



Addressing challenges facing adolescents in knowing and managing their HIV status in sub-Saharan Africa





“ I want to give a sense of hope that there is still life if you are HIV-positive [...] I have a vision of keeping the next generation alive

”
Kananelo
22, Lesotho

LSHTM-Sentebale roundtable meeting in July 2017
Sentebale Let Youth Lead advocates with Prince Harry;
from left to right: Kananelo, Ts'epang and Tlotlo

Photo credit: Chris Jackson, Getty Images

Introduction

In 2016, around two million adolescents aged 10–19 years were living with HIV, nearly 85% of whom live in sub-Saharan Africa. An estimated 260,000 adolescents were newly infected with HIV globally in 2016.¹ In sub-Saharan Africa, three in four new HIV infections among 15–19 year olds were among girls, and HIV-related illnesses remain the second leading cause of death for young women aged 15–24 years in Africa.² Adolescents living with HIV (ALHIV) include both those perinatally infected and those infected sexually,³ and these young people face distinct challenges at all stages of the HIV care pathway including diagnosis, linking to HIV care services, staying in care and maintaining treatment.

Adolescents frequently fall between the cracks of paediatric and adult HIV care services,⁴ and large proportions of ALHIV do not know their status. Treatment adherence among adolescents is generally lower and treatment failure rates are comparatively higher than in other age groups.⁵ Sadly, the main barriers are the psychosocialⁱ circumstances in which adolescents live, the deeply entrenched stigma surrounding HIV, adolescents' limited personal resources and dependence on caregivers, and the health systems which are unprepared to address the specific needs of ALHIV.⁶

This policy paper was conceived at a joint LSHTM-Sentebale roundtable meeting in July 2017; three young people from Lesotho and Botswana presented their personal experiences and challenges of living with HIV to an audience including Prince Harry, leading HIV researchers, and senior staff from organisations such as UNAIDS, PEPFAR and the Global Fund to Fight AIDS, TB and Malaria. This paper profiles some promising approaches to address challenges and barriers identified by ALHIV, which are divided into three categories. Under **services and environment**, we discuss approaches for addressing health system barriers to ALHIV accessing testing and treatment; in **language and discourse**, we consider messaging about HIV/AIDS as experienced by ALHIV, including public health campaigns that resonate with ALHIV, interventions seeking to mitigate stigma, and sensitive and sanguine ways to talk about and disclose HIV status.

Finally, under **agency**, we consider approaches that aim to boost resilience, self-efficacy, knowledge and awareness, and mental wellbeing among ALHIV that can empower them to live happy, healthy and productive lives.

This brief is aimed at organisations working with ALHIV who wish to implement evidence-based programmes.ⁱⁱ The paper provides a snapshot of some promising interventions in sub-Saharan Africa profiled in the recent literature (2010 onwards). It is crucial that interventions make a difference not only to the treatment outcomes but also to the quality of life of ALHIV. Such interventions need not be complex or costly, if they are sustainable, and listen to and work closely with young people living with HIV and their communities.⁷



In partnership with Ministry of Health in Lesotho, Sentebale train “peer educators” who are recruited to deliver support such as HIV testing and counselling services.

ⁱ ‘Psychosocial support’ addresses psychological and social issues experienced by people living with HIV (WHO definition).

ⁱⁱ Many highly effective interventions evaluated and reported on before 2010 or from regions outside sub-Saharan Africa are not covered in this paper. Prevention interventions or approaches are only considered when they concern secondary prevention or onward transmission of HIV. As the emphasis of the paper is on psychosocial support interventions, it does not consider biomedical approaches that could improve adherence such as the development of long-acting antiretroviral drugs, or interventions to reduce their side effects.

Services and environment

Challenges expressed by ALHIV	Promising approaches and interventions
<p>Health services</p> <p>“The health services are open during school hours and we don’t have the time to go for check-ups”</p> <p>Ts’epang, 19, Lesotho</p> <hr/> <p>Accessibility: Opening hours which conflict with school days, the distance of the clinic from home, and particular access challenges for disabled ALHIV.⁹ Concerns about confidentiality, or fear of stigma or judgemental attitudes of healthcare staff.⁹ Difficulties of transition from paediatric to adult HIV services.¹⁰ Health system challenges (e.g. drug stock-outs, health worker shortage and lack of training).¹¹</p>	<p>Youth and adolescent friendly services (YAFS) may help retain adolescents in care, reducing attrition among youth after ART initiation.^{12,13} Testing and counselling at youth centres shows promise for certain age groups, for example using a points-based rewards system to incentivise use of youth centre services.¹⁴ Co-location of services can help integrate HIV care into other sexual and reproductive health services for young people; integrating HIV care and contraception services may reduce adolescent girls’ discomfort with seeking contraception.¹⁵ HIV services for ALHIV should be integrated and co-ordinated with services supporting adolescents with disabilities.¹⁶ Changing opening hours (e.g. a “night clinic” for female sex workers and long-distance truck drivers) has positive impact on engagement with services,¹⁷ while close proximity to healthcare facilities is associated with improved ART adherence.¹⁸ Mobile clinics can help to reach and provide diagnosis to ALHIV.¹⁹ Small ‘nudges’ like appointment reminders delivered through SMS, phone-calls or face-to-face can help increase adolescents’ uptake of repeat testing.²⁰ Helplines specifically for ALHIV, such as the one2one Integrated Digital Platform, can allow ALHIV to engage with a professional and youth-friendly counsellor confidentially at flexible times.²¹</p>
<p>The role of the home environment</p> <p>Unstable family structures: Orphanhood; frequent change of caregivers; caregivers overburdened with competing priorities.²²</p> <p>Ethico-legal barriers: high age of consent can limit adolescents’ access to testing and care, which is mediated through guardians.²³</p>	<p>Providing home-based testing and counselling can identify young people with HIV earlier in the disease progression.²⁴ Supporting caregivers can improve linkage to healthcare and encourage retention; caregivers’ ability to support children in HIV care is facilitated by an open family environment, the availability of practical assistance and psychosocial support from community members.²⁵ Community-based support for caregivers can have a substantial effect on HIV virological suppression in ALHIV.²⁶ Framing access to treatment as a child rights issue, whereby the state or caregiver’s failure to facilitate access is a rights violation, could help in cases where families or religious groups raise objections to the child’s treatment.²⁷ Self-testing at home could improve diagnosis among ALHIV, as these tests are feasible and acceptable to adolescents,²⁸ particularly those wishing to avoid visiting clinics, obtain fast results and for those in non-monogamous relationships.²⁹ For orphaned, HIV-positive children, there is some evidence that group homes may improve wellbeing, and resilience to cope with stigma.³⁰</p>
<p>Psychosocial support groups</p> <p>“We need capacity building and we need finances to support our activities. You need to invest in us if we’re to be the future”</p> <p>Thato, 27, Lesotho</p> <hr/> <p>Lack of knowledge and understanding, and resources and time constraints, may limit the engagement of ALHIV with support groups.³¹</p> <p><i>For the broader mental health challenges faced by ALHIV, see “Mental Health” in the Agency section.</i></p>	<p>PEPFAR highlights youth clubs or youth corners as “points of health access for adolescents, although many were described as dysfunctional or small-scale”.³² Successful clubs often combine sports and games activities with access to knowledge and information on HIV treatment, reproductive health, and on coping with discrimination and stigma, with trained health personnel available to answer questions.³³ ALHIV and carers often perceive support groups as a safe social space for learning and acquiring HIV information as well as gaining confidence, particularly when they can participate consistently.³⁴ These groups can facilitate difficult conversations about sexuality and sexual health.³⁵ Behavioural support groups using laypersons can also facilitate linkage to care for ALHIV and secondary prevention.³⁶ Peer support group therapy may be beneficial, for example by using trained treatment-supporters to deliver structured, community-based psychosocial and adherence support.³⁷ Mobile phone-based support groups can decrease internalised stigma, and increase perceived social support and self-reported adherence.³⁸ Social networking platforms are acceptable to many ALHIV, but could better interface with media like WhatsApp and Facebook, and provide more relevant, topical information.³⁹</p>
<p>The school environment</p> <p>Frequent missed school due to illness⁴⁰ or caring for ill relatives. Stigmatisation by students and teachers. Teachers face difficulties in how to deal with HIV-related issues in pupils.⁴¹</p>	<p>Testing and counselling (HTC) in schools could help increase uptake and scale of HTC,⁴² although protection of testers’ confidentiality and privacy is key.⁴³ Schools may be able to capitalise on the novelty associated with technology- and internet-based HIV education.⁴⁴ Teachers should be supported to acquire basic knowledge and skills in caring and paying attention to learners affected by HIV and AIDS.⁴⁵ School-based education programmes on HIV should link with local communities, to increase effectiveness and influence change among ALHIV not attending school.⁴⁶ Teachers working in partnership in school-based networks can be empowered to promote resilience among ALHIV.⁴⁷</p>
<p>Poverty</p> <p>Leading to missed clinic appointments, poor nutrition, and elevated stress for caregivers.⁴⁸</p>	<p>Economic empowerment programmes such as the conditional and unconditional cash transfers for orphaned and vulnerable children could be scaled up to enhance ALHIV’s wellbeing and to prevent onward HIV transmission.⁴⁹ Interventions like combination social protection (involving child savings accounts, workshops, and mentorship) can reduce sexual risk-taking intentions among ALHIV.^{50,51} Economic incentives for caregivers can improve testing and counselling uptake by adolescents.⁵²</p>

Language and discourse

Challenges expressed by ALHIV	Promising approaches and interventions
<p>How health workers talk to young people</p> <p>“Stop treating HIV like a wound – the bandage doesn’t work”</p> <p>Masedi, 23, Botswana</p> <hr/> <p>Language to discuss a sexually-transmitted, incurable infection rarely emphasises positive, healthy ways to live with HIV.⁵³ Health workers may struggle with their role in disclosing an adolescent’s HIV status.⁵⁴</p>	<p>Tailored, age-appropriate guidelines for health workers on disclosure to ALHIV could help to clarify their roles and responsibilities, and legal and ethical implications.⁵⁵ Disclosure in a healthcare setting can overcome issues associated with caregivers disclosing at home, make a diagnosis more credible to ALHIV, and help ALHIV gain more information about their status from shared experiences with peers at the clinic.⁵⁶ Healthcare providers need continuous training and resources to support disclosure.⁵⁷ Healthcare providers can support and empower caregivers to take the lead in disclosure, and also help caregivers accept their own HIV status, so that they can more effectively support ALHIV.⁵⁸</p>
<p>Adults’ (parents/caregivers’) language towards young people</p> <p>Discussion of sex and HIV is often taboo, and complicated by use of overly polite language and euphemisms.⁵⁹ Different modes and capabilities of communication across generations also present a barrier.⁶⁰ Parents/caregivers’ fear of disclosing their child’s status. While disclosure can improve ALHIVs’ retention in care,⁶¹ caregivers may fear young person will not understand, will not keep their HIV status confidential,⁶² will face stigma, blame the parent/caregiver,⁶³ or experience psychological distress.⁶⁴ For similar reasons, parents may struggle with disclosure of their own HIV status to children.⁶⁵</p>	<p>Improving parent-child communication through structured programmes (e.g. Let’s Talk!, a worksite-based programme) can help parents feel more comfortable discussing HIV-focused topics with their children.⁶⁶ Interventions should support caregivers to feel in control when discussing HIV and sexual health with their children.⁶⁷ Providing both adolescents and caregivers with basic HIV and sexual health knowledge, communication and negotiation skills may facilitate discussions.⁶⁸ Family-based interventions can encourage family cohesion, and HIV testing and linkage to care for all family members.⁶⁹ Tangible support for parents/caregivers to disclose the young person’s status may include tools like a “disclosure book” e.g. a comic book which emphasises healthiness, hope and resilience, avoids medical language and includes cues for caregiver-child discussion.⁷⁰ Caregivers need support to gauge adolescents’ capacity to understand their status, to decide on an appropriate time for disclosure.⁷¹ Caregivers disclosing their own status may benefit from home-based interventions involving the whole family,⁷² and from specific disclosure tools, training and support for parents/caregivers (e.g. the Amagugu intervention).⁷³</p>
<p>Coping with stigma</p> <p>“The moment people start knowing you’re HIV positive, they will try to pull themselves away from you”</p> <p>Tlotlo, 18, Botswana</p> <hr/> <p>Stigma is the overwhelming reason why young people are lost to follow up more than any other age group,⁷⁴ and plays a key role in non-adherence to medication and morbidity.^{75,76} Stigmatising beliefs also undermine HIV testing among adolescents,⁷⁷ with fear of stigma and discrimination following a positive result.⁷⁸</p>	<p>Home-based, community-level universal test and treat approaches (e.g. the PopART intervention) may help destigmatise and normalise HIV testing and care,⁷⁹ especially if targeted testing for adolescents is provided in combination.⁸⁰ Interventions should seek to weaken the association between HIV/AIDS and death, to reduce fear of HIV/AIDS, and to recast HIV as a chronic manageable disease.⁸¹ Participatory workshops and activities in the community have been shown to reduce both stigma felt by PLHIV and stigma enacted by people living close to them.⁸² Targeted education and training sessions on stigma (e.g. through workshops and computer-based resources) for adults who work with ALHIV, such as teachers, can significantly reduce their levels of stigma.⁸³ Research on internalised stigma (where ALHIV accept negative attitudes towards people with HIV as applicable to themselves) suggests that protection from violence within homes, communities and schools is key to combating psychological distress and internalized HIV stigma.⁸⁴ Mass media interventions for stigma reduction may be more effective for young people than older people, as found through the “Radio Diaries” intervention in Malawi, where PLHIV tell stories about their everyday lives.⁸⁵ The soap opera MTV Shuga has helped reduce stigmatising attitudes, e.g. belief that HIV represents “divine punishment”.⁸⁶</p>
<p>Language of (self-)disclosure by ALHIV to family/friends/partners</p> <p>“People struggle to find the right time to disclose”</p> <p>Kananelo, 22, Lesotho</p> <hr/> <p>ALHIV may fear stigma, isolation and lack of acceptance from loved ones or peers if they disclose.^{87,88} Unintended disclosure is a significant fear.⁸⁹</p>	<p>ART programmes should consider disclosure counselling for caregivers/family-members to appreciate and respect the privacy and disclosure concerns of their HIV-infected children,⁹⁰ especially given that disclosure can enable adolescents to better engage with their ART treatment and support groups.⁹¹ Programmes could emphasise the importance of gradual disclosure starting at younger ages,⁹² with ALHIV frequently seeing disclosure as a continuous process, specific to particular relationships and environmental contexts, rather than a one-off event.⁹³ One promising approach could be to provide safe environments for ALHIV to practise disclosure skills.⁹⁴</p>
<p>Limited messaging and campaigns aimed at ALHIV and their peers</p>	<p>Communication programmes can create an environment that encourages open HIV-related discussions, and improve testing uptake.⁹⁵ It is worth noting that HIV campaigns may facilitate difficult conversations, but it is not given that this will change attitudes and beliefs as intended.⁹⁶</p>

Agency

Challenges expressed by ALHIV	Promising approaches and interventions
<p>Age of consent</p> <p>Age of consent at 18 may restrict access to HIV counselling and testing, and creates ambiguity for health professionals working with ALHIV.⁹⁷</p>	<p>Changes are needed at the policy level; countries like Lesotho, South Africa and Uganda have lowered the age of consent to 12, so that adolescents can consent to HIV testing and counselling services without additional parental/caregiver consent. In Uganda this has facilitated comprehensive home- and community-based testing strategies that have increased prevalence of testing among adolescents.⁹⁸ Consent for self-testing by adolescents 12 and over in countries like South Africa could be lawful provided pre- and post-test counselling and psychosocial support were offered in conjunction with self-tests.⁹⁹</p>
<p>Mental health impacts of living with HIV</p> <p>ALHIV may grow up with a “medicalised” identity,¹⁰⁰ and prevalence of anxiety, depression, suicidal ideation and conduct disorders is often high among ALHIV.¹⁰¹ Many psychological problems may be linked to self-directed stigma, shame, and anger among ALHIV.¹⁰² AIDS orphans may be at particularly high risk of mental distress.¹⁰³ Victimisation through bullying may particularly impact on mental distress experienced by adolescents affected by HIV.¹⁰⁴</p>	<p>Contact with community-based organisations (at least monthly) in high-HIV prevalence areas has been shown to reduce suicidal ideation, depression, problems with peers, and perceived stigma.¹⁰⁵ Interventions to improve mental health are also likely to improve medication adherence,¹⁰⁶ and limit onward HIV transmission.¹⁰⁷ Psychosocial interventions may improve certain psychological wellbeing outcomes but not others e.g. a community art programme in South Africa for ALHIV improved self-efficacy but not self-esteem, depression or emotional/behavioural issues.¹⁰⁸ Cognitive behavioural therapy (CBT) can reduce anxiety among ALHIV, although there was limited impact on depression compared to controls receiving standard group counselling.¹⁰⁹ Models of problem-solving therapy delivered by lay health workers (e.g. the “Friendship Bench”), which can successfully reduce depression and anxiety symptoms in adults, may in future prove suitable for ALHIV.¹¹⁰ Participatory activities based on narrative therapy, such as digital storytelling, where ALHIV narrate their experiences on film,¹¹¹ or Photovoice,¹¹² where participants photograph scenes which capture their lived experience, can foster self-understanding, self-control, resilience and hope for the future. The challenging contexts in which ALHIV and their caregivers frequently live necessitates involvement of the whole family¹¹³ e.g. the VUKA family programme aims to improve mental health of young ALHIV, using a cartoon-based curriculum and step-by-step guidance for counsellors to encourage families to launch difficult conversations, on topics such as bereavement, self-acceptance and sexuality.¹¹⁴ Empowering ALHIV to develop their skills and voice can foster wellbeing and agency; ALHIV should be involved in setting programmes, policies and strategies,¹¹⁵ and be supported to work with policymakers and scientists to set research agendas.¹¹⁶</p>
<p>Non-medical barriers to adhering to HIV medication</p> <p>Stigma, lack of disclosure, busyness and peer pressure/influences can affect ALHIVs’ adherence.¹¹⁷ Mental health problems can negatively impact on adherence.¹¹⁸ Denial of the illness when ALHIV feel healthy may be a factor,¹¹⁹ and many ALHIV do not want to be seen taking medication. Certain barriers may be very different for perinatally and behaviourally infected ALHIV.¹²⁰ Alcohol use and violence are associated with missing doses,¹²¹ in both adolescence and later life. Barriers may also be structural, such as lack of nutritional support,¹²² or treatment fees.¹²³</p>	<p>Adults and healthcare providers need to approach non-adherence with empathy, understanding the difficulties associated with taking life-long treatment, rather than a discourse of perfect adherence which obscures the social challenges faced by ALHIV. Parents or guardians accompanying ALHIV to clinic appointments, ALHIV’s participation in group sessions,¹²⁵ supportive healthcare workers, and short waiting times at health services,¹²⁶ can all facilitate better adherence among ALHIV. SMS messaging may be effective at weekly intervals (rather than daily intervals)¹²⁷ to improve ART adherence among ALHIV and reduce treatment interruptions.^{128,129} Combined with social support, SMS reminders can mitigate forgetfulness – but it is crucial to respect the privacy and confidentiality of ALHIV given that they may share phones with family members.¹³⁰ Acceptability of SMS reminders may not always be high, and can depend on factors such as educational level, disclosure and use of internet.¹³¹ Community-based adherence support, such as home visits by patient advocates to address household challenges impacting on adherence among children, may be a low-cost approach to help ALHIV achieve virological suppression.¹³² A home-based nursing programme has shown impact on knowledge and medication refills but had no effect on viral load.¹³³</p>
<p>Sexual health, sexuality and romantic relationships</p> <p>Misinformation and rumours about how ALHIV can minimise risk of onward transmission of HIV (e.g. the idea that circumcision is 100% effective at preventing HIV transmission). Sexual risk-taking among ALHIV is relatively high.¹³⁴ Fears around disclosure, rejection by partners and potential for transmission create challenges for ALHIV engaging in dating and relationships. Health services rarely engage openly with the romantic and sex lives of ALHIV.¹³⁵ Caregivers may express negative attitudes about sex with HIV, and there is limited access for ALHIV to appropriate information and guidance.¹³⁶</p>	<p>“We need more appropriate sexual and reproductive education, and it should be done frequently” Kananelo, 22, Lesotho</p> <p>Relatively short counselling interventions (for example, a 180 minute session among circumcised young men) can reduce sexual risk behaviours in the short-term.¹³⁷ Participatory community events to provide information about sexual health and HIV can empower ALHIV to cope with a diagnosis.¹³⁸ Alongside individual CBT-style approaches, interventions should be mindful to address contextual and structural issues such as gender equality and livelihoods strengthening, and engage with ALHIV’s sexual identity.¹³⁹ ALHIV need support from families, caregivers and service providers to strengthen their self-esteem and pursue romantic and/or sexual relationships in an affirming way.¹⁴⁰ Care programmes should seek to facilitate communication about sexuality between ALHIV, their caregivers, health providers and HIV-positive peers.¹⁴¹ Positive prevention programmes like “Positive Living for a Brighter Future”,¹⁴² or “Supporting Youth and Motivating Positive Action”,¹⁴³ can support young people to better understand sexual risk and learn about assertive communication in the context of sex.</p>

Recommendations for implementing organisations

- Recognise that adolescents living with HIV (ALHIV) face unique challenges that are different to those facing children and adults
- Ensure psychosocial support is reaching ALHIV as they transition into adult care
- Adopt a human rights-based approach to testing, care, virological suppression, and supporting mental wellbeing of ALHIV
- Recognise the crucial role of peers, caregivers, families, teachers and communities, and equip them to best support ALHIV
- Emphasise that ALHIV, while a heterogeneous group facing myriad challenges, can live healthy, happy and productive lives
- Empower ALHIV to lead, participate in and shape youth-friendly services, policies and research
- Find ways to sensitively discuss sex, dating and relationships for ALHIV, as this is a clear gap in current interventions
- Interventions need to consider and address the contextual and structural factors (e.g. unstable family structures, poverty, malnutrition, disability) which limit ALHIV’s ability to manage their status
- Look to reach the “hard-to-reach”, marginalised ALHIV who may not be using any kind of formal or informal health service
- The evidence base around adolescents to support ALHIV needs to be strengthened, through participatory and action-oriented research to overcome key barriers (e.g. stigma among ALHIV; marginalisation of certain ALHIV groups)
- Tailor media, campaigns and approaches used in interventions to age range, geographical/cultural context and (potentially) mode of HIV infection in order to enhance their sustainability and scalability



Sentebale’s Co-Founding Patron Prince Seeiso and youth advocates at the launch of Let Youth Lead, Lesotho.

Photo credit: Michelly Rall, Getty Images



A call to action



Professor Peter Piot, Director of LSHTM, with Prince Harry in July 2017.

Photo credit: Chris Jackson, Getty Images

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For references accompanying the policy brief with details of supporting papers and reports, please see: www.lshtm.ac.uk/HIVadolescents

“ HIV needs to be treated exactly the same as any other disease, and between us hopefully we can eradicate the stigma and give these young people an opportunity to stand up and say, I’ve lived it [...] and I want to come forward and make a difference.

”
Prince Harry

at LSHTM-Sentebale roundtable, July 2017

This paper is intended to profile promising approaches and good practices for supporting ALHIV to overcome psychosocial, ethico-legal and structural challenges associated with knowing and managing their HIV status. One limitation must be stressed, namely that many of the approaches discussed above are preliminary studies of feasibility or acceptability, and are yet to be tested at scale or in other contexts. Furthermore, many of the studies rely on a small sample of adolescents and have methodological issues.¹⁴⁴ There is particularly limited research on the adherence, retention in care and treatment outcomes of young people from marginalised populations.¹⁴⁵ Nonetheless it is hoped that the approaches profiled will spark some new ideas to integrate into existing or new programmes, or inspire collaborations with the organisations involved. The paper looked only at promising interventions for ALHIV in sub-Saharan Africa, but ALHIV themselves or organisations working with them may wish to learn from interventions in other parts of the world or with other groups.

The complexity of needs faced by ALHIV requires a holistic approach that takes account of factors at all levels of the health and social system that adolescents are part of, including their family, their broader community and the policy environment which can facilitate their wellbeing.¹⁴⁶ Some of the most effective interventions work closely with caregivers or families, and emphasise resilience and the possibility of ALHIV to live healthy, happy and productive

lives. That said, it is crucial that the human rights of ALHIV are front and centre, to ensure that adolescents can access testing and link quickly to care in cases where their home or economic circumstances may directly or indirectly limit engagement with HIV services.¹⁴⁷ It is also crucial that the needs of adolescents who do not engage at all – perhaps because of marginalisation, disability, or lack of awareness, resources or independence – are considered and included when planning support interventions.

Most crucially, the literature consistently demonstrates that programmes and services need to step up the engagement of adolescents in programming, going beyond token involvement to listen to youth in meaningful and profound ways. This may involve uncomfortable or unfamiliar conversations about adolescents’ rights, consent, autonomy and sexuality, but these can underpin the most transformative initiatives. It is important to recognise that adolescents do not live their lives in healthcare facilities, and effective models of supporting ALHIV need to move away from a predominant focus on access to drugs to addressing the interlocking complexities of the family, community, school, work or social environments in which adolescents are situated. Adolescents living with HIV can thrive just like any of their HIV-negative peers in all walks of life, but only when provided with support and opportunities that enable them to overcome the challenges they face.

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Introduction

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