19) living with HIV. Rates of HIV-related mortality among adolescents are increasing at a time when HIV-related deaths are steadily decreasing among other age groups.³ HIV is the second highest cause of death among adolescents globally,⁴ and the highest in sub-Saharan Africa.⁵

METHODOLOGY

Community dialogues on adolescent access to HIV treatment and care, designed with and for young people living with and most affected by HIV, took place in Burundi, Bangladesh and Uganda during April 2016. Young people living with and most affected by HIV led dialogues with other young people in their communities, facilitated using a standard discussion guide. A total of 38 young people living with HIV took part in the dialogues, of whom over half were aged 12–19. The results of the dialogue were validated in a meeting in Yangon, Myanmar in June 2016, and further validated among participants virtually in July 2016.

Each community dialogue was facilitated using a discussion guide, which included a set of key questions designed to facilitate discussion and to explore experiences, perceptions, and desires among adolescents and young people living with HIV and access to treatment and care.

Key findings

LEARNING AND ACCEPTING ONE'S HIV STATUS

Many adolescents living with HIV acquire HIV peri-natally, and may receive HIV-related treatment and care without necessarily being aware of their status. Others acquire HIV as young adolescents through sexual activity, drug use or by other means. For young people unaware of their status, adherence to medication – especially when they feel fine – can be a challenge, as some of the focus group discussion (FGD) participants discussed.

For all young people living with HIV, being given a diagnosis or having their status disclosed to them in a positive way and with adequate support was seen as an important step towards acceptance of their status and retention in care.

However, many participants in the dialogues (almost all of whom were diagnosed as adolescents) reported negative experiences related to learning their HIV status, including discrimination and stigmatising, misinformation, lack of counselling or advice, and being given inadequate time from service providers to come to terms with the news. Several participants also felt that the disclosure was not delivered sensitively or in a timely enough manner (from service providers or from family).

“I was told with a good management and there was a counsellor, he helped me to understand about HIV and the way it’s spread.”

YOUNG PERSON LIVING WITH HIV, 17, BANGLADESH

“I went home to tell my mother, who had known of it earlier but she was hiding it from me. I remember she used to take me to the hospital and they would give me tablets, which were ARVs but I did not know. She confessed to me I was born with HIV.”

YOUNG WOMAN LIVING WITH HIV, 19, UGANDA



“They used to give me medication daily, but after refusing to

take it and questioning my mother why I was being given medication daily yet I wasn’t sick she eventually told me that I was HIV [positive]. This wasn’t good news for me especially knowing that I will take the medication for my life time.”

YOUNG MAN LIVING WITH HIV, 18, UGANDA

1. *HIV and sexual and reproductive health and rights: visions, voices, and priorities of young people living with and most affected by HIV*. Available at: www.aidsalliance.org/resources/510-report-visions-voices-and-priorities-of-young-people
2. In this case, “most affected” refers to young people at elevated risk of HIV exposure such as young women, young people who sell sex, young people who identify as lesbian, gay, bisexual, or transgender (LGBT), or young men who have sex with men.
3. http://data.unicef.org/corecode/uploads/document6/uploaded_pdfs/corecode/Epidemiology_of_HIV_and_AIDS_Among_Adolescents_169.pdf
4. www.who.int/maternal_child_adolescent/epidemiology/adolescence/en/
5. www.unicef.org/media/media_86384.html

"I didn't like the way my relatives told me, because they told me I was to die of HIV, so I grew up knowing I am going to die."

YOUNG WOMAN LIVING WITH HIV, 18, UGANDA

DISCLOSING TO OTHERS

For adolescents who often lack privacy and autonomy, keeping their HIV status hidden can lead to challenges with treatment adherence and retention in care. Some participants reported that disclosing their status to friends or family members has helped them gain support and encouragement, which made accepting their status and adhering to treatment and care regimens easier. Some participants also reported that disclosure helped them to navigate early – or perhaps debut – sexual relationships and intimacy.

"We were at a party with my friends and it was time to take my medicine. They asked me why I was taking [it] and I didn't have a choice – I told them. Now they are helping me out."

YOUNG WOMAN LIVING WITH HIV, 18 UGANDA

"I told my boyfriend so that he would know how far we can go in the relationship."

YOUNG WOMAN LIVING WITH HIV, BURUNDI

However, disclosure to sexual partners and family members is also sometimes avoided for fear of repercussions, posing a significant barrier to retention in care and treatment initiation and adherence.

"I did not tell my boyfriend because he refused to go for a checkup with me, so I decided to wait to start these drugs because when I tell him he will say I'm the one who brought the disease."

YOUNG WOMAN LIVING WITH HIV, 19 UGANDA

FEAR OF INVOLUNTARY DISCLOSURE

Fear of others finding out about a person's HIV status can create significant challenges for young people's retention in care and adherence to treatment. Several participants reported wanting to keep their status a secret at all costs, for example seeking services at clinics outside of their own community for fear of being seen. Social obligations, including school and family life, and their relative lack of financial independence and autonomy can make retention in care especially challenging for adolescents.

"There are many patients who feel fear to collect ARVs. In case their family might be aware of that."

YOUNG WOMAN LIVING WITH HIV, 15, BANGLADESH

"I was tired of having to ask permission to leave [the classroom] every time I took my drugs because people would ask 'what do you have?' Then I had the idea of wrapping my pills up in sweet wrappers, and I didn't have to ask to leave the room any more. People just thought I was eating sweets."

YOUNG PERSON LIVING WITH HIV, BURUNDI

SIDE EFFECTS

Several participants reported experiencing debilitating side effects from their medication including headaches, drowsiness, fatigue, lack of concentration, skin problems and sleep disorders or nightmares. These are not only difficult for them, but can draw attention to their health or HIV status, potentially leading to involuntary disclosure (particularly at school, where they are around many other young people each day). Side effects may also impact on adolescents' ability to adhere to HIV treatment, keep up with school work, enter into gainful employment as young adults, and socialise with peers.

"ARVs like efavirenz causes nightmares, you over sweat, the feeling in the body is horrible."

YOUNG MAN LIVING WITH HIV, 17 UGANDA

HIV SERVICE AVAILABILITY

Lack of access to services is a problem for many people living with HIV, and in particular for young people in countries with low HIV prevalence, such as Bangladesh. Distance from treatment clinics, lack of transportation, and long waiting times were also reported as issues in all three countries, which can pose particular barriers to adolescents who are dependent on others to help them access services, or who wish to keep their status hidden. These issues can also disrupt their school, family and social life. For young people from



"After having given me my results, the doctor let me leave, even though I was in shock. He should have given me more time. I wandered around the hospital not knowing what I was looking for. I was truly lost."

YOUNG MAN LIVING WITH HIV, BURUNDI



"When I was 12 years old, my parents both tested positive, so they were advised to take all their children for HIV testing. The results came out that I was positive. I was worried but since my parents were around me I felt strong."

YOUNG MAN LIVING WITH HIV, 17, UGANDA



"We need a safe space for treatment and a positive environment where we can feel safe and get proper treatment. Most of the time the family doesn't know our status and we are taking ARVs."

YOUNG PERSON LIVING WITH HIV, 19, BANGLADESH



"If you go to nearby clinics you are sometimes stigmatised, so I chose to go to other districts."

YOUNG MAN LIVING WITH HIV, 16 UGANDA



"Before I started medication I was fine, but ever since I started on medication I developed a skin rash and I can't explain it to my friends, which makes me not going to school sometimes."

YOUNG WOMAN LIVING WITH HIV, 18 UGANDA



“There are only a few organizations that work for PLHIV in Dhaka, but outside Dhaka no facility for getting ARVs.”

YOUNG PERSON LIVING WITH HIV, 24, BANGLADESH



“I feel good about taking ARVs every day because every time I take the tablets I am adding life. I wish we can have ARVs that I can take the tablet once a week.”

YOUNG MAN LIVING WITH HIV, 18, UGANDA



“We would spend the whole day at the clinic and you don’t even see the nurse and you end up not getting the drugs and you go back home empty handed. And sometimes the nurse could shout at you in the midst of other patients and say ‘Did I give you AIDS?’ and this was so hurting.”

YOUNG MAN LIVING WITH HIV, 18, UGANDA (OTHER MALE AND FEMALE PARTICIPANTS IN THIS DIALOGUE REPORTED A SIMILAR EXPERIENCE)



“In most cases our ART clinics undermine young people. You grew up in this clinic and they still look at you as a kid so most information about your sexuality is not given to you at all because for them you are still their kid, yet this has pushed many young people away from clinics when they get pregnant – the fear of being judged.”

YOUNG WOMAN LIVING WITH HIV, UGANDA

marginalised groups (such as men who have sex with men), services that are tailored to their specific needs may be even more restricted.

TREATMENT FATIGUE

For some participants, taking pills every day can be challenging, but many mentioned the positive outcomes adherence to ARVs has had on their lives – not only in terms of their health, but also in increasing their confidence and motivation.

“Since I was little, I’ve hated taking the treatment, when I started taking it, every day I cried, I took the tablet and I crushed it to put it in water.”

YOUNG WOMAN LIVING WITH HIV, BURUNDI

“It is sometimes boring to take medicines every day, I forgot to take some days. But I must say ARVs changed my life totally. Now I am much confident and capable by heart.”

YOUNG PERSON LIVING WITH HIV, 19, BANGLADESH

QUALITY OF SERVICES

Young people describe mixed experiences of the quality of care they receive. For some, their health providers are holistic in their approach. In contrast, for others services are perfunctory at best. In some cases, participants reported experiencing harassment or insults at the hands of service providers, severely disincentivising further visits and jeopardising retention in care.

“I was satisfied. The health workers were knowledgeable, they asked me about things happening in my life and seemed to care about my life.”

YOUNG MAN LIVING WITH HIV, 18, UGANDA (OTHER MALE AND FEMALE PARTICIPANTS IN THIS DIALOGUE REPORTED A SIMILAR EXPERIENCE)

“It’s not a question of changing my doctor because of my age, it’s more due to their behaviour towards me. Twice I saw Doctor K and I will never go back. Both times she asked me to do a pregnancy test for no reason. Frankly, I hate her.”

YOUNG WOMAN LIVING WITH HIV, BURUNDI

TRANSITIONING TO ADULT SERVICES AND THE NEED FOR YOUTH-LED SERVICES

The transition from paediatric to adult services can pose challenges for adolescents and young people living with HIV. Paediatric services, tailored to children, tend to be smaller, cheaper and more care-oriented. On the other hand, paediatric services do not necessarily address the emerging sexual and reproductive health needs and concerns of young people living with HIV. Young people feared transitioning to adult services and highlighted the need for health facilities to be youth-friendly and where possible, youth led.

“The conversation between adults always discourages us from joining the adult clinic and this is because their discussion is different from young people hence it is difficult for us to open up to adults because we fear them.”

YOUNG WOMAN LIVING WITH HIV, 18, UGANDA

“The health workers at the ART clinic at the youth corner should be young people, who understand the issues of young people”

YOUNG WOMAN LIVING WITH HIV, 23, UGANDA

In addition to the issues discussed in the community dialogues, several challenges were cited in the validation meeting held in Yangon in June 2016. In this meeting, a range of policy issues were identified, from age of consent laws to criminalisation of young people living with and most affected by HIV, that can impact young people’s ability to access HIV treatment. For adolescents below 18, taking an HIV test itself can be the first barrier to accessing treatment. Sex workers, men who have sex with men, transgender people and people who use drugs also often face police harassment and arrest, creating barriers to service access.

LINKUP

Link Up has improved the sexual and reproductive health and rights (SRHR) of almost 940,000 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.aidsalliance.org/linkup

Special thanks to our country partners who led the dialogues: **Bangladesh:** Rokonol Rabbi (GYCA) and Moly Farhana (ATHENA Network). **Burundi:** Cédric Nininahazwe and Mona Ndayizeye (HUMURE). **Ethiopia:** Yoadan Workneh Shiferaw and Akililu Guulay (Talent Youth Association); Hanna Hagos (Nikat Charitable Association). **Myanmar:** Chan Aye San, Ei Mon Kyaw, Moe Kyaw and Myo Thet Oo, (Myanmar Youth Stars). **Uganda:** Allen Kyendikuwa, Mariam Nassaka and Charles Bwire (Uganda Youth Coalition on Adolescent SRHR and HIV (CYSRA-Uganda)); Brian Ssensalire, Stanley Nsubuga and Resty Nalwanga, (Uganda Network of Young People Living With HIV (UNYPAL)).
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