International HIV/AIDS Alliance
Together to end AIDS

LINKUP



LESSONS FROM LINK UP!

LINK UP EXPERIENCES OF REACHING ADOLESCENTS LIVING WITH HIV

Adolescence is a time of physical and hormonal changes that stimulate sexual exploration, formation of sexual identity and development of intimate relationships.[1] Whether living with HIV or not, adolescents have a right to a healthy, fulfilled and safe sex life. Adolescents living with HIV (ALHIV), like all adolescents are having sex or want to have physical relationships in the future; and they have the same hopes of having children.[2] ALHIV have to manage a highly stigmatized sexually-transmitted condition, as well as the impact of this on their sexual health, relationships and emotional wellbeing. HIV services have failed to address the SRHR needs of this population, and there are major gaps in the provision of information, interventions and support.

Link Up, implemented by a global consortium led by the International HIV/AIDS Alliance, aimed to meet the SRHR needs of 10–24 year olds most impacted by HIV, including those living with HIV, by ensuring integration of SRHR and HIV services, information and advocacy. Across five countries in Africa and Asia – Bangladesh, Burundi, Ethiopia, Myanmar and Uganda, Link Up partners (Alliance Linking Organisations (LOs), their implementing partners (IPs) and consortium partners) delivered an expanded package of services through capacity building and by linking community- and facility-based services.[3]

Over time, the additional needs of ALHIV, beyond SRH, became increasingly apparent. Managing a chronic condition requiring lifelong treatment creates many specific challenges for adolescents: ongoing engagement in services, adherence, disclosure and mental health all require further attention and support. Many of these challenges had previously been overlooked by services or they did not have the capacity to adequately address them. By adapting their programmes, LOs and IPs have contributed to a more comprehensive approach to providing adolescent HIV treatment and care.

Adolescents living with HIV in Link Up

From 2013–2016 36,257 10–24 year olds living with HIV were reached by Link Up with 18,625 accessing services. Of those accessing services 35% were adolescents with 30% accounting for those 10–14 years and 70% 15–19 years. Across the 5 Link Up countries Uganda engaged the largest number of adolescents with HIV and in Myanmar adolescents accounted for 69 % of all 10 -24 year olds living with HIV.

This brief highlights the new understanding, gained through Link Up, around engaging and providing services for ALHIV. It outlines opportunities to learn from Link Up experiences, to build upon programme successes, to understand the challenges encountered during programme implementation and to inform future HIV programming for adolescents. The brief builds upon lessons learned, summarized in the Link Up brief titled 'What's so different about adolescents? Unique challenges and opportunities in engaging 10–19 year old in integrated HIV and SRHR services.'[4]

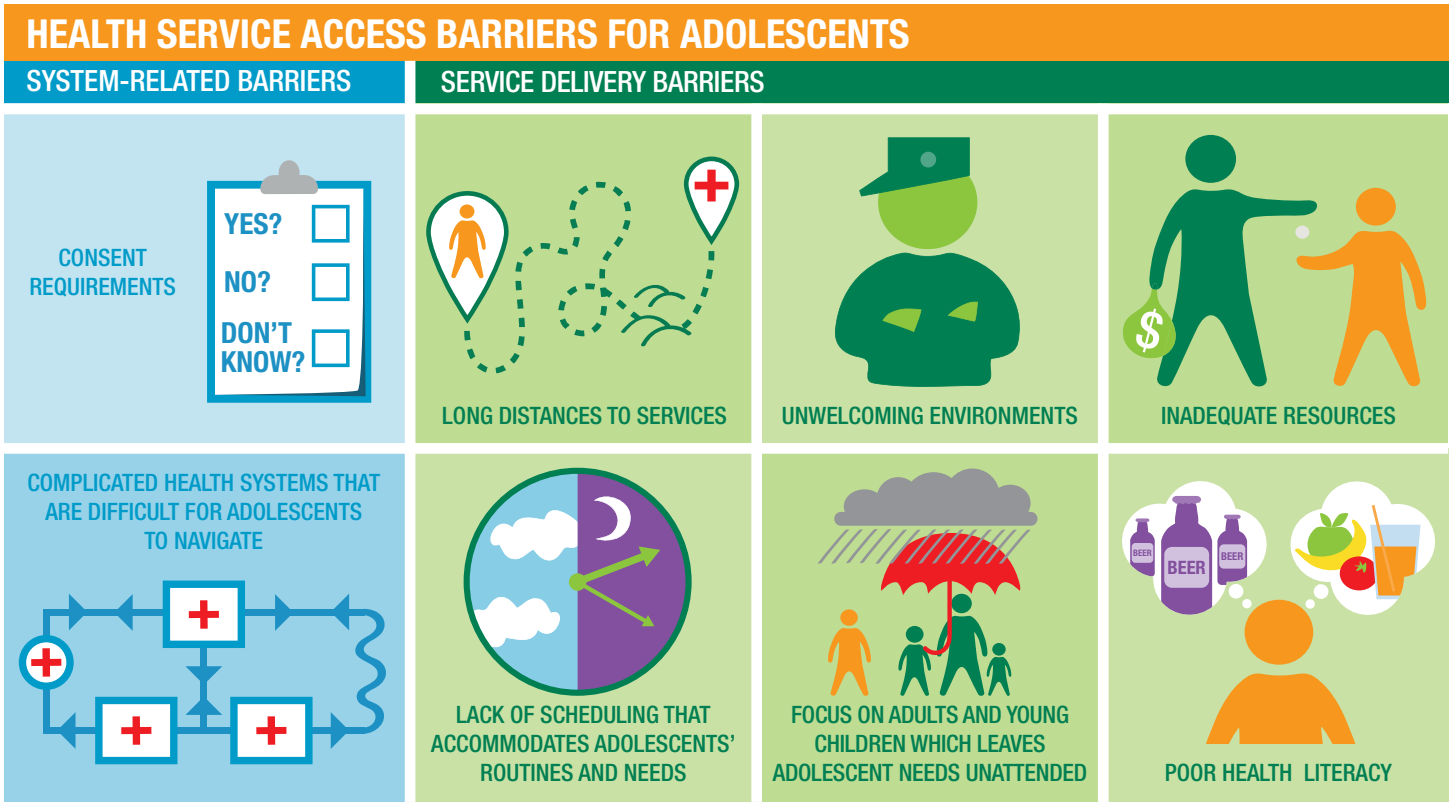
Data from the Link Up monitoring system, findings from research studies and outcomes of community dialogues were all examined for adolescent-specific aspects and considerations. In order to complement this data, interviews with LOs and IPs explored the perspectives of those involved in managing and providing services, including peer providers.

Specific challenges experienced by adolescents living with HIV

AHLIV are first and foremost adolescents. Their development, experiences and worldviews are defined more by this unique life stage than by their HIV status. Through Link Up, programmes recognized that adolescents face similar universal challenges relating to SRHR and HIV, however certain additional challenges, as a result of an HIV diagnosis, were acknowledged as requiring specific programming considerations.

Barriers to accessing services

ALHIV are at high risk of loss to follow up, before and after starting antiretroviral therapy (ART). In research on the impact of Link Up on young people living with HIV, females age 15–19 were more likely to be lost to follow up.[5] The need to regularly engage in HIV services is critical in ensuring the success of ART and good health outcomes for those living with HIV. This means that for ALHIV the usual access barriers faced by all adolescents (see Infographic) are exacerbated by the critical need for continuous engagement in HIV services. Regular, often monthly, clinic visits require resources that adolescents usually don't have such



as finances for transport. Continually attending HIV services also disrupts school, work and social lives for ALHIV, undermining their ability or motivation to remain in services.

Adherence to treatment

Adherence to ART was one of the biggest challenges for ALHIV. Many adolescents did not have the information they needed to support adherence: knowing their status, understanding HIV and ART or how the medications work. Busy and changing daily routines often meant that competing priorities got in the way of adherence for ALHIV. Side effects, particularly those that affect physical appearance, also undermined adherence as fear of disclosure and embarrassment often prevented adolescents from socializing—a vital component of an adolescent's life and development.[6] Economic drivers were also noted as having an impact on adherence, with many adolescents missing treatment due to insufficient food. Unfortunately, most LOs and IPs did not have the mandate to address these basic needs or had very limited capacity to do so.

Disclosure

Despite clear international guidance that children of school age—6-12 years—should be told their HIV diagnosis, many adolescents, in all Link Up countries, did not know their HIV status.[6] Of those who were aware of their status, some reported negative disclosure experiences: occurring too late at a time of life when adolescents often have many other difficulties; information being delivered in an insensitive manner, with inadequate counselling; having no, or minimal, follow-up discussions with, or other support from, service providers. Others who figured out their status by themselves had no sources of critical information or support.

Service providers acknowledge the challenges in assessing adolescents' levels of understanding regarding HIV status or in knowing how to approach disclosure to adolescents in a supportive manner. Working with parents on disclosure created additional complexities; some parents struggled with guilt or with coming to terms with their own status, often preventing open, honest communication with their children. Lack of clarity regarding provider and parent/guardian responsibilities also contributed to delays in the disclosure process. In general, lack of guidance on disclosure—in terms of process and managing challenges that arise, as well as inadequate skills and training for providers—prevented adequate support to parents, families and adolescents.

As adolescents are often not supported with the information on their rights and responsibilities, and the skills they need, to disclose their HIV status, they are less likely to disclose their HIV status to sexual partners and families.[6] The reality of criminalization, stigma, rejection, and even physical harm also discourages many adolescents from disclosing to others. However, not disclosing to others was seen to prevent important support for adherence and engagement in services.[5] Programmes also noted that due to fear of involuntary disclosure adolescents would seek HIV services outside of their own communities, or avoid services altogether—further contributing to loss to follow up.

Ensuring sexual and reproductive health and rights

ALHIV were noted to have less knowledge of sexual and reproductive health and rights (SRHR) and were less likely to use associated commodities and services than older age groups; in most setting there was a lack of SRH resources and materials for this age group.[7] In addition, research conducted by Link Up in Uganda found that young people living with HIV (20–24 years) had 1.9 times higher self-efficacy around using condoms and contraceptives and were 1.6 times more likely to access STI services compared to 15–19 year olds.[5]

Particularly within HIV services, there was often a disconnect between the SRH information and services provided and the actual needs and preferences of ALHIV. For younger ALHIV who are still seen in pediatric services, their emerging sexual and reproductive health needs were rarely acknowledged or addressed. often because of providers' assumptions or judgmental views.[5,6] Concerns were also raised regarding inadequate SRH assessments which often led providers' making assumptions and labels.
Beyond the negative societal views of adolescent sexual activity, those living with HIV face additional judgments of 'spreading HIV'.[8] Provider expectations that ALHIV

should not be having sex or children has led in some cases to denial of services, counselling to avoid pregnancy or coerced termination.

Stigma and discrimination

The ongoing development of coping mechanisms in adolescence means that ALHIV, particularly younger adolescents, struggle with stigma and discrimination and have limited capacity to manage its consequences. In view of the generally limited support ALHIV receive, the experience of rejection and isolation had profound effects on their self-esteem and confidence.[7] As a result, some adolescents often drop out of school or stop attending HIV services, having far-reaching consequences for their health, development and wellbeing.

> 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*

Lack of appropriate support for ALHIV

Empowering support is essential to facilitate the evolving capacities of adolescents, especially in terms of taking responsibility for their health. This is particularly important for those with chronic health conditions such as HIV. Empowering support ensures that ALHIV do not just cope and survive, but they live full, healthy lives and view the future with optimism and confidence.

Prior to Link Up, ALHIV in the five target countries were not receiving adequate support to ensure their consistent engagement in care, to address psychological challenges and to cope with their complex social environments. Where support structures were available, they were mainly for adults and did not allow or cater for adolescents, with many HIV services not having the capacity or resources to expand services to meet the needs of adolescents. In the absence of support groups, the only opportunity for many ALHIV to speak freely about their status was during clinic visits.

Unfortunately, ensuring safe spaces for open, honest discussion were often not facilitated by service providers, with adolescents reporting negative experiences, including harassment and insults. Support within the home also is often minimal, and largely focused on the logistics of clinic visits or taking medications, as parents or other family members usually have limited skills to communicate effectively about complex or sensitive issues.

> 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*

Improving SRHR and HIV services for ALHIV through Link Up

Link Up strategies for all adolescents[4] also serve the needs of ALHIV, but there are several considerations that are key to ensuring targeted, appropriate and effective programming for ALHIV.

Strengthening HTC and linkage to ART care

HIV testing and counselling (HTC), within SRH services, was a priority focus of Link Up. SRH services set out to increase access to HTC and to improve the quality of HTC services offered. For those who tested positive, particular emphasis was placed on providing post-diagnosis support and ensuring engagement in HIV treatment and care services. Through close collaboration between services, clear referral pathways and support from peer navigators, adolescents received timely follow-up care and support and linkage to the services they needed.

Training: key to integrating SRH and HIV services

Training and capacity building provided through Link Up was key to the integration of SRH and HIV services as well as improving overall quality of services for adolescents. Training for SRH services focused on the provision of quality HTC and the importance of linkage to care as well as specific delivery considerations for adolescents under the age of consent. ART service providers were trained on SRHR; training addressed attitudes, communication, clinical competencies such as provision of longer- acting family planning methods. In addition to specific technical aspects, training emphasized a better understanding of the broader needs of adolescents living with HIV and the critical need for comprehensive care and support for this age group.

Providing comprehensive support

Link Up IPs played a critical role in ensuring adolescents received appropriate and comprehensive support. Working with ART services, IPs advocated for adolescents to be referred for psychosocial support services including peer-led groups or networks and other Link Up-supported services. In some settings, IPs were also a part of multi-disciplinary teams and contributed to case management in complex situations. Through delivering community and home based support services Link Up's

Naguru Teenage Information and Health Centre offering services at Kinawataka a Kampala suburb. © 2016 International HIV/AIDS Alliance

The BEZA Anti-AIDS youth group. © 2016 International HIV/AIDS Alliance

Sharing about the Link Up project with meeting participant. © 2016 International HIV/AIDS Alliance in Myanmar

IPs were an essential link back to the facility for adolescents lost to follow up or not receiving ART.

Peers: central to providing support

Peer groups and networks started or nurtured by Link Up provided ALHIV the much-needed space to share, discuss, and learn from others facing similar challenges. This was found to be critical for encouraging and sustaining engagement in HIV treatment and care. Divided into age groups of younger (10-14 years) and older (15-19 years) adolescents, peer-group sessions were led by ALHIV themselves, exploring, earlier and in more detail, topics important them. Sessions focused, for example, on adherence, disclosure and 'hot issues' regarding SRHR, including sexuality. In addition to information sharing, these sessions created opportunities to share experiences and to use motivational approaches for behaviour change. Addressing stigma and correcting HIV myths were also important topics of discussion as well exploring factors affecting self-esteem.

Integration of sexual and reproductive health and rights into HIV services: Mildmay Uganda:

Mildmay Uganda (MUg) is a local non-governmental, not-for-profit organisation specialising in the provision of holistic HIV care and management for people living with HIV.

With Link Up support, MUg integrated SRHR into HIV services for young people living with HIV at the Kisakye youth centre and 12 other youth centres across three districts. The Kisakye youth centre is open once a week and, in addition to a counsellor, clinician, triage nurse, and data clerk, Mildmay employed a young nurse to provide contraceptive counselling and syndromic screening and management of STIs.

Service providers and social workers at the centre are proactive in ensuring that all young people living with HIV are offered an integrated package of services according to their needs and are informing young people of their sexual and reproductive rights. They take into account the age-appropriateness of services, including: HIV treatment, psychosocial support, cervical cancer screening, family planning and antenatal care, STI diagnosis and management, life-skills development.

Girls in care between the age of nine and 13 also receive the HPV vaccine to protect against cervical cancer. The centre provides a stipend to peer educators who lead one-to-one and group sessions, home visits, condom demonstration and distribution in the community and during outreach activities.

Counselling at Naguru Teenage Information and Health Centre, offering services at Kinawataka, a Kampala suburb, Uganda © 2016 International HIV/AIDS Alliance

Recommendations for future programming for adolescents living with HIV

1. **Strengthen psychosocial support aspects of HIV care to increase self-esteem, strengthen communication skills, address mental health concerns and reduce the impact of stigma. This will require:**
   - Further investment in peer support groups and networks;
   - Continued partnerships between IPs and ART services for provision of psychosocial support with clear referral and communication pathways;
   - Ongoing mentorship and training on psychosocial support for ART service providers.
2. **Continue to advocate for ALHIV to be central actors in healthcare and services. It will be necessary to:**
   - Ensure that ALHIV are not just beneficiaries of ART but have an active role in their healthcare decisions;
   - Facilitate opportunities and support structures that enable ALHIV participation in the planning, delivery and monitoring of services.
3. **Support ongoing engagement of ALHIV in HIV services. This can be achieved by:**
   - Actively tracking ALHIV engagement in HIV services and establishing clear loss to follow up protocols and procedures;
   - Strengthening partnership with IPs and ART services to actively follow up and engage with adolescents in the community and at home.
4. **Improve quality of HIV services for adolescents including:**
   - Provide services at convenient times;
   - Provide 'adolescent-only' service times and waiting lines or adolescent-friendly corners
   - Ensure enabling, safe environments that guarantee confidentiality;
   - Empower service providers in their critical role of supporting ALHIV with information, skills and capacity to facilitate links to other support services;
   - Provide ongoing mentorship for service providers to examine, challenge and change their personal attitudes, values, and communication styles and approaches.
5. **Develop new and strengthen existing guidance, manuals and materials on provision of HIV treatment and care for adolescents. This can be done by:**
   - Ensuring practical 'how to' guidance on key issues such as disclosure, adherence, positive living, and specific SRHR concerns for ALHIV;
   - Engaging with national level processes to further support service delivery to ALHIV beyond programmatic reach.
6. **Identify opportunities for collaboration and partnership with other organizations and services to support broader socioeconomic needs of adolescents living with HIV.**
7. **Explore interventions for parents and caregivers to build their skills around communication, encouraging greater involvement in their child's HIV care, and supporting early and more empowering disclosure processes.**
8. **Place greater emphasis on addressing HIV stigma by:**
   - Continuing community dialogues;
   - Investing in school based interventions;
   - Ensuring ALHIV are informed about their rights and have access to mechanisms for reporting stigma and discrimination, especially within the health system.

Endnotes

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Front cover photos:

Left: Panna is a beneficiary of the Link Up project. Poverty drove her into sex work when she was 18. © 2016 Syed Latif Hossain/International HIV/AIDS Alliance.

Middle: Addis Beza youth dance troupe, ages 15-20, raise awareness about HIV prevention. © 2016 International HIV/AIDS Alliance

Right: Nantumbwe Annitah (18) from UYDL Masooli performs a traditional dance. Uganda Development Link Masooli is a home for all ages between 9-25 years. It is supported by Community Health Alliance Uganda and other partners. © 2016 International HIV/AIDS Alliance

Naguru Teenage Information and Health Centre, has an outreach day at Kinawataka. They provide amongst other things, HIV testing and condom distribution and inform the community on benefits of knowing your status.

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Link Up improved the sexual and reproductive health and rights of nearly 940,000 young people affected by HIV across five countries in Africa and Asia. The project was 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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