Breaking down barriers: Empowering young people living with HIV in Uganda

A case study from the Link Up project
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We are an innovative alliance of nationally based, independent, civil society organisations united by our vision of a world without AIDS.

We are committed to joint action, working with communities through local, national and global action on HIV, health and human rights.

Our actions are guided by our values: the lives of all human beings are of equal value, and everyone has the right to access the HIV information and services they need for a healthy life.

About 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.

For more information visit www.link-up.org

Acknowledgements

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About the International HIV/AIDS Alliance

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Designed by: Progression

Cover photo: Residents attend a condom demonstration at kajjansi on Entebbe road, Uganda. Wamala Simon 18 years (the one holding a condom) lives in Kajansi and he is a shop attendant. © Peter Caton/International HIV/AIDS Alliance
Breaking down barriers: Empowering young people living with HIV in Uganda

Ensuring that young people living with HIV know their HIV status and are linked to appropriate care is critical in addressing their sexual and reproductive health and rights (SRHR) and HIV needs. What strategies work to engage young people in services and ensure they stay in care?

This case study describes Link Up’s experience in Uganda of working with young people living with HIV and promoting youth-led interventions to link young people living with HIV to SRHR and HIV services.

1. Introduction

The number of young people living with HIV in Uganda is growing. Many were born with HIV and are now teenagers and young adults. The number of HIV infections is also increasing amongst young people from key populations, such as sex workers and men who have sex with men (MSM). These individuals struggle to access essential health services due to criminalisation1 and discrimination.

The Link Up project aims to increase access to integrated and quality SRHR and HIV information, commodities and services for young people living with and most affected by HIV. In Uganda, this three-year project (between 2013 and 2015) is implemented by a consortium of partners including Community Health Alliance Uganda (CHAU), Marie Stopes International Uganda (MSIU), Uganda Youth Coalition on Adolescent Sexual Reproductive Health and Rights and HIV/AIDS (CYRSA-Uganda), the International Community of Women Living with HIV in Eastern Africa (ICWEA), the Ugandan Network of Young People Living with HIV (UNYPA) and the Population Council.

CHAU delivers its community and facility-based activities through the following implementing partners: Integrated Community Based Initiatives (ICOBI), Mildmay, Family Life Education Program (FLEP), Uganda Youth Development Link (UYDEL),

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The project uses different strategies to support people aged 10 to 24, including young people living with HIV, young people who sell sex, young MSM, and young people who are particularly vulnerable to HIV, including truck drivers, boda boda riders and fisherfolk.

This case study focuses on interventions to link young people living with HIV to SRHR and HIV services.

2. Context

In Uganda, just under half (47%) of the 1.8 million people living with HIV are young people (Uganda National Youth Policy, 2011). Overall, young people account for 37.4% of the population.

Low enrolment of young people onto antiretroviral care: A 2014 baseline survey conducted under the Link Up programme by the Population Council in Luweero and Nakasongola found 29.8% of 473 young people living with HIV had been diagnosed with HIV in the past 12 months. However, almost a third of them had not enrolled on antiretroviral therapy because they were afraid and did not have support to take the next steps after receiving their HIV results.

Additionally, data from different health facilities in two districts suggests children born with HIV receive healthcare until they are adolescents, after which they stop visiting health facilities. As they grow older, they stop following instructions from their parents about accessing care and instead focus on their relationships with peers. The reality of HIV-related stigma subsequently causes them to drop out of care.

Lack of integrated SRHR information and services for young people living with HIV: The baseline survey of young people living with HIV further demonstrates low knowledge of HIV prevention. Of those surveyed, 31.1% believed mosquitoes could transmit HIV and 45% said they had not used condoms with an HIV-negative partner. A significant percentage did not know how to use male condoms and had never seen or used female condoms.

Around a third (33%) of women in Uganda of reproductive age have unmet family planning needs, yet few public facilities provide youth friendly and integrated SRHR and HIV services. Myths and misconceptions about family planning hinder uptake of services, for instance some young people living with HIV believe that family planning services will prevent them from having children due to their status.

Young people living with HIV lack information about preventing parent to child transmission of HIV (PPTCT). Some believe the only way they can have HIV-negative children is by having HIV-negative partners. Many are unaware of their rights and how to assert them, which limits their ability to negotiate safer sex in their relationships.

**Significant experiences of stigma and discrimination:** Experiences of internal and external stigma are a reality amongst young people living with HIV. Half (50%) of those questioned in the baseline study said people’s attitudes towards HIV made them feel worse, and 37.2% described themselves as not feeling as good as others due to their HIV status. More than a third (34.5%) had experienced verbal violence as a result of their HIV status.

There is a double stigma for young people living with HIV who sell sex, or for HIV positive MSM. The anti-homosexuality bill has forced many MSM into hiding for fear of being judged by health workers or even imprisoned.

### 3. Strategies and Results

Several interventions have been implemented in the Link Up project between October 2013 and March 2015 to increase knowledge of SRHR and HIV information amongst young people living with HIV who then play a critical role in empowering their peers and linking them to necessary services.

**Training peer educators:** At the heart of Link Up’s interventions are peer educators: young people living with HIV who have been trained on a range of SRHR and HIV issues.

During the period, 649 young people living with HIV were trained as peer educators. Each attended a three-day training course where issues to do with growing up, body changes, relationships, sex, sexuality, pregnancy, STIs, HIV and sexual and gender-based violence were explored. Peer educators also learn strategies on how to talk to their peers about SRHR issues and what to do if they cannot answer a question. Building a strong team of peer educators who are visible and proud of their work is the foundation for community mobilisation and service provision in the project.

The project’s implementing partners identify peer educators through health facilities and support groups. Ensuring peer educators remain motivated in their work is often a challenge, as young people have many interests, which can change over time. To overcome this, it is important to organise monthly meetings, give them peer educators a space to socialise together, continue building their knowledge, and encourage them in the work they do.

**Supporting peer outreach:** Peer educators play an important role in reaching out to other young people with information, counselling and commodities (e.g. male and female condoms, information materials), referring peers for...
services, and conducting follow-up visits. Implementing partners work with peer educators to find suitable places for outreach work such as support groups, youth clubs, HIV-related events, and groups organised in clinics. Peer educators then visit these locations and engage their peers in discussions about living with HIV and SRHR issues.

### The true value of information

“During training, I did not realise the true value of the information, knowledge and skills the Link Up project provided. Later on in my community, when I started referring and mobilising young people to receive services, I found that young people were still ignorant about SRHR and HIV.

“I realised that the information I got from Link Up was true and good for other young people in my community. Some are now able to make the right decisions – I have become the leader whom all young people can approach.”

**Link Up Peer Educator from Nakasongola District**

During the period, 5980 young people living with HIV were reached with SRHR information, counselling and services in their own communities. Through this work, people who are normally hard-to-reach have been brought closer to SRHR
and HIV services. Many have been referred to the Most At Risk Populations Initiative – an implementing partner – to be enrolled on antiretroviral therapy.

Sometimes, peer educators have to cover large geographical areas, meaning they are unable to return for regular follow up sessions with those they have already reached. Link Up’s implementing partners continue to train more peer educators in order to address this issue.

**Y+ clubs and support groups:** Support groups provide an important space for people living with HIV to meet, discuss their challenges, and give each other practical guidance and emotional support. Yet support groups emerge and often fade away.

In Link Up, support groups of young people living with HIV have been assisted to organise themselves and to create a space where they are comfortable learning and sharing together. Leaders of the groups, sometimes referred to as ‘Y+ clubs’, were trained as peer educators on a range of SRHR and HIV issues.

A challenge has been the turnover in peer educators and, therefore, in Y+ club leadership. Some peer educators have migrated to another part of Uganda, some have moved onto other activities. To overcome this, some implementing partners trained two peer educators per group thereby ensuring there is always a leader should a peer educator become unwell, is too busy to attend or moves on.

**Training health providers**

People living with HIV in Uganda report experiencing discrimination at health facilities. Healthcare providers are part of their communities and are influenced by cultural and social norms, which do not expect young people to be having sex before and outside of marriage, and who sometimes view living with HIV as a result of misbehaviour. Interrogating these cultural and social norms and inspiring change is a long-term process.

For this reason, training health providers on the specific needs and experiences of young people living with HIV – including why they may or may not be currently accessing services, what kinds of services to offer and, most importantly, how best to offer these services – is essential to the project’s success. A key part of this training focuses on how to communicate effectively with young people living with HIV, including the importance of listening, giving non-judgemental responses, recognising their sexual and reproductive rights, helping them think through their own solutions and inviting them back for additional services should they want them.

To challenge the deeply ingrained attitudes of some health providers, young people living with HIV were invited along to provider training sessions to either co-facilitate or share their experiences. Listening to these young people share their experiences in this setting gave participants the space and time to listen. In their day-to-day work, health providers are often under pressure to see the next client and do not have the time to listen to a client’s views.
Promoting youth friendly spaces in health facilities: This is an effective strategy for challenging young people’s perceptions of facilities and encouraging them to attend. Some youth-friendly spaces are simply a corner or a table, dedicated to displaying SRHR information, others include free condoms, indoor games and television. Youth-friendly corners are staffed at specific times by a peer educator who is able to help young people feel comfortable at the health facility, as well as letting them know where to go and what to do.

Some health facilities are too small to allocate a space for young people. In these cases, the entire centre is promoted as youth-friendly through posters and signage inside and outside and the existence of peer educators.

Linking young people with health facilities: A total of 224 completed referrals of young people living with HIV to health facilities were made during the period. Peer educators deployed three main strategies to encourage the young people they met in the community to visit a health facility:

Referral slips These clearly display the Link Up logo. When a young person visits a health facility using a slip, it ensures they are given the time and services suitable to their needs.
**Vouchers** Peer educators can also refer young people to private BlueStar health facilities, which are part of a social franchise supported by Marie Stopes Uganda International and thereby operate to specific standards. Under Link Up, peer educators can provide young people with a voucher that enables them to access HIV, STI and family planning services for free from these clinics. BlueStar clinics are aware of Link Up and are trained to provide tailored, appropriate and friendly services to young people referred through the project.

**Accompaniment** As some young people are afraid of going to health facilities, peer educators are given a budget to accompany them. Providing support in this way, coupled with follow-up home visits for those who access services, is important for enabling SRH in the longer term. Supporting oneself and peers to stay healthy is a lifetime issue. Some people may require more support than others, and some may require support at specific times (for example, when going for CD4 monitoring or for pre-conception advice).

**Taking services to young people through clinical outreach:** In order to reach young people who do not want to go to health facilities, implementing partners take SRHR and HIV services to places where young people living with HIV already meet.

An example is the tuk-tuk service, an intervention led by Marie Stopes International Uganda. Each tuk-tuk is operated by a nurse and two counsellors who use it to provide clinical services at selected spots. The tuk-tuks carry a range of commodities such as short and long-term contraceptives, HIV test kits and STI medication as well as a tent to create space for young people to seek services confidentially. Currently there are four tuk-tuks operating in Kampala under Link Up, with plans for more. Young people have been trained as peer counsellors to assist tuk-tuk teams in service provision, including registering clients, undertaking basic risk assessments, speaking to clients to allay any fears and preparing them to see the nurse.

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**Life as a young couple: testing for HIV together**

Kevin, 20, and Grace*, 18, have been in a relationship for three years. Grace experienced sudden illness and got a chance to meet the peer educator from a BlueStar clinic, who was visiting their community.

On visiting the facility, both were counselled and encouraged to take an HIV test. Grace learnt she was HIV positive while Kevin learnt he was HIV negative. Grace found the results disturbing and could not accept a referral for specialised care. She was continuously monitored by the clinical officer at the BlueStar facility until she was comfortable being enrolled in care. Kevin is currently being mentored by a peer educator at the BlueStar facility.

The collaboration between the peer educator and clinical officer is important in supporting both Kevin and Grace with their physical and mental health.

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Story shared by MSIU, September 2014
When conducting clinical outreach for young people living with HIV, collaboration with local organisations of people living with HIV is key. These organisations are able to identify young people who may want services and promote those services so that, when the clinical outreach team comes, they are already aware of the services on offer. It also helps young people living with HIV understand that those offering the services have been trained on important issues such as confidentiality and informed consent.

During the period, 3794 young people living with HIV were reached with SRHR information, counselling and services in health facilities and through clinical outreach.

Through Link Up, a ‘snowball method’ has been used in order to mobilise young people to access services. This means working with a group of young people who then mobilise other young people, who in turn mobilise their peers.

**Community dialogues:** Community dialogues with gatekeepers such as police workers and brothel owners have proved helpful in making them more knowledgeable about key populations and HIV. Some police workers are beginning to improve how they handle issues of gender-based violence against sex workers as a result.
“We helped other young people living with HIV to identify the different talents they had like dancing, painting, singing, modelling and also how much information they knew about HIV and SRHR.”
Jacquelyne Alesi, Director, UNYPA

**Youth camps:** Through Link Up, young people have come up with their own ideas of how to attract peers to events. One example is Link Up’s youth camps, which were jointly organised by UNYPA and MSIU. Young people living with HIV participated in weekend youth camps offering a programme of fun activities, including rowing, music, dancing and sports. During the weekend, MSIU set up a tent where young people could drop in, ask questions and receive a service if they wanted to.
The youth camps were promoted by UNYPA through word of mouth and on Facebook. This made young people living with HIV who already knew UNYPA feel safe and excited about participating in the activities.

**The Y+ beauty pageant:** Another idea generated by young people living with HIV was the Y+ Beauty Pageant, conceived as a way to address stigma by championing inner beauty and confidence. The pageant was then supported by MSIU.

## 4. Tips for adapting the approaches in other settings

**Knowing what you know and when to refer:** The peer educator trainings are packed with information, and peer educators often stated in their evaluation forms that three days was not long enough to absorb the information given. Over the course of the project, implementing partners learnt to encourage peer educators to feel comfortable about what they knew and what they do not know, emphasising that they were not expected to know everything about every subject. It is important peer educators know where to get additional information and where to refer their peers to so the young people they are working with can access the information and services they need.

**Importance of positive and innovative messaging:** A health promotion campaign called *Stay on top of your game* sought to reach young people with messages about growing up, relationships, safer sex, the use of modern contraceptives, stigma, discrimination, living with HIV, sexual violence and the prevention of HIV and other STIs. Information leaflets and a radio song were produced to support the campaign. The campaign was bright, colourful and positive in design. It was developed in collaboration with young people who gave their perspectives on different messages and images.

The campaign’s materials were really useful as they gave peer educators information to refer to if they were unsure of something. These materials also included information about where to access services, which is important when trying to link young people with services.

**Activities to keep clubs together:** Young people involved in the project said they would like to do more in their Y+ clubs and support groups besides discussing SRHR topics. They requested small club projects to be introduced, such as growing mushrooms, rearing chickens or making and selling food. Programming with young people living with HIV should include activities that keep them engaged with, and connected to, their broader community. This contributes to building confidence and self-esteem, key ingredients to empowering young people to access SRHR services.
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Peer Educator Christopher Ssenoga, 21. Peter Caton/International HIV/AIDS Alliance
Ongoing mentorship with providers: Changing attitudes takes time. As such, ongoing mentoring from implementing partners is critical in reminding providers about the needs and rights of young people living with HIV. Joint activities between young people living with HIV and health providers is one way to break down barriers and encourage communication. For example, a sports event was organised by a youth organisation and health facility around World AIDS Day.

Budgets for accompaniment: The value of young people living with HIV accompanying their peers for services cannot be underestimated. This requires a budget to cover peer educators’ time and costs. Without this service, young people may want to visit a health facility but fear of the unknown, or fear from what others have told them, may prevent them from doing so.
Role of young people in service provision: The role of young people living with HIV in service provision enhances the quality of programming. They speak the same language as their peers, and other young people do not feel intimidated to ask them questions. They also generate ideas about how to make services more attractive and accessible to their peers.

Partnership with youth organisations and networks: Meaningful collaboration with youth organisations and networks is key to the success of interventions aimed at young people. Youth organisations and networks play a critical role in championing community-based work to young people. They know their members, how to reach them, what they need and how to engage them in an effective way. Part of ‘meaningful collaboration’ means ensuring young people have a budget to lead interventions, trusting young people to be successful in implementing initiatives and providing support when needed.

5. Plans for the future

Link Up’s experience in Uganda demonstrates the success empowered young people living with HIV can have in achieving greater access to SRHR and HIV services for their peers.

Future programming should continue to invest in interventions led by young people living with HIV and extend this type of programming to other districts in Uganda.

It is important to promote strategies that engage young people living with HIV in all their diversity – including young people living with HIV who sell sex, young people who identify as lesbian, gay, bisexual, transgender or intersex and sell sex or use drugs – as they may be the best placed to reach others living similar lives with the tailored information and services they need to access their sexual and reproductive health rights.
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

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