



Family planning 2013:

Visions, voices, and priorities of young people living with and affected by HIV

Young people living with and affected by HIV, especially young women living with HIV, young people who engage in sex work, young men who have sex with men, young transgender people, and young people who use drugs, among others, are often unable to access sexual and reproductive health (SRH) services, including family planning, without facing stigma and discrimination based on age, gender, HIV status and sexual orientation as well as attitudes and norms around 'appropriate' sexual behaviour.

Link Up aims to advance the sexual and reproductive health and rights (SRHR) of one million young people affected by HIV across five countries in Africa and Asia. A key component of Link Up is to support the meaningful participation of young people from marginalised populations in national and global policy debates.

The programme is being implemented by a consortium of partners led by the International HIV/AIDS Alliance. As part of Link Up, consortium members Global Youth Coalition on HIV/AIDS (GYCA) and the ATHENA Network led a **consultation with young people living with and affected by HIV**. Nearly 800 people from every region of the world responded to a **global online survey** that collected quantitative and qualitative data in five languages¹, and over 400 young people² participated in a series of **community dialogues and focus groups** with national partners in Ethiopia, Uganda, Burundi, Bangladesh and Myanmar.³

These face-to-face dialogues focused on and created a platform for key stakeholder groups, specifically young women living with HIV, young people who engage in sex work, young people who use drugs, and young LGBTQI people. The consultation aimed to learn directly from young people living with and affected by HIV about their lived experiences of accessing HIV and SRH services, including family planning; participating in decision-making as young people most affected by HIV; and, their vision for realising their sexual and reproductive rights.

1. The online survey was 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 people who engage in sex work, and 0.1% as people who use drugs. Of respondents who gave their age (ranging from 15 to 30 and above): 7% were aged 15–19; 32% were aged 20–24; 38% were aged 25–29, and 23% were aged 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 themselves as young people living with HIV, 7.5% as LGBTQI, 11.3% as young people who engage in sex work, 5% young men who have sex with men, 7.1% as young people who use drugs, and 6.7% as transgender young people. 33.9% of total participants chose not to identify themselves. Cultural and social factors may have led some to avoid identifying with a marginalised group.

Nearly 20% of respondents in the online survey said they never or rarely felt free to make decisions about whether or not, and when, to have children without fear that anyone would get angry with them, discriminate against them, or act violently towards them.

Young people's recommendations, visions for positive change, and lived experience

Young people most affected by HIV have a strong emerging advocacy agenda on access to SRH services, including family planning. This paper highlights five key priorities that surfaced from the online global survey and community dialogues, and recommends actions to increase access to SRH services (including family planning) for, and realise the sexual and reproductive rights of, young people most affected by HIV.

1. Provide integrated HIV and SRH services, including family planning, delivered by knowledgeable, ethical, and supportive healthcare providers

“I would like the HIV programme to be integrated into family planning programmes so that women-centric contraceptives are still made available to HIV-positive women. Currently, they are only told about condoms to reduce transmission, but may not access to a contraceptive to prevent unwanted pregnancies.”

WOMAN, AGED 25-29, ASIA AND THE PACIFIC

Participants overwhelmingly cited issues of harassment, discrimination, ignorance and lack of confidentiality when seeking SRH and family planning services. Consultation responses strongly emphasised the need to train health service providers on sexual and reproductive rights and the importance of respecting the rights of all human beings, especially young people affected by HIV. Correspondingly, they argued for more commitment to holding health service providers to high standards of ethical conduct, including confidentiality, respect, and the obligation to protect the SRHR of young people. They also called for tailored services that address the integrated needs of young people affected by HIV. While married women of reproductive age have traditionally been targeted for family planning programmes, integrated family planning can be a good entry point for youth who may not have otherwise encountered family planning providers (or who did not have access to them), especially in contexts where HIV prevention services for youth are more accepted or available than SRH services.

“[My visions are] access to family planning, counselling and contraception for all but a focus on making services easily accessible to young people – males and females in clinic and community settings. Less judgmental attitudes from services to young people seeking family planning and contraception. Increase knowledge about dual protection to prevent both HIV and unintended pregnancies. Improve access to safe termination of pregnancy and emergency contraception.”

WOMAN, AGED 30+, EAST AND SOUTHERN AFRICA

2. Ensure full access to age-appropriate comprehensive sexuality education, including information on HIV and SRHR

Focus groups with young people who engage in sex work in Burundi and Ethiopia revealed that some participants did not know how to prevent unintended pregnancy, or lacked the freedom to negotiate use of contraceptives. Participants maintained that comprehensive sexuality education should be provided in schools and at home, and must include information on family planning, HIV, gender identity and sexual orientation. They called for universal access to holistic, rights-based comprehensive sexuality education for all young people, especially those living with and affected by HIV.

“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 realised that my life and my baby were in danger.”

YOUNG WOMAN LIVING WITH HIV, BURUNDI

“When I do not have a pill, I take two paracetamol and a Coca Cola lemonade, so I am sure I cannot get pregnant.”

YOUNG WOMAN ENGAGED IN SEX WORK, BURUNDI

Participants also recommended providing caregivers with training or resources on how to communicate about family planning and other aspects of SRHR with young people in the home.



“[My vision is that] all youth have access to the knowledge required to demand and want to use modern contraception, and modern contraception services and commodities are available to all who want them. In this vision, schools and television and even parents give correct information about growing up, about sexuality and the healthiness of sex at some point in our life cycle (though the points may differ according to belief). Services and advice are offered without discrimination or stigma, and commodities needed for contraception are continuously available and affordable.”

ACTIVIST MAN, AGED 30+, EAST AND SOUTHERN AFRICA

3. Protect, respect and promote young people’s human rights, of which sexual and reproductive rights are an integral part



“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 ENGAGED IN SEX WORK, ETHIOPIA

Participants across the board emphasised that rights violations and gender inequality were a key barrier for young people in accessing family planning and sexual and reproductive rights services. Ensuring young people’s rights and access to quality, youth-friendly services will increase demand and uptake among those at greatest risk of HIV and unintended pregnancies. Participants called on governments to protect, respect, and promote young people’s human rights, including their rights to self-determination and freedom of association. They advocated for policy and legal reform including the elimination of discriminatory laws and policies that contribute to gender-based violence, inhibit access to services and criminalise or stigmatise HIV exposure and transmission, sex work, drug use, same sex relationships and abortion.

Participants also called on governments to eliminate restrictive laws and policies that prevent young people – especially young women – from accessing family planning and other sexual and reproductive health information and services. They identified key barriers such as parental consent laws and laws forbidding the publication of sexual material, as well as laws and policies preventing condom distribution in schools or access to long-term contraception for young women below the age of 18.

4. Address gender-based violence, including sexual violence and violence on the basis of sexual orientation or gender identity



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

FEMINIST WOMAN, AGED 30+, DEMOCRATIC REPUBLIC OF CONGO

Violence against women and girls was brought up many times as a human rights violation in itself and as a key barrier to accessing sexual and reproductive health services, including family planning. Alarming, this violence took place not only in young women’s homes and communities, but in health centers, police stations and schools. Participants called for broad reaching efforts to make societies safer for women and girls, changing attitudes to violence and protecting women and girls in their homes and enabling them to move about freely, at any time of the day.

Citing high levels of violence based on sexual orientation and gender identity, participants also called for recognition that gender-based violence is not only violence



“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.”

WOMAN, AGED 20–24, EAST AND SOUTHERN AFRICA



“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?”

YOUNG LGBTIQI WOMAN, EAST AND SOUTHERN AFRICA



“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



“I wish there was a law to protect the human and sexual rights of sex workers, and a law that encouraged sex workers to report any sexual abuse or sexual violence whenever it happens.”

YOUNG WOMAN ENGAGED IN SEX WORK, ETHIOPIA



“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.”

YOUNG MALE ACTIVIST, UGANDA

against women, but can also encompass violence against men who have sex with men, transgender people, and any others who are seen to have defied cultural gender or sexual norms. They demanded that governments implement and enforce laws against gender-based violence that use a broader definition.

5. Meaningfully and directly engage young people in decision-making on HIV, SRHR and family planning

While the consultation highlighted the visions, experiences and priorities of young people most affected by HIV, a baseline survey undertaken at the start of the Link Up programme found that these young people participate little in policy development processes around HIV, SRHR or family planning. Increased participation would result in the increased visibility of young people most affected by HIV, and could secure appropriate interventions intended to meet their HIV, SRH and family planning needs and rights.

Participants called for policy makers to encourage and support young people to engage in the design, development, implementation, monitoring and evaluation of HIV, SRHR and family planning programmes. They also called for training opportunities to enable young people, especially those most affected by HIV, to become peer outreach workers, mentors and service providers themselves. They recommended that decision makers invest resources in youth advocacy and in supporting the meaningful participation by young people most 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

2013 International Conference on Family Planning: A call to action from young people most affected by HIV

To date, efforts to increase access to family planning, SRH and HIV services have not adequately addressed barriers to reaching young people, particularly those most affected by HIV. Reaching the most marginalised young people is essential and the 2013 International Conference on Family Planning (ICPD) takes place at a critical juncture, in advance of the ICPD’s 20-year culmination and just as the framework to replace the Millennium Development Goals (MDGs) is being negotiated. The next framework must support an integrated and rights-based approach that meets the need of young people, especially those affected by HIV.

Through the Link Up global consultation, young people, especially those living with and affected by HIV, have vocalised their vision for **comprehensive SRH services** including family planning, **delivered by knowledgeable, ethical, supportive and qualified health service providers**. They seek **comprehensive sexuality education** and **the protection of young people’s human rights**. They have asked governments and donors to **address gender-based violence, including sexual violence and violence on the basis of sexual orientation and gender identity**. As Link Up partners, we ask that delegates at the 2013 International Conference on Family Planning and other decision-makers address these priorities. Moreover, we call for **the meaningful engagement of young people in decision-making on HIV, SRH and family planning**, both at a national level and in key policy forums such as the post-MDG discussions and 2014 ICPD+20 dialogue.

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LINKUP

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