



Adolescent HIV programming

READY – Here we come!



About the International HIV/AIDS Alliance

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.

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READY is a movement that is working for and with adolescents and young people living with and affected by HIV. It aims to ensure that adolescents and young people become *ready* to make informed decisions about their health and rights; that parents and caregivers are *ready* to support young people to talk about sexuality; that service providers are *ready* to provide youth-friendly services; and that decision-makers are *ready* to champion access to information, services and commodities for adolescents and young people living with HIV.

READY stands for **R**esilient, **E**mpowered **A**dolescents and **Y**oung people. There are projects underway in seven countries under the READY umbrella with more exciting projects under development.

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Cover photos: Top: Young people relax at a youth centre through a Link Up project in Burundi.

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Middle: Young sex workers discuss their aspirations at a Link Up project in Bangladesh. © Syed Latif Hossain

Bottom: Peer educators hand out condoms to young people through a Link Up project in Naguru, Uganda.

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Design: Jane Shepherd



Alliance HIV programming good practice standards for adolescents

This Good Practice Guide contains information, strategies and resources to help programmers meet the standards for Alliance HIV programming for adolescents. Implementing these standards is one of the ways that the Alliance, our partners and other organisations define and promote a unified and quality-driven approach to HIV programming.

The Alliance HIV programming standards can be used at any time in the programme cycle to assess good practice, and to help develop proposals and monitoring and evaluation frameworks.

 **Key resources**

For more information about the Alliance's accreditation system go to: www.aidsalliance.org/resources/336-alliance-accreditation-system

Alliance HIV programming good practice standards for adolescents

| | |
|---------------------------------|---|
| Good practice standard 1 | Our organisation promotes the meaningful participation of adolescents in all their diversity. This includes ensuring that adolescents are actively involved in all stages of planning, delivering and monitoring our programmes. |
| Good practice standard 2 | Our organisation ensures the provision of a comprehensive HIV and sexual and reproductive health and rights package of services for adolescents by integrating or linking services. |
| Good practice standard 3 | Our organisation uses a variety of relevant, innovative approaches and platforms for reaching and providing services to adolescents to ensure access and engagement, especially peer-led and community-based interventions. |
| Good practice standard 4 | Our organisation uses a person-centred approach to ensure that our programmes and services respond to adolescents' diverse needs, recognising adolescence as a distinct period of developmental and social change . |
| Good practice standard 5 | Our organisation recognises the evolving capacity of adolescents and promotes their empowerment to develop resilience and leadership skills. |
| Good practice standard 6 | Our organisation recognises that adolescents are part of broader communities that influence their lives and decisions. This requires that our programmes work with key gatekeepers, such as parents and schools. |
| Good practice standard 7 | Our organisation promotes human rights and gender equality for adolescents, including by challenging harmful social norms that act as barriers to individual agency, decision-making and wellbeing. |

Abbreviations and acronyms

| | |
|-------|--|
| ART | Antiretroviral therapy |
| GNP+ | Global Network of People Living with HIV |
| IEC | Information, education and communication |
| OI | Opportunistic infection |
| PMTCT | Prevention of mother-to-child transmission |
| PrEP | Pre-exposure prophylaxis |
| SRH | Sexual and reproductive health |
| SRHR | Sexual and reproductive health and rights |
| STI | Sexually transmitted infection |
| VMMC | Voluntary medical male circumcision |
| WHO | World Health Organization |

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Introduction

HIV and adolescents

A greater understanding of HIV in high prevalence countries has increased awareness of the need to prioritise adolescents in HIV prevention, treatment, care and support. At the same time, a growing recognition that adolescence is a distinct time of life has focused attention on adolescents' different needs. Adolescents are now included as a separate target group in global and national strategies. Guidance to tailor the response to meet adolescents' specific needs includes Global Accelerated Action for the Health of Adolescents (AA-HA!) and All In to #EndAdolescentAIDS. Increased investments have also been seen, with initiatives such as DREAMS and the Global Fund adolescent information note.

Adolescents in sub-Saharan Africa are key in determining the course of the HIV epidemic, yet adolescents continue to be underserved by current HIV programming. Reversing this trend requires an intensified focus on adolescents and young people. Currently, AIDS is the leading cause of death for adolescents in sub-Saharan Africa. In 2015, there were an estimated 250,000 new HIV infections among adolescents aged 15–19, while an additional 1.8 million adolescents (aged 10–19) were already living with HIV.¹ Adolescent girls are more vulnerable to HIV than boys. UNAIDS estimates that in sub-Saharan Africa, three in four new infections in 15–19-year olds are among girls.²

Increased access to HIV testing and treatment means that, more than ever, adolescents living with HIV know their status and are living longer on antiretroviral therapy (ART). Much more work is needed, however, to meet adolescents' needs for prevention, care, treatment and support services. Barriers to access, poor uptake of both prevention and treatment services, stigma and discrimination, as well as challenges with adherence to treatment contribute significantly to HIV-related morbidity and mortality among adolescents.

Responding to adolescents' needs

Health service providers must find ways to meet adolescents' ever changing needs. This entails delivering services in appropriate ways that increase access and support engagement, providing a comprehensive package of care and referrals and, ultimately, improving the health and overall wellbeing of adolescents. Link Up³ highlighted promising practices and key considerations for adolescents that can be built upon and adapted. Future programming for adolescents needs to continue to be reflective. It must allow for 'learning while doing', identifying and exploring gaps in the way adolescents' needs are being met, monitoring interventions, and documenting successes and lessons learnt.

It is vital that health service providers improve programming for adolescents under 18 years of age in settings where the legal environment restricts their access to services. Policies and programmes should encourage and strengthen the role of parents/caregivers and other key gatekeepers in minimising the effect of barriers related to consent. They should also further adolescents' and caregivers' understanding of the age of consent for different services. In culturally conservative settings, health services

1. UNAIDS (2016), 'Get on the Fast-Track'.

2. UNAIDS (2016), 'Get on the Fast-Track'.

3. The Link Up programme improved the sexual and reproductive health and rights of 940,000 young people most affected by HIV in Bangladesh, Burundi, Ethiopia, Myanmar and Uganda. For more information see <http://www.aidsalliance.org/our-impact/link-up>

Icons used in this guide



Key resources



Case study



Advocacy opportunity



International guidance



Key principles



Tips



Key resources

UNICEF (2016), 'Seventh stocktaking report on children and AIDS'. Available at: <http://st7.childrenandaids.org>

GNP+ and UNAIDS (2011), 'Positive Health, Dignity and Prevention: a policy framework.' Available at: www.gnpplus.net/resources/positive-health-dignity-and-prevention-a-policy-framework/

UNICEF and UNAIDS (2015), 'All in to end adolescent AIDS'. <http://allintoendadolescentaids.org>

may need to extend outreach to communities and adolescents, forging greater understanding of adolescents' needs for health services and autonomy.

This Good Practice Guide was developed to offer programme managers and service providers concrete implementation guidance and support as they seek to address adolescents' needs more effectively. It is intended to shape a provider's approach and work so that adolescents living with HIV and those from key populations can obtain the services they need and live healthy, productive lives. The Good Practice Guide is shaped by the principles of the Positive Health, Dignity and Prevention Framework,⁴ with adolescents and young people at the centre, managing their own health and wellbeing.

Overview and aims of the Good Practice Guide

What are the aims and objectives of the guide?

This is a 'how to' guide. Each topic area provides key principles, practical ideas and case studies. International policy recommendations and advocacy opportunities are highlighted. Links to other resources are also provided.

Who is the guide for?

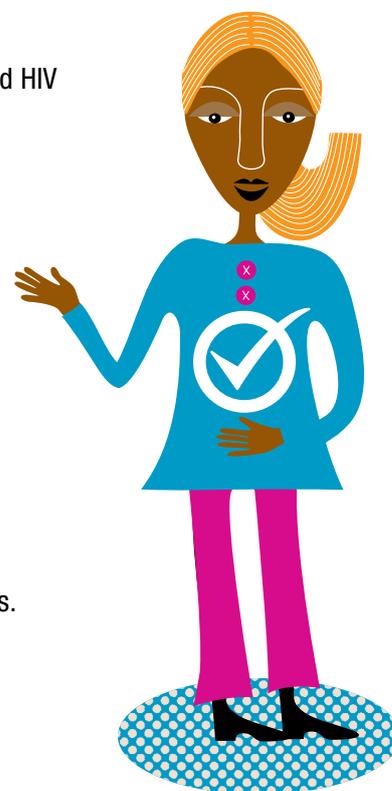
- Alliance Linking Organisations and implementing partners – mainly community-based organisations
- Programme managers and service providers designing and delivering services for adolescents living with HIV or at high risk of acquiring HIV.

What topics does it cover?

- Adolescent development
- Delivering services to adolescents
- Adolescent-responsive sexual and reproductive health and rights (SRHR) and HIV package of care
- Data for change: improving outcomes for adolescents
- Meaningful participation of adolescents
- Evolving capacity, decision-making, autonomy and consent
- Communicating with adolescents
- Psychosocial wellbeing.

How can the guide be used at programme level?

- In planning and reflecting on programming
- In fulfilling the Alliance accrediting processes
- In developing policies, protocols and standard operating procedures
- For training and the development of resources for providers and adolescents.



4. UNAIDS, GNP+ (2013), 'Positive Health, Dignity and Prevention: Operational Guidelines'. Geneva and Amsterdam.

Language matters

Adolescents

The World Health Organization (WHO) defines adolescents as those between 10 and 19 years of age. Most adolescents are therefore included in the age-based definition of 'child', adopted by the Convention on the Rights of the Child as a person under the age of 18. But age is not the only characteristic of adolescence: a 10-year-old is very different from a 19-year-old. To address the different phases of development, adolescence is often divided into early (10–14 years) and late (15–19 years) stages. Health service providers need to consider these differences when planning HIV prevention, treatment and care interventions for adolescents. There are also clear differences in the ways that girls and boys develop. Adolescent girls often reach developmental milestones up to two years ahead of adolescent boys. In society, boys' and girls' lives are influenced by different socio-cultural norms and behavioural expectations.

Gender

Gender expression is a term used to refer to the way in which a person acts to communicate gender within a given culture, for example, in terms of clothing, communication patterns, and interests. A person's gender expression may or may not be consistent with socially prescribed gender roles, and may or may not reflect their gender identity. Gender identity refers to each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth.⁵

Key populations

Key populations are groups whose specific behaviour places them at increased risk of HIV, irrespective of the epidemic type or local context. Legal and social issues related to their behaviour fuel their vulnerability to HIV. UNAIDS identifies five main key population groups as men who have sex with men, people who inject drugs, sex workers, transgender people and people in prisons and other closed settings. However, each national epidemic will include many others as key populations, for example, fisher folk, migrants etc. It may often not be appropriate to label younger adolescents (aged 10–14) as 'key populations', especially adolescents who sell sex.

Adolescents may belong to one or more key populations, or engage in activities associated with these populations. As identity formation develops during this time of life, however, some adolescents may not see themselves as part of a particular key population or risk group. Because of this fluid period of identity formation, some adolescents may have several overlapping risks that change over time. As a result, some adolescents may not seek appropriate services and remain 'hidden', even when engaged with services.

Adolescents from key populations face widespread stigma, discrimination and violence, combined with the specific vulnerabilities posed by youth and power imbalances in relationships. Many adolescents in key populations are also alienated from family and friends. These challenges can increase the risk that they may engage – willingly or not – in behaviour that puts them at risk of HIV, such as unprotected sex and the sharing of needles and syringes to inject drugs.



Key resources

UNAIDS (2015), 'UNAIDS terminology guidelines 2015'. Available at: www.unaids.org/en/resources/documents/2015/2015_terminology_guidelines

5. American Psychological Association (2012), 'Guidelines for Psychological Practice with Lesbian, Gay, and Bisexual Clients'. *American Psychologist*, 67(1), 10–42. doi: 10.1037/a0024659.

Adolescents living with HIV

Adolescents can acquire HIV infection in the perinatal period through vertical (mother-to-child) transmission, or during childhood and adolescence.

Perinatally acquired: Many adolescents living with HIV acquired the virus at birth. Modelling has suggested that up to 70% of adolescents living with HIV were perinatally infected. Some will have been identified in infancy and will be receiving care as follow-up from prevention of mother-to-child transmission (PMTCT) programmes. However, many were missed by PMTCT programmes, due to loss to follow-up or poor coverage, and they present to services later in life and often very unwell.

Acquired during adolescence: Adolescents acquire HIV through sex without consistent and correct condom use, coerced sex and/or sexual exploitation. These risks may also occur during childhood. Non-sexual transmission includes injecting drug use and certain medical procedures such as unsafe surgical procedures, injections and blood transfusions.

Although both groups of adolescents living with HIV experience many similar challenges, differences do exist that affect their engagement with health services and how programmes can best support their needs.

Adolescents who acquired HIV perinatally may:

- experience delayed puberty, stunting and cognitive development
- be unaware of their HIV status, and will need to be supported to understand the elements of positive living and disclosing to others
- have parents and caregivers who are aware and usually engaged in care
- have lost one or both parents, with variable support from other family members or caregivers. They may have been moved around frequently or be in institutionalised care
- struggle against caregivers and health care providers to establish independence
- have long-term experience of ART with side effects, and they may experience treatment fatigue
- be on second- or third-line treatment due to treatment failure
- have a history of illness and frequently attend hospital or clinics
- feel concerned about a normal sex life, having a family and the future
- hold views of HIV shaped by family and service providers.

Those who acquired HIV during adolescence may:

- cope with initial diagnosis alone
- be asymptomatic, which can reinforce denial and affect health-seeking behaviour
- have parents and caregivers who are often unaware of the diagnosis
- feel a critical need for support in disclosing status to partners, family and peers
- already be sexually active and have established sexual behaviours and risks
- have acquired HIV through sexual violence and are therefore coping with other psychosocial issues
- receive limited parental/caregiver support – this may limit resources for transport and other clinic-related expenses
- hold fixed knowledge, attitudes and beliefs that may have an impact on their engagement in care
- already have developed stigma about HIV, which they then internalise.

1

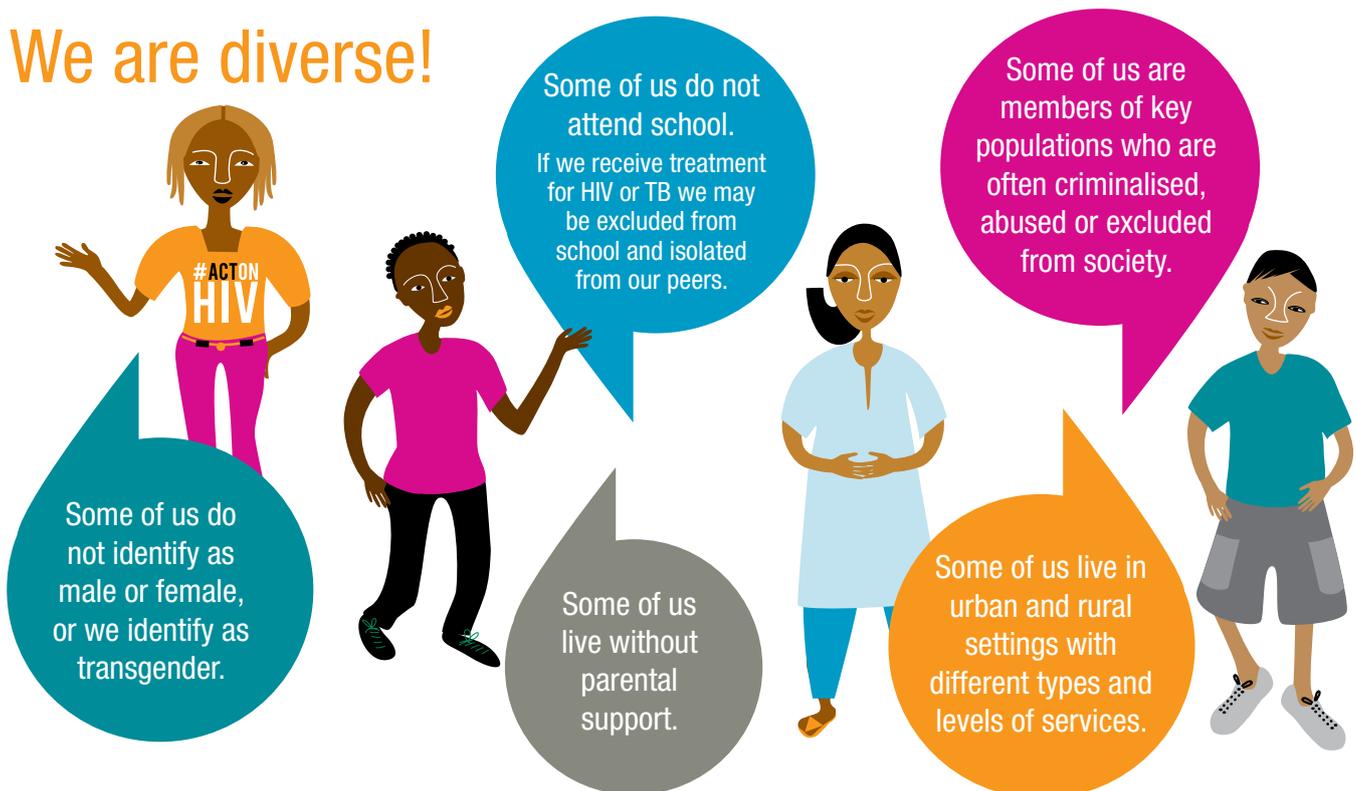
Adolescent development

Adolescence is a distinct time of life. It is a period of important physical, cognitive and emotional development that affects how adolescents think about themselves and their world. These changes influence their attitudes, decision-making and risk assessment skills, and behaviour. The changes experienced are some of the most rapid across the life course. They not only affect health in adolescence but throughout their lives. It is important that programme managers and service providers understand what is taking place during adolescence as it provides insights into how to approach services and programming for this age group.

Adolescents are different from younger children (under 10 years of age) and adults. They also vary from each other. Developmental milestones happen at different times throughout the ten years of adolescence, and the changes and growth rates they experience vary significantly from one adolescent to another. So there can be great differences in development and vulnerabilities among adolescents of the same age, as well as significant differences between adolescent girls and boys.

Adolescents also differ from each other in non-physical ways that affect their health seeking knowledge and practices. Given the heterogeneity of adolescents, it is important for service providers to consider the broad and specific needs of sub-populations of adolescents.

We are diverse!



Key growth and development changes during adolescence

Physical changes



In the early and middle stages of adolescence, rapid growth and the appearance of secondary sexual characteristics (pubic and facial hair, enlarged breasts, the Adam's apple) appear. Hormonal changes spark the onset of menstruation, increased perspiration, growth of testicles and penis, wet dreams and deepening of the voice.

Cognitive changes



As the brain grows during adolescence, the way an adolescent thinks and acquires knowledge changes. In the early stage of adolescence, an adolescent uses concrete thinking (emphasising the 'here and now') and s/he does not fully grasp the repercussions of an action in the present. At the same time, the younger adolescent experiences a deepening of moral thinking and expanded intellectual interests. By the middle stage of adolescence, an adolescent begins to think more theoretically or abstractly, but often reverts to concrete thinking when under stress. While adolescents at this stage are very self-absorbed, they are better able to understand the results of their own actions. In the late stage, an adolescent is capable of thinking abstractly and planning for the future. S/he understands how choices and decisions in the present can affect the future.

Sexual changes



Sexual changes occur throughout adolescence. These range from self-exploration and romantic fantasising in younger adolescents, to learning to establish stable relationships, exploring ways to attract potential sexual partners and experiencing emerging sexual drives for middle adolescence. Among older adolescents, changes include participating in mutual and balanced sexual relations, planning for the future and learning to manage close and long-term sexual relationships. Health care providers should use Tanner staging to assess the stages of growth and functionality of sex organs and address challenges that might arise. Tanner staging is used to differentiate abnormal and normal sexual maturity.⁶

Emotional and social changes



These changes can be the most powerful for adolescents: influencing the way they see themselves and their motivation to take responsibility for their health and wellbeing. Younger adolescents spend a lot of time thinking about their rapid physical growth and body image, and they can experience a sense of awkwardness and dramatic mood swings. They often struggle with a sense of identity and worry about being seen as 'normal'. Younger adolescents also begin to experience more conflict with parents and are more influenced by peer groups⁷ as they feel a growing desire for autonomy and independence.

Adolescents in the middle stage strive to create their body image, have ambitious plans and dreams, feel a sense of power and experiment with sex, drugs, friends and risks. Older adolescents tend to make plans and set long-term goals, become more comfortable with their body image and have a good understanding of right from

6. WHO (2014), Tanner scale. Available at: <http://apps.who.int/adolescent/second-decade/section2/page3/adolescence-physical-changes.html>

7. Scholastic, 'The science of decision-making and peer pressure'. Available at: <http://headsip.scholastic.com/students/the-science-of-decision-making-and-peer-pressure>

wrong. They also take fewer cues from peer groups and have a greater capacity for independent thinking and decision-making.

A significant challenge for adolescents is how they perceive risk. This is often complicated by self-consciousness, concern about socio-cultural norms and the views of others, including parents and families. As they become aware of risk, they may still be reluctant to expose themselves to disapproval or unfair judgment – this can serve as a barrier to accessing services.

The peer effect

| TEEN DRIVERS AND RISK TAKING |  |  |  |
|------------------------------|---|---|---|
| Number of Teen Passengers | 01 | 02 | 2 or more |
| Driving Risk | Normal | 2.5x more likely to take risks | 3x more likely to take risks |

In experiments using a driving simulator, adolescents were twice as likely as adults to take risks while driving when peers were in the car, or when they thought their peers were watching.

Did you know?



Effects of HIV infection on adolescents' growth and development

Growth problems



- An adolescent may experience delays in physical development, including the physical changes of puberty (for example, delayed or irregular menstrual cycles in girls) due to the effect that HIV has on the metabolic and endocrine systems during development.
- As a result, adolescents living with HIV may appear younger and smaller than other adolescents. This may lead to low self-esteem and affect how other people view them.
- Adolescents living with HIV may experience changes to their physical appearance due to side effects related to drugs and opportunistic infections, such as fat distribution and skin rashes.

Cognitive problems



- Adolescents living with HIV may experience cognitive challenges such as learning difficulties and memory problems. The impact of HIV on the developing adolescent brain is complex, influenced by many factors and not well understood. It has, however, been linked to advanced stage of disease and longer exposure to ART.

Psychological and social



- Adolescents living with HIV experience a number of emotional challenges.
- Illness may prevent adolescents living with HIV from going to school regularly, making friends, learning sports and hobbies. This reduces the number and range of activities that adolescents need to define their identity.
- Managing a chronic disease, including taking multiple medications daily, can have an impact on adolescents' mental health, sense of fitting in and being like their peers.
- Many adolescents living with HIV do not live with one or either birth parent. Although they may live with extended family, in some cases the adolescent may not feel part of their adopted home, leading to a sense of isolation or feeling unloved.

Effects of HIV infection on adolescents' growth and development

Peers problems



- Adolescents may feel unable to identify with their peers or may feel singled out due to stigma and discrimination.
- Adolescents living with HIV may have to regularly miss school to attend clinic appointments. This can affect their educational achievement and sense of fitting in with peers. If adolescents feel different from their peers, they have a harder time bonding with them. This has an adverse effect on their attachments, making it difficult for them to separate from their parents or caregivers.

Interacting with health services

The developmental changes of adolescence described above affect the way in which adolescents interact with health services. They exacerbate barriers to health services and intensify the impact of negative experiences that many adolescents face when using services. Adolescents are often reluctant to see providers who appear insensitive, uninformed or judgmental. In many situations, particularly where laws that require consent restrict access to services, adolescents prioritise trust and confidentiality as well as privacy.

Adolescents may be self-conscious about using services that are aimed at children or adults. They are also discouraged by long waiting times for multiple services that reduce time with friends or force them to miss school or work. Additional financial considerations act as obstacles to access when adolescents lack resources to pay for transport or services. Breaking down barriers and finding effective ways to deliver services for adolescents that take into consideration their development is a primary challenge for health providers.

Lessons learnt from Link Up

LINKUP Adolescents are open to new experiences and show a willingness to learn

Adolescents typically have more fluid behavioural patterns and are therefore more easily influenced in positive or beneficial ways. Those engaged by the Link Up project were eager to learn, open to new ideas, and receptive and responsive to information and activities related to their sexual and reproductive health (SRH) needs. In Ethiopia, Uganda and Burundi, adolescents acquired new skills, such as how to make decisions, including how to stay safe and form lasting friendships.

Needs beyond health

Due to the diverse changes during adolescence, as well as adolescents' evolving capacities and increased vulnerabilities, their needs transcend health services alone. In order to meet adolescents' needs, service providers must consider the other types of services and support that are vital to adolescents' overall health and wellbeing and make sure that referral networks are in place. Adolescents need access to shelter, nutritional support, livelihoods training, and legal representation and protection services.

Key resources

WHO (2014), 'Health for the world's adolescents: A second chance in the second decade. Section 2 Adolescence: a period needing special attention'. Available at: <http://apps.who.int/adolescent/second-decade/section2>

Sarah-Jayne Blackmore TED Talk, 'The mysterious workings of the adolescent brain.' Available at: www.ted.com/talks/sarah_jayne_blackmore_the_mysterious_workings_of_the_adolescent_brain

2

Delivering services to adolescents

Adolescents face many obstacles in accessing and remaining engaged in services. Addressing service delivery challenges is critical to ensure that adolescents obtain the health services they need to protect and improve their health and wellbeing. Programmatic strategies for delivering services to adolescents must reflect the diversity of their multiple needs. They must also create spaces and opportunities for adolescents to take on a range of roles in shaping and delivering services and helping their peers to navigate them.

Barriers to adolescents accessing health services

| System-related barriers | | Service-related barriers | |
|--|--|--|---|
|  <p>Consent requirements</p> |  <p>Services are far away or adolescents don't know where they are or how to access them</p> |  <p>Unwelcoming environments</p> |  <p>Inadequate resources</p> |
|  <p>Complicated health systems that are difficult for adolescents to navigate</p> |  <p>Lack of scheduling that accommodates adolescents' routines and needs</p> |  <p>Focus on adults and young children, which leaves adolescent needs unattended</p> |  <p>Poor health literacy</p> |
| Poor quality services | | | |
|  <p>Judgemental and stigmatising attitudes of providers</p> |  <p>Limited competencies and skills of providers</p> |  <p>No privacy and lack of confidentiality</p> |  <p>Lack of involvement in decisions that affect their lives</p> |
| Unrelated to services | | | |
|  <p>When they feel healthy, they aren't concerned about health issues</p> |  <p>Adolescents don't actively seek health services</p> |  <p>Adolescents have busy lives and other priorities</p> |  <p>Adolescents generally have poor risk perception</p> |

Key programmatic actions when delivering services to adolescents



Spotlight: Power of peers

Peers, of similar age, status and ability, are central to the success of service delivery interventions and strategies. Lessons from Link Up show that adolescents are more likely to engage in activities that include their peers, and use services if supported by a peer.

Peers provide vital information through personal stories and accessible language. Within health facilities, peers' proactive and friendly approach helps adolescents feel more comfortable and welcome. Peer groups and networks provide a much needed space to share, discuss and learn from others facing similar challenges.

The types of peer roles can include the following:

- **Community mobiliser:** creates demand for services by providing information that is critical for accessing services.
- **Navigator:** accompanies clients to health services and supports them in accessing and moving through complex health systems.
- **Educator:** educates peers on specific health topics, such as HIV transmission, using language that is easily understood.
- **Service provider:** delivers a service to their peers. Normally the services provided by a peer provider do not require medical training (for example, condom distribution).
- **Support group or network leader:** conducts or is responsible for leading support groups and networks. Their responsibilities tend to vary, according to the group or network.
- **Role model:** creates an ideal of a certain lifestyle, behaviour or way of living that peers want to aspire to. They present a character that shapes the lifestyle of their peers.



Key principles of peer interventions

- **Provide appropriate training, mentorship and supervision:**
 - Build on previous knowledge and skills through regular training.
 - Match peer workers with an older, more experienced peer worker.
 - Offer weekly debrief sessions with supervisors.
 - Facilitate opportunities for further education and qualifications.
- **Provide appropriate resources for peers to carry out their responsibilities:**
 - Ensure adequate supplies of IEC materials, job aids and referral forms.
 - Cover associated costs, including transportation and mobile phone use.
 - Pay acceptable remuneration.
- **Ensure the protection and safety of all peer workers:**
 - Require pair or group work.
 - Ensure peers know how and who to ask for help and provide access to phones for emergencies.
 - Ensure peers have a mechanism to ensure protection of children and that complaints are dealt with appropriately.
- **Establish clear mechanisms of referral and support:**
 - Provide protocols and policies that outline when and how to refer, including contact details for immediate support.
- **Recognise that adolescents are diverse and need different types of support:**
 - Not all will want to participate in peer activities.



Key principles of peer interventions

- **Ensure that peers are as diverse as the group of adolescents they are supporting or serving.** This is key to establishing trust and a sense of safety. Consider age, sex, key population group etc.
- **Ensure peer-based interventions do not replace the roles and responsibilities** of service providers, parents, caregivers or other community members.
- **Foster collaboration between health facilities and youth organisations** to facilitate regular ongoing feedback and opportunities for shared creative activities.
- **Reward and acknowledge young people for their contribution.**

1. Community mobilisation

Mobilising communities can generate important information that encourages health seeking behaviour. It boosts demand among adolescents to access and engage in community- and facility-based services.

Barriers and challenges to address

- When adolescents feel healthy, they are not concerned about health issues.
- Adolescents generally have a poor perception of risk.
- Most adolescents do not know where services are or how to access them.
- Most adolescents are concerned about the costs of accessing services.
- Most adolescents are not informed about SRH and HIV issues.
- Social barriers, especially for adolescent girls as a result of gender roles and classification.



Key principles of community mobilisation

- **Safe spaces:**
 - Identify a youth organisation or network to support to create safe spaces.
 - Establish, strengthen or support existing safe spaces where adolescents can engage, discuss and learn about sexuality, HIV and SRHR without fear or judgement.
 - Identify existing tools or adapt tools for use in the safe spaces around topics such as sex, sexuality, gender, relationships, self-esteem, resilience, gender-based violence and forming healthy relationships.
 - Train youth leaders on what constitutes a 'safe space', how to run a safe space and potential topics for discussion.
 - Ensure adult mentors are available during the safe spaces to provide input to topics and to assist youth leaders on running exercises, as needed.
 - Ensure that the safe space is well equipped with indoor/outdoor games and other forms of 'edutainment' which make the sessions interactive and attract adolescents to services.



Key principles of community mobilisation

■ Peer to peer support:

- Train young leaders as peer supporters to deliver tailored, age-appropriate support to adolescents in community safe spaces and in clinical settings, including counselling through hotlines.
- Assist peer supporters to lead support groups for adolescents living with HIV, conduct home visits and accompany peers to navigate health systems.
- Provide peer supporters with strategies to correct misinformation that peers may have received from others.

■ Campaigns:

- Tailor messages to the right audience – consider the needs of different population groups, such as young or older adolescents, adolescents from key populations, and adolescent boys or girls.
- Produce attractive materials with clear messaging.
- Ensure messages are based on and incorporate accurate evidence or data.
- Harness a range of communication channels, such as local media, radio, community level sessions, street theatre, newsletters, and social media.

■ Social media:

- Establish what kind of content should be distributed or discussed through the various social media tools.
- Use a variety of communication channels such as SMS, WhatsApp, Facebook, Twitter, YouTube.
- Identify and train adolescents and young people to facilitate online discussions.
- Create groups of interest around specific themes.
- Ensure the content is visual and engaging: change the visuals often.
- Use video as well as written content.
- Promote self-expression by inviting adolescents to send in clips on different issues.
- Consider developing a social media strategy – what, when, how, who etc.
- Translate virtual social media activities into ‘real life’ mobilisation events and activities.

■ Vouchers facilitate functional and completed referrals by providing something tangible that is linked to the task of accessing services:

- Establish which services should be covered by a voucher.
- Produce attractive vouchers with clear reference codes.
- Collaborate with health facilities to provide appropriate services.
- Monitor use of the voucher and authenticity.
- Consider e-vouchers through online activities.

■ Collaborate with schools by building relationships:

- Arrange meetings with key education officials to explain the benefits of adolescents using SRHR and HIV services, discuss concerns and clarify proposed health promotion messages.
- Offer training sessions for teachers and students to build skills and capacity.
- Establish pathways for schools to refer students to facilities and organisations for specific types of care and support.

Advocacy opportunity



Include comprehensive sexuality education (including gender, rights and sexuality) in school policies and the curriculum.





Key principles of community mobilisation

- Support students to advocate for non-discriminatory environments, including ensuring confidentiality.
 - Support students to advocate for engagement in health services, especially for those living with HIV.
-
- **Interactive, fun activities** – especially for younger adolescents – convey health messages, and facilitate learning, expression and discussions. Music, dance, drama, sports and group discussions explore important, sensitive issues such as sexuality and stigma through drama and film. Art, drawings and other visual activities facilitate communication and the expression of emotions.
 - Share visual information for younger adolescents and those who have had less access to education.
 - Organise adolescent camps to engage adolescents and create spaces where they feel free to express themselves.
 - Facilitate spontaneous discussions led by peers, and other activities in spaces that adolescents consider safe, confidential and acceptable.
 - Encourage adolescents to prioritise topics and concerns for discussion.
 - Ensure adults or older peer workers facilitate sessions so that misconceptions are corrected and appropriate information is provided, as necessary.
 - Organise discussion groups for older and younger adolescents that take into account their evolving needs.
 - **Community dialogues with gatekeepers and community members** – parents, guardians, teachers, pimps, religious leaders – can trigger discussions that challenge socio-cultural attitudes and norms, including stigma.
 - Provide strong facilitation to guide discussions, pose key questions, correct misinformation and create the space for parents and guardians to talk and reach their own conclusions.
-



Key resources

Read more about effective strategies and approaches to reach adolescents at: www.aidsalliance.org/resources/849-whats-so-different-about-adolescents



Case study: Interactive fun activities were central to capturing the attention of adolescents

Working closely with adolescents, Alliance Linking Organisations implementing the Link Up project in Uganda, Ethiopia and Burundi and other implementing and consortium partners, became increasingly aware of the developmental differences and unique needs of adolescents and the challenges they confront in accessing SRHR and HIV services. Consequently, programme managers and service providers became better informed and equipped to adapt their services in order to address adolescents' evolving needs.

In all countries, interactive activities, such as drama, music, sports, and tea ceremonies, were not only successful in engaging adolescents, they also conveyed key messages and information. Drama and film were used in engaging adolescents' attention while exploring important and sensitive issues such as sexuality

and stigma. With additional role plays, they were able to 'break the ice' and facilitate conversations. Art and drawing were also very popular as they facilitated expression and allowed for a different way of communication. For young adolescents and those of lower educational status, sharing information with pictures was extremely useful in overcoming communication barriers. Through play and fun, these activities encouraged discussion around SRH and HIV in a non-threatening and entertaining way.

Youth clubs were also a successful strategy to engage adolescents. Their less formal structure, away from authority figures, facilitated a fun and free learning environment where adolescents felt comfortable to express themselves.



Key principles of community mobilisation

- Identify and support older, trained peer educators (aged 18–24) or trained community health workers to serve as facilitators.
- Explore different interventions that support and build gatekeepers' skills, especially regarding communication.
- Empower gatekeepers to understand their key role in supporting adolescents' health and wellbeing.
- Be aware of power dynamics that can affect engagement and participation, and use strategies that facilitate engagement of everyone within the group.

2. Delivering services to adolescents

Providing services outside the formal health system: reaching out and meeting adolescents where they are – where they socialise, live, study or work – overcomes a number of barriers to access. While the services provided in these settings may be limited, they can actively link adolescents to other providers, as needed.

Bearing in mind that adolescents are diverse is essential. As such, services should consider the best settings and approaches for different groups of adolescents and developmental stages. For example, for adolescents who sell sex, outreach services at their evening workplaces may be more appropriate; for younger adolescents, home-based services may be more suitable.

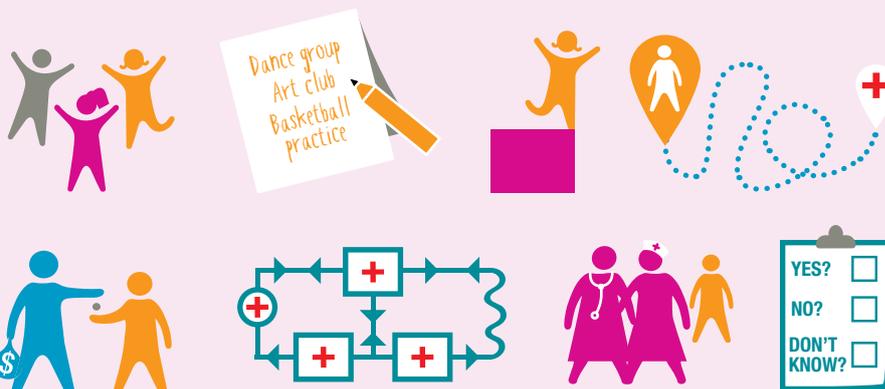
International guidance



HIV service delivery through primary health care and community-based settings is recommended by the World Health Organization.

Barriers and challenges to address

- When adolescents feel healthy, they are not concerned about health issues.
- Adolescents have busy lives.
- They do not actively seek out health services.
- They generally have a poor perception of risk.
- Are not well informed about health.
- May live far from services.
- Have limited resources, including money for transport and identification documentation.
- Struggle to navigate complex health systems.
- Lack involvement in decisions that affect their lives.
- Legal barriers, for example, laws requiring parental consent for access to or uptake of services.





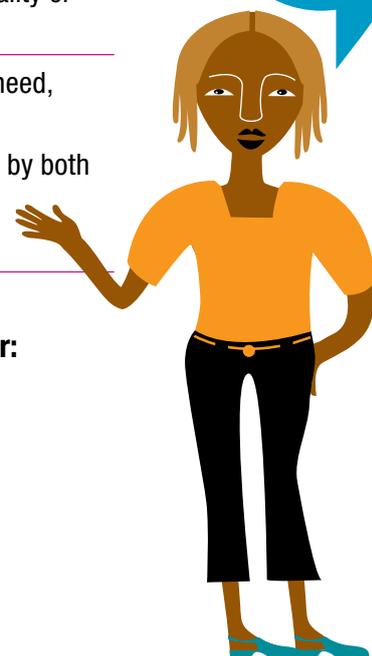
Key principles of service delivery to adolescents

- **Home-based services facilitate follow-up, support and encourage adolescents to re-engage in services when they have not attended regularly:**
 - Assess and understand the situation at home and relationship dynamics between adolescents and other household members.
 - Obtain permission from the adolescent to be contacted at home – it is best to establish this when they first use services.
 - Check and update the adolescent’s contact details at each visit.
- **Mobile services bring health care to those who are unable to access facility-based services:**
 - Undertake community mobilisation efforts to generate demand.
 - Establish pre-arranged times and locations through consultation with adolescents.
 - Map out hot spot areas.
 - Provide services in environments that are safe: public and easily accessible spaces.
 - Utilise low-cost versions of mobile services, such as tuk-tuks.
- **Outreach services provide health care in other venues**, for example, youth centres, drop-in centres and other hot spots like brothels and night clubs:
 - Define which services should be made available in outreach and which ones should be available through referral.
 - Ensure that a functioning referral system – capable of tracking referral completion – is in place.
 - Include peers in service provision as much as possible (for example, as counsellors).
 - Provide services in a way that respects the client’s ‘territory’, particularly when services are being delivered in places of work, such as brothels and night clubs.
 - Be mindful of the amount of time it takes for a service to be dispensed, referrals made and instructions provided, and be patient with the client.
 - Provide services in places that are safe and where adequate confidentiality or support can be guaranteed.
- **Peer navigators accompany adolescents to the health services** they need, supporting them to access complex health systems and allay fears:
 - Ensure that peer navigators’ role is clearly defined and well understood by both the peer navigator and service provider.
 - Ensure that they are easily identifiable.

For all these community-based service delivery approaches consider:

- data collection, protection and storage requirements
- supply of appropriate equipment, resources and commodities
- security and transport – especially for peer workers
- biosafety and waste disposal
- referral and linkages to comprehensive, quality services.

See page 13 for more information on peer roles



3. Improving the quality of health services for adolescents

Enhancing the quality of health services is critical to ensure adolescents' continued uptake of health care. This is particularly important for the health and wellbeing of adolescents living with HIV, who require regular – often monthly – appointments. Efforts to improve quality make services more appealing to adolescents. When adolescents feel that services are welcoming and providers understand and address their needs, they will be more likely to return, and may bring their friends along as well.

Barriers and challenges to address

- Service providers' judgmental and discriminatory attitudes.
- Service providers' limited skills.
- Unwelcoming environments.
- No privacy and lack of confidentiality.
- Long waiting times.
- Lack of services available: most are aimed at young children or adults.



Key principles in improving quality of care for adolescents

Competent providers

- **Provide appropriate training and skills development:**
 - Include adolescents – with clearly defined roles – in training. Use creative and exciting ways to include them as co-facilitators.
 - Incorporate specific adolescent models within existing training packages.
 - Hold regular education sessions with providers, allowing them opportunities to present or inviting other experts.
 - Adopt training approaches that facilitate experiential learning and interaction through role plays and imaginative group activities, not just PowerPoint slides.
- **Ensure ongoing mentorship, supervision and support:**
 - Facilitate opportunities for support, reflection and sharing experiences among team members, for example, regular team discussions of challenging clients and reflection on how challenging situations were handled.
 - Seek out opportunities with other similar services for mentoring sessions among providers.
 - Facilitate opportunities to practise new skills.
- **Develop guidance and protocols**, including management policies that encourage and support training and skills development.

International guidance



Global standards to improve quality of health care for adolescents:

- Adolescent health literacy
- Community support
- Appropriate package of services
- Providers' skills
- Facility characteristics
- Equity and non-discrimination
- Data quality improvement
- Adolescent participation

Training topics should include:

- adolescent development
- rights and evolving capacities
- effective communication skills
- consent and assent
- gender and social norms
- values clarification
- understanding sexuality
- stigma and discrimination
- meaningful participation
- delivering services to adolescents – service delivery approaches, improving quality and peer interventions
- comprehensive package of services for adolescents
- **HIV prevention** – condoms, PMTCT, harm reduction, risk reduction including associated behaviours such as drug and alcohol abuse, voluntary medical male circumcision (VMMC) and pre-exposure prophylaxis (PrEP)
- **sexual and reproductive health and rights** – sexually transmitted infections (STIs), contraception, safe abortion and post-abortion care, safe conception and antenatal care, male and female condoms (for dual protection), lubricants and dental dams, comprehensive post-rape care
- **key populations** – understanding their diverse challenges and needs and how to support them
- **HIV treatment** – ART, adherence, drivers of non-adherence, resistance, CD4 and viral load
- **disclosure** – helping adolescents to know their status and supporting them to disclose to others
- **psychosocial support and mental health** – self-management, dealing with stigma, addressing death, loss and bereavement.



Key principles in improving quality of care for adolescents

Health facilities

- **Provide services at convenient opening times:**
 - Offer after-school or weekend appointments.
 - Open at specific times or days for adolescents only.
- **Minimise waiting times:**
 - Establish separate clinic times or queues for adolescents.
- **Have flexible appointment systems:**
 - Ensure that adolescents can be seen with or without an appointment.
 - Offer less frequent appointment options for those living with HIV to minimise disruption to school, work and social lives.
- **Provide a welcoming and clean environment:**
 - Ensure access to clean bathroom facilities and comfortable waiting areas.
- **Provide adolescent-friendly spaces:**
 - Create a space that is informal, lively, and appropriate for the age groups using the service.
 - Designate adolescent-friendly spaces that are private and comfortable, such as rooms, corners and outside spaces.
 - Offer activities in waiting areas, such as appropriate IEC materials and access to peer support and education.
 - Employ and engage peer counsellors, navigators and receptionists.

Advocacy opportunity



- Include adolescent content within the pre-service training curriculum for all service providers.
- Ensure a national standard driven approach to improving quality of all health services for adolescents.
- Include specific adolescent service delivery needs in national guidance.



Key principles in improving quality of care for adolescents

Ethical and rights-based services

- **Develop policies and protocols that outline a code of conduct** for providers and adolescents and appropriate repercussions:
 - Ensure that providers understand these policies and protocols and that they are accessible to providers.
 - Display a version suitable for adolescents in the waiting area.

- **Have clear reporting mechanisms for any concerns and inappropriate behaviour:**
 - Ensure that adolescents are aware of these mechanisms and how to use them.

- **Guarantee confidentiality:**
 - Make the limits of confidentiality clear before starting any consultation.
 - Discuss with the adolescent the need to inform others about aspects of their care before doing so.
 - Close the door where possible.
 - Minimise disruptions during consultations.
 - Provide condoms and medication discreetly, for example, place them in a bag and offer them behind closed doors.

- **Provide equitable services:**
 - Deliver services to all adolescents irrespective of their ability to pay, age, sex, marital status, HIV status, education level, disability, ethnic origin, sexual orientation or gender identity.

International guidance



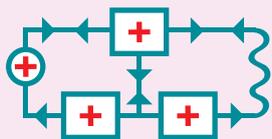
Integrating HIV services with harm reduction, antenatal care and SRH services is recommended by the World Health Organization.

4. Delivering a comprehensive package of care

Adolescents have diverse and evolving needs. It is important that services and interventions are responsive to individual adolescent needs and that a comprehensive package of care is provided. This allows adolescents to access all the services they need in one place, ideally in one visit, or through linkages and facilitated referrals.

Barriers and challenges to address

- Multiple appointments.
- Difficulty navigating complex health systems.
- Long distances to reach services.
- Limited resources, including money for transport.
- Adolescents are not all the same!





Key principles of a comprehensive, responsive package of care for adolescents

Integrated services

- **Provide a range of services and interventions in one visit to a clinic – a “one stop shop”:**
 - Host satellite clinics to expand access to other services. This could include a) a family planning provider or social worker holds a clinic session on a designated day within the ART service, b) an HIV provider offers ART care within an adolescent or drop-in centre, c) a community-based organisation participates in multidisciplinary case management.
 - Extend providers’ scope of work through appropriate training and capacity building to enable shared tasks, roles and responsibilities.

Linkages and referrals

- **Establish clear mechanisms and pathways of linkages and referrals:**
 - Establish agreed policies and protocols with referral services and organisations.
 - Ensure special attention is paid to confidentiality and data sharing responsibilities.
 - Where appropriate, develop a memorandum of understanding with other services and organisations.
- **Ensure adolescents are supported to engage with other available services:**
 - Provide information on referral service locations, hours of operation and contact details.
 - Make appointments directly with the adolescent.
 - Utilise peer navigators to accompany adolescents to other services.
 - Establish clear channels of communication (including referral forms) between referring and referral services.
 - Invite other service delivery organisations to multidisciplinary case management meetings.
 - With permission from the adolescent, provide contact details to other organisations, including support groups, to facilitate direct follow-up with the adolescent.
 - Use SMS, WhatsApp and call centres to remind adolescents of appointments or other vital information.
 - Encourage supportive adults to be involved, if appropriate.
 - Host various events or campaigns to increase awareness of the services and support organisations offer.
- **Develop loss to follow-up procedures and data systems** that keep track of adolescents to ensure linkages with appropriate services and re-engagement in care.

See Section 3 for what should be in the package



Hot topics: key considerations for service providers

Self-testing

- How do you make sure adolescents receive information and counselling and have an opportunity to ask questions?
- How can adolescents be linked to services they need after testing, including other prevention services, SRH services and HIV treatment, care and support?
- How do you best respond to an adolescent in crisis following a positive diagnosis?
- Self-testing may remove some barriers to consent. What would be the best way to encourage support, including from parents, after diagnosis?

Pre-exposure prophylaxis (PrEP)

- How would access to PrEP differ from other SRH and HIV interventions?
- What are additional health delivery considerations for the provision of PrEP to adolescents? What needs to be different and why?
- How would you determine who should receive PrEP?

Lessons learnt from Link Up

Peer interventions were central to the success of Link Up

LINKUP Link Up found that services delivered by peers proved highly acceptable to adolescents. Peers were critical in facilitating access to SRH services: adolescents were more likely to engage in activities that included their peers and were more likely to use a service if supported or accompanied by a peer. Even through word of mouth, peers' stories of quality services encouraged access.

Peer educators were central in facilitating the sharing of information. Using their personal stories, peers provided basic facts about SRHR and HIV and focused on life skills, such as decision-making, friendships and staying safe. Within health facilities, younger providers and peers were based in waiting areas, youth-friendly corners and regular services. Although many peer providers were slightly older than the adolescents, their proactive and friendly approach helped adolescents feel more comfortable and welcome in a setting that is perceived to be very intimidating.

Don't forget diversity. We are not all the same!





Key resources

International HIV/AIDS Alliance (2016), 'Lessons from Link Up: Link Up experiences of reaching adolescents living with HIV'. Available at: www.aidsalliance.org/resources/848-link-up-experiences-of-reaching-adolescents-living-with-hiv

International HIV/AIDS Alliance (2016), 'Lessons from Link Up: What's so different about adolescents?' Available at: www.aidsalliance.org/resources/849-whats-so-different-about-adolescents

International HIV/AIDS Alliance (2016), 'Uganda: Working with young adolescents (10-14 years old) on sexual and reproductive health rights and HIV'. Available at: www.aidsalliance.org/resources/740-uganda-working-with-young-adolescents-on-srhr-and-hiv

International HIV/AIDS Alliance (2016), 'Vouchers for sexual and reproductive health in Uganda'. Available at: www.aidsalliance.org/our-impact/making-it-happen-old/681-vouchers-for-sexual-and-reproductive-health-in-uganda

GNP+ and UNESCO (2012), 'Positive learning: meeting the needs of young people living with HIV in the education sector'. Available at: www.gnpplus.net/new-publication-positive-learning-meeting-the-needs-of-yplhiv-in-the-education-sector/

International HIV/AIDS Alliance (2008), 'Our future. Preparing to teach sexuality and life skills. An awareness training manual for teachers and community workers'. Available at: www.aidsalliance.org/assets/000/000/708/293-Preparing-to-teach-sexuality-and-life-skills_original.pdf?1406297227

International HIV/AIDS Alliance (2016), 'Service delivery outreach models for men who have sex with men: Experiences from Kenya and Uganda'. Available at: www.aidsalliance.org/resources/771-service-delivery-outreach-models-for-men-who-have-sex-with-men

WHO (2015), 'Global standards for quality health care services for adolescents'. Available at: www.who.int/maternal_child_adolescent/documents/global-standards-adolescent-care/en/

WHO (2015), 'Core competencies in adolescent health and development for primary care providers'. Available at: www.who.int/maternal_child_adolescent/documents/core_competencies/en/

International HIV/AIDS Alliance (2015), 'Sexual and reproductive health and rights, and HIV: 101 workshop guide'. Available at: www.aidsalliance.org/resources/592-sexual-and-reproductive-health-and-rights-and-hiv-101-workshop-guide

International HIV/AIDS Alliance (2016), 'Step Up, Link Up, Speak Up: Mentoring toolkit'. Available at: www.aidsalliance.org/assets/000/002/574/step_up_link_up_speak_up_a_facilitators_guide_for_a_workshop_on_mentoring_for_youth_advocacy_original.pdf?1464865364

ATHENA Network and Global Youth Coalition on AIDS (2016), 'Visions, voices and priorities: young people talk about pre-exposure prophylaxis'. Available at: www.aidsalliance.org/assets/000/002/663/Link-Up-com_dialogue_prep-FINAL_original.pdf?1468842422

ATHENA Network and Global Coalition on AIDS (2016). 'Visions, voices and priorities: young people talk about self-testing for HIV'. Available at: www.aidsalliance.org/assets/000/002/664/Link-Up-Comm_dialogue_self_test_FINAL_original.pdf?1468842444

STOPAIDS (2016), 'Fact sheet: adolescents and young people and HIV'. Available at: <http://stopaids.org.uk/wp-content/uploads/2016/12/STOPAIDS-Factsheet-Adolescents-and-young-people-and-HIV.pdf>

3

Adolescent-responsive SRHR and HIV package of care

To be effective, services must be tailored to meet adolescents' needs. This means that providers should be prepared to adjust to the rapid changes of adolescence, constantly recognising adolescents' varying needs over time and each individual's different rates of change. Providers also need to recognise that adolescents' vulnerabilities and risks will change over time. Understanding this diversity is critical in order to guarantee that adolescents receive comprehensive and appropriate services – when they need them.

In delivering a package of care to adolescents, service providers often find it difficult to know which interventions, services or support are needed and when is best to offer them. Understanding adolescent development and its stages (see Section 1) as well as experience of working with this age group can provide key insights.

It is crucial that providers are aware of – and guard against – personal belief systems influencing adolescents' decision-making. These may include harmful social norms and gender stereotypes: assumptions that can prevent adolescents from getting the support they need. Additionally, power imbalances between adolescents and providers may limit free and open sharing. The best way to ensure that adolescents have access to a comprehensive and responsive package of quality care is by offering a wide range of interventions and carrying out a robust assessment.

Comprehensive package of care

The table below outlines key SRHR and HIV interventions, services and support for adolescents. Such a package of care can be viewed as a toolbox that takes into account the evolving nature of this time of life. Section 2 highlights the important role of integrating and linking services in order to expand access to a range of interventions.

Comprehensive package of care: interventions, services and support

SRH and HIV prevention

- HIV testing and counselling
- Condoms and negotiation skills
- Family planning and pre-conception advice – a full range of contraceptives, including long-acting methods and emergency contraception
- STI screening, diagnosis and treatment
- Voluntary medical male circumcision
- Harm reduction services
- Antenatal care, safe delivery services and postnatal care
- Human papilloma virus vaccination
- Cervical and breast cancer screening
- Post-exposure prophylaxis
- Safe abortion and post-abortion care, including treatment of incomplete and unsafe abortion and comprehensive gender-based violence/post-rape care
- PrEP for partners

See Section 1 for information on understanding adolescent development



Comprehensive package of care: interventions, services and support

HIV and other treatment

- Antiretroviral therapy (ART) initiation
- Viral load and CD4 monitoring
- Adherence support
- Understanding and managing side effects
- PMTCT services
- Opportunistic infection screening and treatment
- Hepatitis C screening and treatment
- Hepatitis B screening and vaccination

Information

- Full information and counselling should be provided on all these topics within the package as well as where to access and link to other services

Care and support

- Psychosocial support
- Mental health screening and management
- Disclosure support
- Support groups and networks of adolescents living with HIV
- Comprehensive post-rape care and counselling
- Shelter and nutritional support
- Life skills development, vocational training and support in accessing social services and available benefits
- Legal information and services
- Violence prevention and support, including sexual and gender-based violence
- Capacity development for caregivers to be able to provide information and support on SRHR.

See Section 7 for tips on effective communication



Assessment

A robust assessment enables providers to know which tools to use and which referrals are required. Assessment helps providers to eliminate assumptions and share information. It allows providers to identify risks and gaps in adolescents' understanding, assess their readiness to change, and understand the context of the adolescent's home and social life. Assessment also offers opportunities to praise accomplishments and to discuss specific strategies for the individual.

The HEADSS assessment has been successfully used around the world in adolescent health. It provides a structured approach to asking adolescents about key aspects of their lives and ensures a broader understanding so that providers can offer responsive interventions, services and support. **For adolescents living with HIV**, important aspects of their care have been added to the framework, to form HEADSS +.

In cases where adolescents are seen regularly, it may not be necessary to explore each aspect in great detail at every visit. It is, however, essential to remember that adolescence is a time of constant flux and that a previous assessment may need to be adjusted to reflect changes that have taken place. When adolescents remain engaged

in care, providers can build upon their understanding of their clients, developing a rapport, encouraging them to open up gradually and reflect on resilience and progress. In resource-limited settings where time is short, some aspects of the assessment may need to be undertaken by different services: providers with concerns may need to refer clients or consult with senior staff members or multi-disciplinary teams.

| Key considerations for service providers | |
|--|--|
| HEADSS | HEADSS + |
| <p>Home and environment</p> <ul style="list-style-type: none"> ■ Where is home? Who else lives there? ■ Relationships at home ■ Recent moves? Running away? ■ Feeling safe | <p>Physical health</p> <ul style="list-style-type: none"> ■ Fever and night sweats? ■ Cough and difficulties breathing? ■ Headache, eyesight problems? ■ Rashes or skin problems? |
| <p>Education and employment</p> <ul style="list-style-type: none"> ■ School attendance and grades – any changes? ■ Favourite/worst subjects? ■ Suspension, termination, dropping out ■ Plans for the future: education/employment? ■ Current/past employment? Upcoming opportunities? ■ Relationships with friends, teachers, employers | <p>ART</p> <ul style="list-style-type: none"> ■ CD4 and viral load – results and understanding ■ Adherence – tablets taken in the last month, reasons for missed doses ■ Understanding of HIV, ART and adherence ■ Side effects and management ■ Other medication? ■ Storage when away from home, e.g. at friends' houses ■ Supply and access ■ Steps to self-management |
| <p>Activities</p> <ul style="list-style-type: none"> ■ Activities for fun? With friends, family, church etc? ■ Any hobbies – reading, exercise, music? ■ Boredom? ■ Safety | <p>Psychosocial issues</p> <ul style="list-style-type: none"> ■ Self-stigma – negative feelings toward themselves ■ Resilience, aspirations and agency ■ Experiences of stigma, discrimination and violence ■ Awareness of rights and responsibilities ■ Neurocognitive difficulties? Impaired motor skills, language difficulties and memory impairment? ■ Grief and impact of death of parents/siblings |
| <p>Drugs – including alcohol and tobacco</p> <ul style="list-style-type: none"> ■ Use – by peers, family members? ■ What, how much and how often? ■ Source of payment? ■ Feelings of control? Safety? ■ Access to clean equipment? | <p>Support system</p> <ul style="list-style-type: none"> ■ Who offers support? At home, school, friends? ■ Is more support needed? Who else could provide this support? ■ Shared status with others? Reactions and experiences. Would like to share? ■ Attending support group or network? |

Key considerations for service providers

| HEADSS | HEADSS + |
|---|---|
| <p>Sexuality</p> <ul style="list-style-type: none"> ■ In a relationship? Ever in a relationship? ■ Ever had sex? Sex regularly? Types of sex, including oral? Readiness and desire to be sexually active? ■ Condom use – never, sometimes, always ■ Condom splits? ■ Masturbation? (normalise) ■ Sexual orientation? ■ Age and sex of partner? ■ Number of partners in last three months? ■ Signs of an STI – pain, discharge, sores? ■ STI history, knowledge and understanding of prevention? ■ History of pregnancy or abortion ■ Periods? Regular? Painful? ■ Use of contraception ■ Enjoyment? Comfort of sexual activity? Unwanted? Violence? ■ Money or gifts in exchange for sex? | <p>Sex and relationships</p> <ul style="list-style-type: none"> ■ Delayed puberty and growth – feelings and impact ■ Understanding of how to reduce risk of transmission – adherence, types of sex ■ Sero-discordant counselling ■ HIV testing and counselling for couples ■ Which hormonal contraception – interactions ■ HPV vaccination ■ Cervical smear test? (for sexually active) |
| <p>Suicide and depression</p> <ul style="list-style-type: none"> ■ Problems sleeping – waking, taking a long time to get to sleep, sleeping too much? ■ Appetite changes? ■ Emotional outbursts? Impulsive behaviour? ■ Feelings of hopelessness? Boredom? Withdrawn? ■ History of depression? Suicide? In the family or peers? ■ **Observe for avoidance of eye contact, low mood** | <p>Uptake of services</p> <ul style="list-style-type: none"> ■ Barriers experienced in using services? ■ Who assists them to engage? ■ Extra support needed? |



Key resources

WHO (2010), 'Adolescent job aid: A handy desk reference tool for primary level health workers'. Available at: www.who.int/reproductivehealth/publications/adolescence/9789241599962/en/index.html

WHO (2015), 'Global standards for quality health care services for adolescents'. Volume 3: tools to conduct quality and coverage measurement surveys to collect data about compliance with the global standards. Available at: www.who.int/maternal_child_adolescent/documents/global-standards-adolescent-care/en/

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Younger adolescents

- Open up conversations by asking about friends and their friends' experiences.
- Explore rapid growth, puberty changes and body image. This helps to lead into a discussion around sex.
- Consent requirements and capacity assessment.
- Parental or gatekeeper influences are still strong. Focus on these relationships and interactions.
- The adolescent may not yet be sexually active but is probably thinking about it, therefore, as a service provider, discuss intentions, readiness and need for information and skills.

Older adolescents

- Improved understanding of the results of their own actions, therefore, as a service provider, explore consequences of risk.
- Increased experimentation and risk taking, therefore focus on drug use, sexual activity and other risk taking activities.
- Explore the implications of a stronger sexual drive.
- Emerging sense of identity, therefore, as a service provider, explore sexuality and understanding of different risk behaviours.
- Discuss how feelings of power may alter risk perceptions.

Key populations may:

- not identify as being at risk or with certain population groups
- experience barriers to accessing services related to the local legal context
- be subject to violence and exploitation, and have critical safety concerns
- have been rejected from society or home, leading to homelessness or unsafe environments
- experience self-stigma and associated mental health difficulties
- have overlapping complex vulnerabilities that require urgent attention.

Gender

- Explore the ways adolescence is experienced differently by girls and boys: which differences are the result of biological sex (e.g. during puberty)? Which are the result of gender (social expectations of what boys and girls should be and do)? For example, in some societies it is considered inappropriate for girls to know too much about sex. How does this affect their ability to access information about SRHR, including information about available services? Similarly, in some contexts, boys are expected to be more sexually experienced. What does this mean for an adolescent boy who is unsure of his sexuality or gender identity?
 - Decision-making and autonomy related to age and gender.
 - Harmful gender norms and gender power dynamics.
 - Gender-based violence, including sexual violence; different forms of gender-based violence and their relation to HIV; seeking redress/justice; and the associated mental health challenges.
 - Sexual debut: when, where, how, with whom? For many girls, their first experience of sex is coerced, resulting in a lack of ability to decide on or negotiate the boundaries.
 - Male/female condom use.
 - Perceptions and attitudes about sex and sexual pleasure.
-

4

Data for change: improving outcomes for adolescents

Data is one of the most powerful tools available to health services. Data about uptake, coverage and quality of services, along with detailed information about the adolescents who use services, provide valuable insights into adolescents' needs and preferences, how they are using services and the effectiveness of these services. Routine data collection is essential for the delivery of quality health care. Simply collecting data, however, is not enough to influence health outcomes. Data must be disaggregated by age and sex, and it must be analysed to identify trends, gaps in coverage, effectiveness and quality. What's more, it must be used to improve existing services, inform decisions about the way they are delivered, and shape new programmes.

Programmes must respond to and be informed by the lived realities, desires and priorities of adolescents living with and most affected by HIV. Qualitative data builds a more complete understanding of how adolescents perceive their needs and the services that are meant to serve them, and how providers can respond more effectively to their needs. This requires the meaningful involvement of adolescents – not just as subjects of data collection and studies – but as partners in monitoring, evaluation and research. Adolescents need to be at the centre of defining and implementing routine data collection and studies: deciding what data is collected, how it is collected, by whom, and participating in its analysis and validation. This adds value beyond the collection and analysis of data itself. It is empowering as it builds skills while ensuring that the data collected – what gets counted – is at the heart of the issues that really affect adolescents.

International guidance



The World Health Organization recommends that, where possible, data should be collected in five-year age categories i.e. 10–14 years, 15–19 years, 20–24 years.

Disaggregating data

Disaggregating data is one of the keys to making programmes respond better to adolescents' needs. When health service providers know how adolescents (disaggregated by specific age categories and sex) are using and benefiting from services, they can track progress more precisely. This enables them to answer vital questions about specific adolescent sub-groups with regard to uptake, coverage and quality of services. Using disaggregated data also makes it easier to identify gaps in coverage and understand specific

sub-groups' needs for targeted interventions.

Disaggregation by age (10–14 and 15–19 years) is essential to understand changes in HIV prevalence and incidence, and to characterise how the epidemic is evolving in a given setting and age group. This helps monitor equitable access to services and supports the planning of programme responses for specific adolescent age groups.

Disaggregation by gender is important to understand variations in service uptake, to monitor

equitable access to services and to understand the different effects of specific interventions or services on adolescent girls and boys, and on transgender adolescents. This facilitates planning for appropriate interventions to address the specific needs of each group. Disaggregation by sex does not capture the complexities of gender (in relation to gender non-conforming adolescents) – the unmet needs of these adolescents should be considered in certain settings and included in programme design.

Using data to improve programmes and services

The value of data is only fully realised when it is used to respond to the challenges or problem areas identified by the data. Well documented and analysed data can reveal and explain outcomes such as adherence to treatment, retention in care, mortality and the incidence of new infections, as well as the overall impact of services on clients' health and wellbeing. Using data specifically relating to adolescents as the basis for changes in health services ultimately improves the quality of services and outcomes for adolescents.

In order to understand the effectiveness of interventions and services, consider:

- uptake of testing services
- linkages to other key services and completed referrals
- adolescents who test positive for HIV
- adolescents who enrol in treatment and care services
- adolescents on ART
- adherence to treatment
- retention in care.

See Section 5 for information on participation and Section 6 for information on consent



Lessons learnt from Link Up

Case study: adolescents favoured community-based over facility-based services

LINKUP  Link Up engaged with adolescents in their own environments; providing services in the places they typically socialise and meet with others. This was key to ensuring access across all Link Up countries (Bangladesh, Burundi, Ethiopia, Myanmar and Uganda). Analysis of Link Up data indicated that adolescents were more likely to use community-based services than facility-based services. This was particularly evident for those aged 10–14, with over 85% of interaction in this age group through community-based services.

In Uganda, the Community Health Alliance Uganda (CHAU) worked closely with the Naguru Teenage Health and Information Centre (NTHIC), a pioneer in the provision of adolescent SRH services in Uganda. Under Link Up, NTHIC implemented outreach activities to communities around the health facilities so that services are taken to young people, rather than young people having to visit the facilities.

During community outreach, NTHIC organised teams of service providers and peer educators to go to specific sites (sometimes referred to as 'hotspots') identified by NTHIC and the team. At hotspots, the team provided reduced service packages such as short-term family planning, HIV counselling and testing and STI syndromic management. If young people required additional services, following a consultation, they were referred to the most appropriate health facilities (those specialising in certain aspects or the closest one, according to the young person's preference). During outreach activities, young people from key populations were also identified and offered services at a community centre, hotspot or a known public health facility where trust with communities of young key populations had already been established and service providers had been sensitised to work with key populations, in this case, the Most At Risk Populations Initiative (MARPI) clinic located within Mulago Hospital.

Advocacy opportunity



Data is a powerful advocacy tool. Being able to accurately describe challenges and successes helps generate change.

Advocacy statements and actions are stronger when backed up by data.

Case study: the strength of qualitative research methods

LINKUP  The *Visions, voices and priorities* project illustrates the strength of using qualitative research methods, for example, the use of focus groups to really understand the needs of young people. The project explored access to and priorities of SRHR for young people living with and most affected by HIV through an online survey and community dialogues involving over 1,200 young people. Among areas of consultation were: access to HIV treatment and care among adolescents living with HIV, with particular 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.

Link Up supported five community dialogues in Uganda, Burundi, Ethiopia and Myanmar involving young people, including those selling sex and those living with HIV, adolescent mothers and young men who have sex with men. These dialogues were led by and for young people living with and most affected by HIV, using discussion guides which included a set of key questions and background information on the main issue at hand (PrEP, self-testing, adherence etc.). The results of the dialogue were validated among participants.

Resources on findings from these dialogues are available here:
www.aidsalliance.org/our-impact/link-up/youth-advocacy

In order to assess service quality, consider:

- coverage of services and interventions
- choice of services
- adolescent's understanding of health and access to information
- community support for delivery of services to adolescents
- delivery of the appropriate package of services through integration and linkages
- accessibility of services, including distance and location of facilities, opening and waiting times
- acceptability of services and interventions
- affordability of services for adolescents
- barriers for adolescents and key populations
- gender norms, roles and responsibilities, and how these act as barriers or enablers for access to information and services
- provider attitudes and skills
- health facility characteristics
- equity and non-discrimination of services
- data collection and systems
- participation of adolescents at all levels of programming.

In order to identify operational efficiencies, consider:

- workflow
- bottleneck analysis
- referral systems.



Tips

Use these methods for assessing quality of services:

- Adolescent client exit interviews
- Focus group discussions
- Independent observations
- Interviews with services providers, programme managers and peer workers
- Interviews with adolescents and parents in the community to assess coverage.



Looking at data along the HIV care continuum

Unique identifier codes enable service providers to:

- understand the client pathway through services and along the HIV care continuum
- ascertain the number of people reached with a service as well as the services each individual is receiving
- ascertain numbers of people lost to care in between stages and find out reasons why
- avoid double counting of clients who are attending several services to access comprehensive care.

Ethical considerations for adolescent data collection and research

- Preventing the adolescent's physical and emotional harm is of utmost priority.
- Ensure community participation in research design, data collection and analysis and validation of results.
- Establish clear objectives of the research, including how the information will be used and where it will be presented.
- In order to obtain informed consent, provide information in language that is easy to understand.
- Facilitate parental/guardian consent and allow for mature minors for those under 18 years of age.
- Guarantee confidentiality in writing and orally, and ensure confidentiality during collection and storage.
- Provide access to supportive and protective services, if required.
- Ensure findings are communicated back to the community.
- Consider the need for formal ethical approval when doing research with adolescents, especially if the results are to be published.

Do no harm is of the utmost priority when doing research



Key principles on how to critically appraise data

Hold regular team meetings with data management officers

- Ask to present an overview of the recent data or provide them with an area of data that needs closer analysis.

Identify interesting or new information from the data about your programme and service

- Look out for data that challenges your assumptions and expectations.
- Don't overlook routine data – check for trends over time, trends between age groups and within age groups or by sex.
- Explore the reasoning behind the data – qualitative methods, such as interviews or focus group discussions, are helpful.
- Agree on ways to make changes to services that will address the issues identified.
- Review the data periodically to assess improvement.

Example of how data can be used to improve service delivery



Key resources

UNICEF, UNESCO, UNFPA, UNAIDS (2013), 'Young key populations at higher risk of HIV in Asia and the Pacific: Making the case with strategic information: guidance report'. Available at: www.unicef.org/eapro/Young_key_populations_at_high_risk_of_HIV_in_Asia_Pacific.pdf

UNICEF (2016), 'Collecting and reporting of sex- and age-disaggregated data on adolescents at the sub-national level'. Available at: <https://data.unicef.org/resources/collecting-reporting-sex-age-disaggregated-data-adolescents-sub-national-level/>

International HIV/AIDS Alliance (2015), 'How unique identification codes are transforming community programming'. Available at: www.aidsalliance.org/news/670-how-unique-identification-codes-are-transforming-community-programming

UNAIDS (2014), 'Considerations and guidance for countries adopting national health identifiers'. Available at: www.unaids.org/sites/default/files/media_asset/JC2640_nationalhealthidentifiers_en.pdf

UNICEF (2015), 'Adolescent assessment and decision-makers tool: Adolescent HIV prevention, treatment and care programme'. Available at: www.youngpeopleandhiv.org/iatt_1424.htm

International HIV/AIDS Alliance (2015), 'Visions, voices and priorities' series. Available at: www.aidsalliance.org/our-impact/link-up/youth-advocacy

5

Meaningful participation of adolescents

Participation entails ensuring that the people most affected by a policy, project or decision are meaningfully involved in decision-making, research, design, planning, implementation and evaluation. This should happen at all levels: in clinical care, as part of service delivery, programme planning, implementation and evaluation, and at the national level in policymaking and planning processes.

The meaningful involvement of adolescents in all their diversity is a key component of effective SRH and HIV programming. As a right for all, including adolescents, participation must be prioritised, encouraged and supported. This means that adolescents take part in and influence processes, decisions and activities related to their health, according to each adolescent's evolving capacities. In all aspects of adolescent programming, programmers and providers should:



Upholding the right to participation yields benefits for health services and adolescents. Providers gain a better understanding of how adolescents perceive problems and the reasons behind certain behaviour, enabling them to be more responsive to the needs of the populations they serve. This increases the likelihood that more adolescents will seek and remain engaged in care. The importance of listening to, learning from, and involving adolescents is also recognised as a way to build empowering partnerships with the communities in which adolescent clients live.

Adolescents have the capacity to identify approaches or solutions that will best accommodate their personal circumstances or needs. When supported to make decisions about their own health care, adolescents are encouraged to remain engaged in care, taking more responsibility for self-management and facilitating the transition to adulthood. Involving adolescents in meaningful ways can transform their ability to live positively. Participation can foster their hope for the future, their sense of belonging, confidence and self-esteem, knowledge and skills, opportunities for future employment, and, ultimately, their health.

International guidance



UN High-Level Meeting on Youth in 2011 declaration:

“Full and effective youth participation in society and decision-making, in both rural and urban settings, striving to include young people with disabilities, young people living with HIV, indigenous young people, young people from minorities, young migrants, young people who are stateless, internally displaced, young refugees or those affected by humanitarian situations or armed conflict.”

Ten strategies for the meaningful participation and engagement of adolescents

1. Agree roles, responsibilities and expectations among youth, other partners and stakeholders.
2. Support adolescents' leadership by giving them decision-making roles in all stages of the project.
3. Regularly ask adolescents whether their views and ideas are being heard, and how the meaningful participation of adolescents can be improved.
4. Identify advocacy opportunities and support adolescents to campaign for their issues, and to safely share their experience and knowledge as experts.
5. Build adolescents' skills and knowledge – including through mentorship – so they can confidently and effectively take part in both decision-making and implementation.
6. Use clear language that is easy to understand, respectful and accessible to everyone (this includes providing translation support).
7. Give adolescents enough support and resources (financial and other) in a timely manner – do not expect them to volunteer their time for nothing.
8. Value and respect adolescents' perspectives and views.
9. Support consultation and feedback between adolescents and the communities they represent.
10. Trust adolescents to take responsibility and be accountable for programme delivery.

Don't expect young people to volunteer their time for nothing



Tips for making sure participation is safe

- Establish clear, up-to-date protection policies and safeguarding procedures for adolescents involved in programming.
- Be aware of national laws, policies and possible exemptions, for example, reporting may require the adolescent's consent, or reporting is only required for certain professions.
- Ensure adolescent participants are aware of these laws prior to engaging in activities, and obtain their permission where reporting may be required.
- Ensure adolescents are aware of who to speak to, or report instances of bullying encountered within safe spaces, school or social media platforms.



Spotlight: The power of mentoring

Mentorship is a supportive relationship between more and less experienced people to develop skills, expertise and strengths. Mentoring programmes build the confidence of adolescents and young people to participate in processes. They help identify and expand the knowledge, leadership skills, and abilities that young people feel they need to meaningfully participate and advocate for their priorities. Both mentors and mentees can benefit from mentoring programmes.

Mentoring aims to provide a sense of direction that develops confidence and skills as well as supports achievements and creates new opportunities. Forms of mentorship vary. They may include structured and formal programmes; informal personal arrangements; older-to-younger or experienced-to-inexperienced relationships. Mentorship thrives with honesty, open communication, and a mentor with an approachable and caring nature, good listening skills, commitment, patience, confidentiality and a non-judgmental attitude.



Key principles in facilitating the meaningful participation of adolescents

Community mobilisation

- Deliver community mobilisation activities that fully engage adolescents.
- Implement education sessions – led by adolescents – for teachers, school staff and parents, with the support of older peer educators and community health workers.
- Provide peer education training and mentoring.
- Use social media for feedback on community mobilisation activities and suggestions for new ones.

Service provision

- Employ peer providers, navigators and support group workers.
- Utilise peer providers to conduct feedback sessions with adolescents, including ways to improve services. Use interactive activities, such as drawing, to facilitate expression.
- Use ‘mystery clients’ to evaluate service provision.
- Conduct adolescent exit interviews to explore experiences and generate suggestions for improvement.
- Ensure adolescent representation on a service or facility management board.
- Provide a suggestion box in the designated adolescent space.
- Display posters that outline adolescents’ right to have a say in their service – and how to participate.

Clinical care

- Include meaningful participation of adolescents as part of service provider training.
- Encourage adolescents’ participation in decisions regarding their health care.
- Through provider mentoring, reflect on clinical practice and opportunities for encouraging self-management and independence among adolescents.

Monitoring, evaluation and research

- Ensure adolescents’ participation in the design and implementation of research and monitoring activities as co-researchers.
- Seek opportunities for adolescents to present programmes and research findings at national, regional and global conferences.
- Support adolescents to co-author research papers and abstracts.
- Provide mentorship through ‘buddying’ with data management officers and local researchers.

Programming

- Create a youth constituency – including adolescents and young people – to form part of the programme management team.
- Allocate space at programming meetings to ensure the participation of adolescents in the planning, implementation, monitoring and evaluation of all programme activities.
- Financially support youth network focal points to dedicate time to engaging in programming.
- Actively engage with adolescents for feedback on adolescent participation.

See Section 6 for information on evolving capacities



See Section 2 to find out more on the power of peer interventions





Key principles in facilitating the meaningful participation of adolescents

National level

- Seek out opportunities to engage with national policy processes – contact provincial and national ministry of health staff to identify key policy developments and entry points for advocacy.
- Ensure adolescent views are included in policy processes through consultations, think tanks, and collaborative feedback on key documents.
- Engage with national level youth advocacy groups and networks; offer support where appropriate; and facilitate the participation of adolescents.
- Share experiences and effective programmes with national stakeholders during forums and meetings as well as setting up youth dissemination events, including online through webinars.
- Provide training on leadership and advocacy as well as mentorship.



Case study: Meaningful engagement of young people in advocacy

In Ethiopia, the Organisation for Social Services, Health and Development (OSSHD), in partnership with the National Network of Positive Women Ethiopians (NNPWE), hosted 19 youth dialogues in 2014 in 11 sites across the country to establish the SRHR and HIV priorities and needs of young people.

Following the youth dialogues, NNPWE and Link Up Ethiopia partners OSSHD, Talent Youth Association, and Nikat Charitable Organisation led a stakeholder workshop with local government health workers and service providers to present the findings. Stakeholders represented included the ministry of health, the Federal HIV/AIDS Prevention and Control Office (FHAPCO), local youth centres and government clinics and hospitals. Representatives from the ministry of health were surprised and impressed to see young people voicing their needs directly in the workshop, and said, “This

[direct testimony] is the evidence we need, rather than only papers and research.” Youth participants were equally impressed to hear health service providers acknowledge current gaps around HIV and SRH interventions for young people, such as the lack of educational materials and youth-friendly services.

Key advocacy achievements from this intervention include the development and distribution of press kits in local language outlining the SRH needs of young people. Additionally, partnerships with the ministry of health were established and led to good results, including the participation, at the invitation of the ministry of health, of both NNPWE and OSSHD in consultations on the development of the second national growth and transformation plan and the health sector transformation plan (HSTP) which was launched in October 2015.



Key resources

International HIV/AIDS Alliance (2015), ‘Aiming high: 10 strategies for meaningful youth engagement’. Available at: www.aidsalliance.org/our-impact/strongcommunities-old/744-aiming-high-10-strategies-for-meaningful-youth-engagement

International HIV/AIDS Alliance (2016), ‘Step Up, Link Up, Speak Up: Mentoring toolkit’. Available at: www.aidsalliance.org/resources/745-step-up-link-up-speak-up-mentoring-toolkit

Student Partnership Worldwide (2010), ‘Youth participation in development: a guide for development agencies and policy makers’. Available at: <http://restlessdevelopment.org/file/youth-participation-in-development-pdf>

Choice for youth & sexual health. ‘Meaningful Youth Participation: Flower of participation’. Available at: <https://choiceforyouth.org/srhr>

UNAIDS, ALL IN (2016), ‘Ending the AIDS epidemic for adolescents, with adolescents: A practical guide to meaningfully engage adolescents in the AIDS response’. Available at: www.unfpa.org/sites/default/files/pub-pdf/210079_UNAIDS_ENDING_THE_AIDS_FINAL_SO.pdf

6

Evolving capacity, decision-making and consent

One of the most important features of adolescence is young people's evolving capacity to make decisions, take responsibility for their actions, assess risk, provide informed consent for health services and adopt a healthy lifestyle. While age is commonly used to establish legal limits and make assumptions about an adolescent's ability to make decisions, evolving capacity occurs gradually, at a different pace for each adolescent. Within any age group, some adolescents will be more mature and experienced than others.

Useful legal frameworks allow adolescents below the legal age of consent to access treatment if they can demonstrate competency. Rather than a strict age-based approach to legal capacity, these frameworks take a developmental approach to decision-making. They aim to strike a balance between the need to protect adolescents and the importance of supporting them to exercise their emerging autonomy.

In recognition of their evolving capacity, adolescents should be given opportunities to gain more independence and experience in taking responsibility for their health care. They should be informed of their rights and how to claim them, educated about their options, and supported to make informed choices. Above all, adolescents need to feel that providers and services are responsive to their needs and requests.

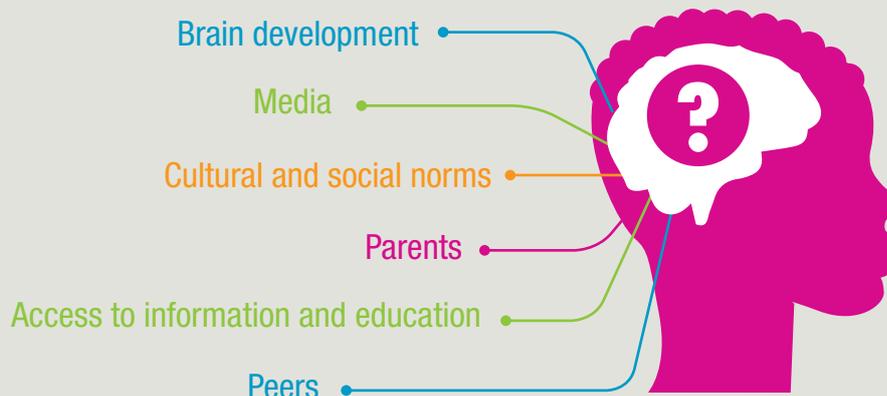
The principle of 'best interest' requires that health service providers consider adolescents' perspective, regardless of their age. Adolescents' best interest must be framed within the context of all the rights to which they are entitled, in particular, the right to be heard and have their views taken seriously. The best interest of adolescents includes consideration of their physical and emotional wellbeing through safeguarding policies and mechanisms. Safeguarding adolescents prevents and responds to violence, exploitation and abuse, and helps to create safe and healthy environments in which children can grow and thrive.

Remember!

Adolescents have rights to:

- life
- health
- education
- express their views freely
- be heard
- privacy and confidentiality
- access services and information free of discrimination or judgement
- access confidential medical counselling and advice without parental consent, irrespective of age.

Factors influencing adolescent decision-making



Consent to sexual and reproductive health and HIV services

Requirements for parental or guardian consent often prevent adolescents from receiving the services, interventions and support they need. Boys and girls receive different messaging as it relates to sexuality and sexual debut. Laws and reporting requirements regarding age of sexual activity, types of sexual activity and drug use can also serve as barriers to adolescents accessing services. Some legal frameworks allow for the best interest of the adolescent, mature minors and individual capacity to be considered. This enables service providers to exercise some discretion in the delivery of services to adolescents who have not yet reached the legal age of consent.

Key definitions

Consent: An adolescent gives permission before receiving any type of medical treatment, service, test or examination. Consent must be voluntary and informed. Accurate and comprehensive information must be provided, in an easily understandable way, before decision-making. The adolescent must have the capacity to make the decision.

Capacity: The ability to use and understand information to make a decision, and communicate the decision. Under many legal systems, age informs when an adolescent is considered to have the capacity to make a decision. Adolescent capacities change, however, over time and must be continually assessed.

Mature minors: Some countries have exceptions to age of consent laws for certain groups of adolescents or adolescents in certain situations. This includes those adolescents who live alone or look after other siblings, are pregnant, have no contact with parents/guardians, and have a clinical condition indicating they are unwell or will become unwell without immediate medical intervention.

Parental or guardian consent: For adolescents under the age of consent who are not considered mature minors, a parent or guardian will have to give permission on behalf of their child.

Assent: When parental/guardian consent is required, the adolescent's permission should also be obtained. Obtaining assent from an adolescent is vital as it facilitates joint decision-making with the adolescent.

Advocacy opportunity



- Lowering the age of consent for access to health services, including SRH.
- Harmonising consent laws.
- Allowing for mature minor and best interest exceptions.

Understand your country's legal context when considering consent

International guidance



The World Health Organization:

- recommends the provision of sexual and reproductive health services, including contraceptive information and services, for adolescents without mandatory parental and guardian authorisation/notification
- encourages countries to examine and potentially revise their current age of consent policies, taking into account how best to address age and access issues within their own legal and social context
- encourages countries to consider lowering the age of consent for HIV testing.



Key programmatic guidance

- Understand your country's legal context, including child protection and whether it is consistent with the principles of the Convention on the Rights of the Child.
- Promote supportive relationships between the adolescent and service provider through training and mentorship, especially on adolescent development and communication.
- Guarantee confidentiality and privacy.
- Provide clear protocols and policies to support providers' actions and decisions, including:
 - ensuring best interest
 - assessing capacity
 - boundaries of confidentiality
 - involving parents
 - managing difficult decisions
 - coercion and safeguarding.

Assessing capacity

In some countries, laws and policies allow a health provider to assess the capacity of those under the age of legal consent and provide services if they are satisfied that the adolescent has met certain mature minor criteria. These criteria require that the adolescent:

- understands the advice given
- demonstrates previous decision-making capacity regarding their health and other aspects of their life
- seems comfortable and confident in their decisions regarding SRH and HIV and shares details
- cannot be persuaded to inform parents or allow the provider to inform them
- is very likely to continue having sexual intercourse with or without access to interventions and treatment
- physical and/or mental health are likely to suffer unless given advice, treatment and services
- best interest requires the provider to proceed without parental consent.

Parental or guardian engagement

Adolescents, especially younger adolescents, are influenced by their parents; their values, expectations and responsibility to their children. Although increasing independence is a key aspect of this developmental phase, the involvement of supportive parents or guardians can be highly beneficial and is often undervalued. There are, however, potentially negative consequences of unsupportive parents or guardians engaging, and signs of possible abuse should be observed and protection ensured.

Managing difficult decisions

Making decisions regarding an adolescent's capacity to decide and give consent to services and interventions can be very challenging for providers. This is especially true when moral, religious or personal belief systems – compounded by laws – result in judgements about adolescents, particularly those from key populations.



Tips

In order to assess that adolescents understand advice given, service providers should:

- question their knowledge about SRH, including family planning and HIV
- discuss their options and concerns
- allow time to decide and offer follow-up sessions to support the decision-making process.



Key principles in engaging parents and guardians

- Allow time for discussion, especially with those who initially may experience negative reactions to their child's request to access SRH and HIV services.
- Provide information on the benefits of services, SRHR and HIV and the bounds of confidentiality.
- Enhance parents' communication skills through workshops and community dialogues.
- Offer adolescents an opportunity to discuss their assent and ask questions in private, without the presence of their parents or legal guardians.
- Explain the benefits of seeing the adolescent alone – evolving capacity and encouraging independence – and that it is the preferred procedure.

Approaches to support decision-making

- Difficult decisions should not be made in isolation. Discuss and think through decisions with other members of the multidisciplinary team.
- Include evolving capacity, decision-making and consent as part of service providers' training.
- Allow time within regular staff meetings to reflect on difficult decisions and how they were handled, or provide possible scenarios to explore actions.

Four steps to ethical decision-making⁸



8. Ibarra, K; Miller, J; Wagner, F (2014), 'Difficult Decisions: a tool for care workers. Managing ethical dilemmas when caring for children and families of key populations – people living with HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men'. Available at: <http://careworkerethics.org/wp-content/uploads/2014/07/Difficult-Decisions-ENGLISH-officeprinter-version-low-res.pdf>



Key resources

United Nations Human Rights Office of the High Commissioner (1989), 'Convention on the Rights of the Child'. Available at: www.ohchr.org/en/professionalinterest/pages/crc.aspx

WHO (2014), 'Ensuring human rights in the provision of contraceptive information and services'. Available at: http://apps.who.int/iris/bitstream/10665/102539/1/9789241506748_eng.pdf?ua=1

WHO (2013), 'HIV and adolescents: Guidance for HIV testing and counselling and care for adolescents living with HIV'. Geneva: Available at: <http://who.int/hiv/pub/guidelines/adolescents/en/>

International HIV/AIDS Alliance (2014), 'Safeguarding the rights of children and young people: a guide to facilitating a workshop with partners working with vulnerable children and young people', complete with PowerPoint slides to support your workshop. Available at: www.aidsalliance.org/resources/553-safeguarding-the-rights-of-children-and-young-people

IPPF (2012), 'Keys to youth-friendly services: understanding evolving capacity'. Available at: www.ippf.org/resource/evolving-capacity

IPPF (2012), 'Keys to youth-friendly services: obtaining informed consent'. Available at: http://www.ippf.org/sites/default/files/informed_consent.pdf

IPPF (2012), 'Understanding young people's right to decide: Why is it important to develop capacities for autonomous decision-making?' Available at: www.ippf.org/resource/young-peoples-autonomous-decision-making-capacities

IPPF (2012), 'Understanding young people's right to decide: How can parents effectively support the autonomous decision-making of young people?' Available at: www.ippf.org/resource/how-can-parents-effectively-support-autonomous-decision-making-young-people

The Coalition for Children Affected by AIDS (2014), 'Difficult decisions: A tool for care workers. Managing ethical dilemmas when caring for children and families of key populations'. Available at: www.careworkerethics.org

7

Communicating with adolescents

Communication underpins all interactions between health services and adolescents. Yet it can also be one of the biggest obstacles to providing care for adolescents. Social and cultural norms, along with inadequate skills, have a huge impact on the information provided to adolescents and the way in which it is communicated.

Communication is challenging for both service providers and adolescents. Many providers find it difficult to know how to communicate with adolescents and how to approach sensitive topics. They lack expertise in what to say and how to say it. Often, providers' own value systems, as well as limited training and skills development, influence their ability to communicate effectively with adolescents. Adolescents are often anxious about accessing services as they are sensitive to judgmental and disrespectful attitudes. Aware of power imbalances, they lack the confidence to speak, and their needs remain unmet.

When providers are able to communicate effectively with adolescents, they can put adolescents at ease and assist them to open up. This allows providers to understand adolescents' problems and needs, and provide information so that adolescents can make informed decisions about their own health, and access appropriate treatment, care and support.

Many adolescents have limited knowledge of health issues, especially SRHR and HIV, mainly due to poor access to information. They are rarely exposed to the information they need at home, school or in other environments. When information is provided, it is often not presented in an interesting or creative way to capture their attention. The messages presented may not use appropriate language or may include limited and biased information, reflecting sex and sexuality in a negative light. In the absence of accurate, comprehensive information, adolescents often rely instead on their peers as a source of knowledge. This can result in the promotion of misinformation, myths and uncertainty among adolescents regarding their sexual rights, including the right to access services.





Key principles of effective communication with adolescents

Guarantee confidentiality. All adolescents have the right to confidentiality. It is a key aspect of providing quality health services to adolescents. For adolescents, confidentiality is often their biggest concern about accessing services.

- Understand your country's legal context regarding confidentiality and consent.
- At the start of any discussion, explain the health facility's or country's policy on confidentiality and its limits, e.g. *"Everything we discuss is confidential unless I am concerned about your safety. If I am, I will talk about it with you before I speak to others."*

Develop rapport. This is a crucial first step in building a trusting relationship with an adolescent. It entails relating to each adolescent as a unique individual and connecting with them in a meaningful way.

- Introduce yourself and describe your role. Say that you are there to help them and understand their needs.
- If parents or caregivers are present, give your attention to the adolescent – ask them questions directly, not through their parent.
- Start with non-threatening issues that show interest in the adolescent's life, such as hobbies, school and friends.
- Focus on the adolescent and not on their problem – show interest in them and how the problem is affecting their life.
- Identify and compliment the adolescent on areas in their life that are going well.
- Persevere, as it may take a number of interactions to fully engage some adolescents.
- Plan enough time to spend with each adolescent. Don't make them feel rushed.

Explore beyond the presenting problem. Adolescents may not volunteer information about a problem. They may attend with a complaint that is not really their main concern, or they may not really understand the reason behind their behaviour.

- Use structured assessments, such as HEADSS, to systematically ask about all aspects of their life that affect their health and wellbeing.
- Help the adolescent understand the reasons behind their behaviour – this will indicate the type of support needed. For example, an adolescent who is not using condoms because she/he does not have any requires different support from an adolescent who is not able to negotiate condom use.
- See guidance on communication skills to support questioning and exploring actions (page 46).

Support evolving capacity and emerging independence. An adolescent's ability to manage their health care and engagement in services is a process that needs to be supported over time. Many adolescents do not have support structures within their homes or communities, so greater help is required from service providers. This is particularly important for adolescents living with HIV.

- For an adolescent accompanied by parents or caregivers, facilitate time alone with them:
 - This can be at the start of the visit, and the parent joins later, or by asking the parent(s) to leave for the second part of the consultation.
 - Highlight the benefits and importance of seeing the adolescent alone. Mention that this is routine practice.
 - Gradually work toward the adolescent being seen alone for longer periods.



Tips

Grunts ... One-word answers ... Crossed arms

This behaviour is often a normal part of development. It reflects adolescents' fear and lack of experience of engaging in health services.

Acknowledge their feelings and experiences rather than forcing responses. Be patient and don't get stressed! It can take time to develop a trusting relationship.

See Section 3 for the HEADSS assessment





Key principles of effective communication with adolescents

- Ask the adolescent what they would like to know or discuss. Encourage them to ask questions.
- Provide information, don't just ask questions. Go through and explain information provided – do not just hand out leaflets.
- Assess the adolescent's understanding and address gaps and misinformation. Ask adolescents to say in their own words what they understand.
- Take a participatory approach. Ask adolescents for ideas about what they could do about their health. Provide them with options and include them in decision-making.
- Develop a plan together with the adolescent and agree milestones to support their self-management, including how best to involve supportive adults in their care.
- Inform and empower adolescents by making sure they know their health care rights.

Involve parents and caregivers, where appropriate. Parents and family are an integral part of an adolescent's life and care. They can provide insights on the adolescent's health care and behaviour, and they can support ongoing care and engagement in services:

- Acknowledge the importance of involving parents.
- Facilitate space for communication between the adolescent and the parent.
- Support parents' understanding of adolescence and developmental changes.
- If the adolescent is seen alone, summarise the key points at the end of the consultation that can or must be discussed with their parent.

Tips for effective communication skills

- Reduce the stigma around certain sensitive issues by normalising them, e.g. *"This is a concern for many other young people your age"* or *"I ask all my clients about..."*
- Use indirect questions about their peers' experiences to open up discussion on more sensitive issues, e.g. *"Have any of your friends started drinking?... What about yourself?"*
- Use open questions. This helps adolescents to express themselves and to make decisions. For younger adolescents and those who are less talkative, however, more direct questions can be helpful.
- Ask questions that help them reflect on their feelings and behaviours. For example: *"Think about the time you missed your tablets. Tell me about it. What was different about that time from the times when you remembered to take them?"*
- Use a rating scale and multiple choice questions to facilitate expression.
- Listen for facts and feelings.
- Repeat back paraphrased versions of key aspects of what the adolescent has just said to ensure understanding.
- Use clear, plain language that is easy to understand.
- Give practical demonstrations and use visual aids e.g. condom demonstrations.
- Avoid writing during the interview, especially during sensitive questions.
- Do not lecture or give your own personal opinion.

Use different types of questions to help adolescents to open up



- Show respect and empathy through your speech, facial expressions and body language.
- Develop provider communication skills through role plays and observations with other colleagues.

Information, education and communication (IEC) programming

These include:

- Engaging activities such as sport, drama and dance
- Group activities
- Social media
- Harness celebrities
- Multisectoral approaches – schools, communities e.g. REPSSI journey of life community conversations
- Deliver those IEC activities developed with adolescents for adolescents, using their language

Lessons learnt from Link Up

Activities used by Link Up

LINKUP Communicating with adolescents was noted to be particularly challenging in all Link Up countries. Strategies such as music, dance, drama and sports were implemented as part of outreach activities as a means to attract other adolescents and young people to join them. Once the group was large enough, they reflected on health messages and conveyed additional health messages on different topics such as growing up, accessing health services, violence, STIs and HIV. Community health workers complemented the work of peer educators by clarifying and answering questions that they were not able to answer. Information, education and communication (IEC) materials, including leaflets and posters on growing up, were distributed during outreach and at youth-friendly corners in health facilities.

Service providers also found it difficult to know how to communicate with adolescents and how to approach sensitive topics. Expertise in ‘knowing what to say and how to say it’, especially with those aged 10–14, and those from key populations, was consequently developed by providers over time.

Conversations within the home were minimal, with many parents unsure of how to approach discussions around SRHR. Link Up actively sought the buy-in and proactive engagement of parents in speaking to their children through participation in community dialogues. In Uganda, 30 community dialogues addressing an SRHR topic were organised and conducted with parents and guardians from January 2014 to July 2015. These dialogues were facilitated by older trained peer educators (aged 18–24) or trained community health workers where they would answer technical questions or correct inaccurate information and myths. During these dialogues, parents and guardians learned techniques for supporting their children.



Key resources

WHO (2010), ‘Adolescent job aid: A handy desk reference tool for primary level health workers.’

Available at: www.who.int/reproductivehealth/publications/adolescence/9789241599962/en/index.html

WHO (2010), ‘IMAI one-day orientation on adolescents living with HIV. Participants’ manual and facilitator guide’.

Available at: www.who.int/maternal_child_adolescent/documents/fch_cah_9789241598972/en/

REPSSI journey of life community conversations.

Available at: www.repssi.org

8

Psychosocial wellbeing

As discussed throughout this guide, adolescence is a time of rapid developmental changes, and adolescents need many types of support as their capacity to take responsibility for themselves evolves. One of these is psychosocial support, which, despite increased awareness, remains medicalised. Psychosocial support describes a wide range of care, support and protection activities that aim at ensuring the social, spiritual, emotional and psychological wellbeing of individuals, their families and communities. Psychosocial wellbeing is when individuals feel good about themselves, have people around them who will help them, are able to deal with life's demands, manage relationships well, participate in decisions about matters that affect them, and have hope for the future. Psychosocial wellbeing covers many aspects of one's life, including psychological, social, cultural and spiritual factors.

Effective psychosocial support can have a significant impact on adolescents' social wellbeing, education and health. It must cover broader aspects of family life, relationships with peers and their communities. Psychosocial support can empower adolescents as they form their identities and sense of autonomy. With stronger self-esteem and confidence, adolescents are more likely to lead happy, productive and fulfilled lives.

Mental health

Many mental health issues emerge during adolescence. Alcohol and other substance abuse are especially common during adolescence, and are known to fuel the risk of mental health challenges.

Adolescents living with HIV and those from key populations are often at greater risk of experiencing mental health problems. These can affect disclosure and cause poor adherence to treatment and inconsistent engagement with services, while increasing the likelihood of engaging in risk-taking behaviour. These adolescents are particularly vulnerable due to loss of family or rejection. They often have to live independently or in institutionalised care, taking financial and emotional responsibility for themselves sooner than other adolescents, and they are often exposed to poverty and exploitation. Adolescents living with HIV face the stigma of a chronic illness, while some adolescents in key populations are discriminated against because of their sexual orientation, gender identity or behaviour. Both factors render these adolescents highly susceptible to abuse or violence. Some adolescents living with HIV, especially those who acquired HIV perinatally, experience neurocognitive disorders, such as language and memory difficulties, as they did not receive HIV treatment during critical brain development in childhood.

Like all adolescents, adolescents living with HIV and those from key populations are still developing internal resilience. Limited support structures can significantly affect their mental health and ability to manage their health. Although there are barriers to providing mental health services in many countries, programme managers and service providers can play an important role in supporting vulnerable adolescents.

Guidance in supporting adolescents' mental health

- Provide training to ensure service providers know basic mental health categories, can recognise signs and assess for mental health challenges. This includes basic observations (appearance, attitude, mood, alertness), past history and routine assessment – use HEADSS.
- Ensure mental health is part of routine assessments for all adolescents.
- Use a multidisciplinary case management approach toward mental health.
- Map out available mental health and psychosocial support services.
- Outline clear referral pathways to available services.
- Establish protocols and procedures for assessing, supporting and referring for mental health, including for emergency situations such as suicide.

Adherence

Adherence to antiretroviral therapy (ART) is one of the most significant challenges in optimising the health of adolescents living with HIV. There are many, often overlapping, reasons why adolescents do not adhere to ART. These include individual, medical, social and health service factors. It is important to understand what the reasons are in order to offer the right strategies and support. A comprehensive assessment gives providers a clearer understanding of the reasons for non-adherence and an opportunity to explore these with the adolescent. Factors that influence adherence, especially during this stage of rapid development, change over time and require different approaches.

Assessing adherence

Commonly used ways to gauge adherence, such as counting pills, may not provide an accurate measurement. Adolescents often want to avoid disappointment and disapproval and may exaggerate their adherence. More accurate measures of adherence, such as viral load monitoring, are not frequently available and are costly. Routine and comprehensive assessments are key to understanding the reasons for non-adherence as they rely on open and honest communication.



Key programmatic guidance for adherence assessments

A comprehensive adherence assessment should be carried out before starting or changing ART or when non-adherence is identified. This should include:

- acceptance of their status
- beliefs and experiences of HIV and ART, for example, side effects
- understanding HIV, ART and how it works, the importance of adherence and its benefits, and the consequences of non-adherence
- understanding the adolescent's daily routine: school, home, work, changes in routine such as going away
- access to and uptake of services
- other psychosocial factors – as in the HEADSS assessment in Section 3.

Routine adherence assessments should take place each time an adolescent is seen. Key questions include:

- *“What treatment are you currently taking? What time do you take it?”*
- *“How many doses have you taken in the last week/month?”*
- *“How many doses have you missed in the last week/month?”*
- *“When was the last time you missed a dose?”*

See Section 3
for the HEADSS
assessment



See Section
7 for tips on
communicating
with adolescents





Key programmatic guidance for adherence assessments

Exploring non-adherence is essential to provide the right support for adolescents. Open-ended questions help adolescents and providers to understand reasons for non-adherence. Key questions include:

- *“Think about the time you took your medication(s). Tell me about it. What helped you to take it/them?”*
- *“Think about the time you missed your tablets. Tell me about it. What was different about that time from the times when you remembered to take them?”*
- *“What do you think you could do to prevent this from happening again?”*
- *“How do you think we can help you to avoid this?”*

Individual

- Busy and erratic daily routines
- Competing priorities such as school work, socialising and family commitments
- Forgetfulness
- Not carrying medications with them or not taking doses on time
- Lack of motivation to adhere to treatment
- A wish not to be defined by their HIV status
- ART is a constant reminder of having HIV
- Sick of taking medication on a daily basis
- Fear that taking pills in public may disclose their status or invite unwelcome curiosity and questions
- If an adolescent is unaware of their HIV status they won't have the knowledge and motivation that can support adherence
- Difficulty accepting or coming to terms with their HIV status
- Mental health issues and substance abuse
- Poor understanding of HIV, ART and the importance of adherence
- Beliefs about health and medication that discourage adherence
- Religious teachings or cultural traditions
- Impaired neurocognitive functioning

Medication

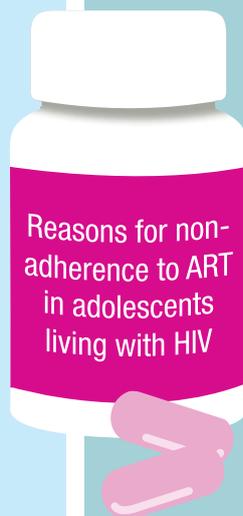
- Number of pills
- Unpleasant taste
- Frequency of doses
- Side effects of medication, especially those that change physical appearance

Health system

- Long distances to services
- Inconvenient service times and frequent appointments disrupt school and other activities
- Costs of transport, clinic fees and other medical charges
- Limited access to accurate adherence measures, such as viral load monitoring
- Limited availability of ART
- Poor relationships between adolescent and provider
- Lack of experience and training in providing care to adolescents
- Service provider's judgmental attitudes
- Limited information provided or discussion encouraged regarding adherence to ART

Social

- Lack of social or emotional support
- Not sharing their HIV status with a supportive friend or family member
- Stigma
- Limited availability of food
- Looks after sick family members or younger children
- Death of parent/s can result in unstable support structures
- Moving from the household of one family member/caregiver to another causes instability



Supporting adherence

Once the reasons behind non-adherence are identified, the right strategy to support adherence can be implemented.

Guidance in supporting adherence

- A combination of strategies to provide support may be required.
- A multidisciplinary approach can ensure that the different challenges experienced by an adolescent in adhering to ART are fully addressed. Each provider has different skills to offer and a unique role in supporting adherence.
- Supportive approaches may work for some adolescents but not others - service providers need to be flexible and responsive to the needs of each adolescent.
- Trust and respect for adolescents' concerns are key to ensure effective support for adherence. Health providers are responsible for encouraging honest and open discussion through non-judgmental attitudes and by guaranteeing confidentiality.
- Adolescents should be provided with the information they need to understand HIV and ART. This enables them to have more control over their health and make informed decisions.
- Providers can support adherence by recognising adolescents' evolving capacity and facilitating their independence.
- Providers can help adolescents to integrate ART into their daily routines. Even the smallest difficulties can have a significant impact and lead to non-adherence. If possible, health providers should select ART for adolescents that best fits their lifestyle.
- Once daily dosing is normally preferred by adolescents. If possible, reduce the number of tablets and the frequency of doses.
- Managing and treating side effects and switching to other ART should be considered in an effort to improve adherence.

Disclosure

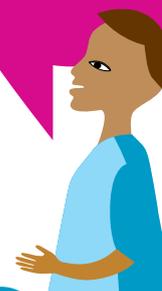
Knowing their HIV status

All adolescents have a right to health, to information about their health needs and to participate in decisions about their health care. Knowledge of one's HIV status is an integral part of this right.

Adolescents have many questions about their health. They are inquisitive, observant and eager to learn. Adolescents living with HIV want to know what is wrong, why they have to take medications and attend clinic, and what having HIV means for them. Disclosure helps adolescents to understand HIV and allows them to access the services they need to safeguard their own health and protect others.

Early disclosure in a supportive manner can improve adherence, reduce self-stigma, increase opportunities for support, facilitate open discussions and help adolescents accept their HIV status. Delayed disclosure may mean that adolescents learn about their HIV status in an unsupportive way, leaving them with little information or appropriate support to discuss their concerns or questions. This ultimately can contribute to adolescents feeling isolated, ashamed and fearful.

See Section 6
on facilitating
independence



Tips

Practical adherence tools:

- adherence diary
- pill boxes
- calendars
- alarms
- mobile phone applications
- SMS reminders
- cues, triggers, associations with daily activities
- peer treatment buddies

International guidance



The World Health Organization recommends that adolescents should be:

- informed of their own HIV status during school age (i.e. 6–12 years old) before sexual exploration and the complexities of adolescent development
- counselled about the potential benefits and risks of disclosing their HIV status to others
- empowered and supported to determine if, when, how and who to disclose to.

Despite clear recommendations and proven benefits, many adolescents remain unaware of their status. Parents and caregivers are often reluctant to disclose, as they may feel ashamed and burdened with guilt as well as fearful of stigma toward their child and themselves. Programme managers and service providers have a responsibility to uphold the rights of adolescents to know about their health and support them and their families to ensure that this process can be truly empowering.



Key programmatic guidance in disclosing to an adolescent

- Disclosure is telling an adolescent that he/she has HIV and helping him or her understand what this means.
- Disclosure is an ongoing process.
- The aim is to build an understanding of health and the immune system and the importance of medication to a point where they are prepared and supported to take responsibility for their care, including adherence to treatment.
- Full disclosure and naming HIV should happen by school age i.e. 6–12 years.
- One or more parents and caregivers should be involved in disclosure discussions. Ideally, they should jointly decide at which point full disclosure is necessary and how it should be done.
- Parents or caregivers should be encouraged to lead the full disclosure process and name their child's HIV status. It is important to recognise that this may not be possible for all parents or caregivers.
- Service providers should start by finding out what the adolescent already knows. Have they been asking questions, overheard conversations or received information from other sources?
- Conversations should begin as soon as the child is able to ask questions.
- Discussions about HIV should not end after full disclosure. Adolescents will continue to have questions and will need ongoing support and information.
- It is critical to provide clear guidance and protocols on disclosing to children and adolescents, including how to manage difficult situations with unwilling parents/caregivers.



Supporting parents and caregivers with disclosure

- Start talking about disclosure early to give them time to prepare.
- Explore their fears and concerns and work together to address them.
- Outline the benefits of their child knowing their status and the risk of them not knowing.
- Facilitate opportunities to speak to other parents who have gone through the same experience.
- Go through potential questions their child may ask and practise answers.
- Encourage them to continue conversations about HIV in the home after disclosure.

Sharing their status with others

Sharing their HIV status with others can provide adolescents with much-needed support. On an emotional level, disclosing to others can reduce feelings of isolation and fear. On a practical level, adolescents who share their status with others may no longer need to hide their medication. They can be supported to attend services and take their treatment, and they can more easily negotiate condom use.

Many people are still not properly informed about HIV and stigma is very evident in most societies. It is vital to recognise the reality of the potentially negative effects of disclosure faced by adolescents – the fear of rejection, unwilling disclosure to others, physical harm, and legal consequences. Allowing time to process information and options, providing the opportunity for discussion and ensuring that adolescents develop skills and confidence are all critical to empowering adolescents and making sure they are ready to disclose.



Supporting newly diagnosed adolescents

- Allow plenty of time for questions and discussion.
- Ask them what they know about HIV.
- Explore positive and negative aspects of knowing their HIV status.
- Acknowledge their feelings and responses.
- Encourage them to seek out others who they trust to tell. Look at current support systems.
- Book a follow-up appointment within a week.
- Connect them with a peer supporter or arrange a community or home visit.



Key programmatic guidance in supporting adolescents to disclose to others

- Adolescents disclosing to others about their HIV status is also a process.
- Adolescents should not be rushed or pressured as this may discourage their ongoing use of services.
- A country's legal requirements of disclosure to sexual partners, in the workplace, at school or in other situations should be discussed with adolescents so they are aware of their responsibilities and rights, especially their right to confidentiality. Discuss the steps to reduce the chances of onward transmission, including lower risk sexual activities, condoms and treatment adherence.
- Adolescents should be empowered and supported to decide if they share their status, who they share it with, when, where and how they share it:
 - Who: explore the possible benefits and risks of disclosing their HIV status to family, friends, work, school, community members and religious leaders.
 - When: discuss HIV acceptance, feeling prepared, other life events or factors triggering stress.
 - Where: identify a safe place. This could be in the health facility with a provider present.
 - How: write out a plan. Practise questions and answers through role play. Connect them with peers to learn from their experiences.

Advocacy opportunity



Laws requiring disclosure to sexual partners violate the rights of people living with HIV.

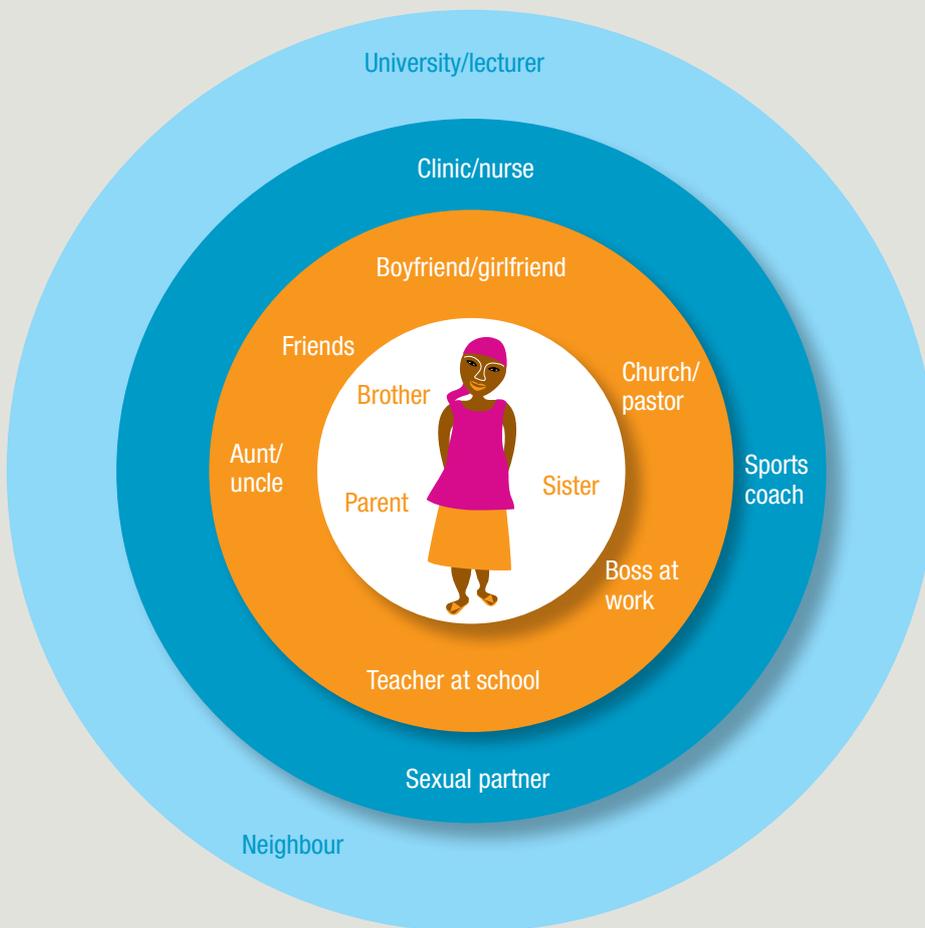
If this is the case in your country find out if there are other networks/ organisations already involved in advocating for change and join them.



Key programmatic guidance in supporting adolescents to disclose to others

- After an adolescent has shared their status with someone, a debrief is helpful to reflect on their experience, explore lessons for next time and offer further support.
- Those now aware of the adolescent's status should be offered an opportunity to attend the health facility with the adolescent to ask questions and, if required, to receive HIV testing and counselling. This also facilitates ongoing conversations about their HIV status.
- It is essential to establish clear guidance and protocols on how to support adolescents to disclose to others, including negative disclosure outcomes.

Identifying who to disclose to



Adapted from WHO

Promising practices and key resources



Peer support groups

Baylor International Pediatric AIDS Initiative (2012), 'Teen club life skills curriculum'.

Available at: www.botswanateenclub.org/what-we-do/life-skills-curriculum

Baylor International Pediatric AIDS Initiative (2010), 'Teen talk: A guide for positive living'.

Available at: http://jsi.com/JSIInternet/Inc/Common/_download_pub.cfm?id=13957&lid=3

Anova Health Institute (2011), 'Sexual and reproductive health for young HIV positive adolescents: The club concept in support groups'. Available at: <http://hivhealthclearinghouse.unesco.org/library/documents/sexual-and-reproductive-health-young-hiv-positive-adolescents-club-concept-support>

ICAP Columbia Mailman School of Public Health (2011), 'Positive voices, positive choices: A comprehensive training curriculum for adolescent peer educators'. Available at: <http://icap.columbia.edu/resources/detail/positive-voices-positive-choices-a-comprehensive-training-curriculum-for-ad>

Interactive activities

REPSSI Body mapping. Available at: www.repssi.org/living-with-x-a-body-mapping-journey-in-the-time-of-hiv-and-aids/

REPSSI journey of life community conversations. Available at: www.repssi.org/the-journey-of-life-community-workshop-to-support-children/

WHO (2014), 'Adolescents disclosing to others', online discussion tool. Available at: http://apps.who.int/adolescent/hiv-testing-treatment/page/Helping_adolescents_disclose_their_HIV_status_to_others

Chair role plays for disclosure by Eve for Life, Jamaica. Available at: www.youtube.com/watch?v=H7sLaQ0KMWU&feature=youtu.be

WHO (2014), 'Staying healthy, understanding HIV, ART and adherence', animation drawing. Available at: www.youtube.com/watch?v=vpODI-IrAhg&feature=youtu.be

Disclosure guides and tools

KZN health (2009), 'Step by step guide for conversations with children towards disclosure' (poster). Available at: www.kznhealth.gov.za/arv/Disclosure_Poster.pdf

Stellenbosch: South-to-South program for comprehensive family HIV care & treatment (2012), 'Disclosure process for children and adolescents living with HIV: Practical guide'. Available at: www.teampata.org/uploads/S2S_Disclosure%20Process%20for%20Children%20and%20Adolescents%20Living%20with%20HIV%20-%20Practical%20Guide.pdf

Service provider training manuals and toolkits

WHO (2014), 'Adolescent HIV testing, counselling and care: Implementation guidance for health providers and planners'. Available at: <http://apps.who.int/adolescent/hiv-testing-treatment/page/>

WHO (2010), 'IMAI one-day orientation on adolescents living with HIV: Participants manual and facilitator guide.' Available at: www.who.int/maternal_child_adolescent/documents/fch_cah_9789241598972/en/index.html

ICAP Columbia Mailman School of Public Health (2012), 'Adolescent HIV care and treatment: A training curriculum for health workers'. Available at: <http://icap.columbia.edu/resources/detail/adolescent-hiv-care-and-treatment>

AIDSTAR-One (2013), 'Toolkit for transition of care and other services for adolescents living with HIV'. Available at: http://pdf.usaid.gov/pdf_docs/PA00JQ6D.pdf

Community and home-based support

Community Adolescents Treatment Supporters (CATS): Africaid's innovative model provides community-based prevention, treatment, care and support for children and adolescents living with HIV. At the centre of the model are HIV positive 17–24 year olds known as CATS who work in health facilities and the community to support health workers and deliver child- and adolescent-friendly services.

Read more: www.africaid-zvandiri.org/programmes-adolescent-treatment-supporters/

Peers to Zero: PATA and the African Youth Positives Network (AY+) launched the PEERS 2 ZERO (P2Z) Coalition in 2016 to improve access to effective treatment and care for adolescents living with HIV (aged 10–19) and young people living with HIV (aged 18–24). The collaboration is a unique platform that brings together frontline health care workers and HIV positive young people. Young people living with HIV are at the forefront of the programme, as they take the lead in designing adolescent-friendly HIV service models across P2Z's target countries. Highlighting their perspective is a critical part of the P2Z initiative, as adolescent and young people living with HIV tend not to be consulted on the development of policies and programmes that significantly affect their treatment and care.

Find out more at: [www.teampata.org/what-we-do/Peers%20%20Zero%20\(P2Z\)%20Coalition?findtext=peers 2 zero](http://www.teampata.org/what-we-do/Peers%20%20Zero%20(P2Z)%20Coalition?findtext=peers%20zero)



Good Practice Guide series

This guide is one in a series of good practice guides produced by the International HIV/AIDS Alliance in collaboration with partner organisations. This series brings together expertise from our global community-level HIV programming to define and guide good practice in a range of technical areas, including:

- HIV and human rights
- Family-centred HIV programming for children
- Greater involvement of people living with HIV (GIPA)
- HIV and drug use
- Employing people who use drugs
- Integration of HIV and sexual and reproductive health and rights
- Community-based TB and HIV integration

Alliance Good Practice Guides:

- are user-friendly 'how to' guides
- target HIV programmers working in community settings in developing and transitional countries
- help to define what is good practice for community-level HIV programmes.

To download resources please visit: www.aidsalliance.org/resources