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FACTSHEET Adolescents and young people and HIV

Introduction

Adolescence and early adulthood is a critical period of development with significant physical and emotional changes taking place. Adolescents and young people have growing personal autonomy and responsibility for their individual health and will be building on experiences from childhood to establish lifelong health behaviours. The transition from childhood to adulthood is a time for exploring and navigating peer relationships, gender norms, sexuality and economic responsibility cumulatively resulting in the inclusion or exclusion from society and shaping young people's vulnerability to acquiring and living with HIV.

This factsheet is intended for STOPAIDS members and the wider international development sector. It takes a life course approach and considers how biological, behavioural, social and structural factors during adolescence and early adulthood influence HIV outcomes and effective HIV programming strategies.

DEFINITION

The United Nations define an **adolescent** as aged 10-19 and a **young person** as aged 10-24.

While a person's transition from childhood to adulthood will be context specific and not bound prescriptively by age, there is now a global effort to collect disaggregated data across three 5-year age bands around adolescents and young people: 10-14, 15-19 and 20-24. Because epidemiological data and research are increasingly structured around these age groups, the response and effective programming strategies can usefully be discussed in similar terms.

Approaches to HIV programming with children under-10 are not explicitly considered in this resource, however, the themes and challenges discussed in it may be relevant to children under-10.

The HIV epidemic

Adolescents and young people continue to be disproportionately affected by HIV. In 2014, 3.9 million young people (15-24) were living with HIV and 62,000 young people (15-24) newly acquired HIV.[1] AIDS is the leading cause of death amongst adolescents in sub-Saharan Africa, and the second leading cause globally. Adolescents are the only age group amongst which AIDS-related deaths are increasing.[2]

The HIV epidemic is underpinned by gender inequality, which exposes girls and women to gender-based violence and restricts access to sexual and reproductive health and rights (SRHR), increasing their vulnerability to HIV. In 2015, 20% of people who had newly acquired HIV globally were young women aged 15-24 (despite representing just 11% of the population).[3] In areas of sub-Saharan Africa young women are up to eight times more vulnerable to HIV acquisition than young men in the same age group.[4]

Multiple and intersecting forms of discrimination and structural inequality can impact the lives of young people as they experiment with identity. Young people who are men who have sex with men; use drugs; transgender; sex workers; sell sex; and in prison are disproportionately affected by HIV. For example, in Asia, 95% of young people diagnosed with HIV fall into at least one of the above groups.[5]

There are considerable data gaps around adolescents and young people and HIV, particularly for younger adolescents because of the challenges in getting parental approval for their involvement in surveys and a lack of age-appropriate questions. Where data exist, limited sample sizes and lack of disaggregation limits the available evidence to inform programming. In part because of these gaps, adolescents and young people are often missing from national HIV strategic plans, particularly in a way that goes beyond preventing vertical transmission.

Life course approach

A life course approach considers a person's progression through life to explain why certain outcomes result. Applied to the HIV context, a life course approach means examining the biological, social and behavioural factors that independently, cumulatively and interactively affect adolescents' and young people's vulnerability to acquiring HIV and while living with HIV.

The start of adolescence is often marked by the beginning of puberty. At this stage, boys and girls begin to acquire secondary sexual characteristics and will explore and evaluate their own sexuality. While global data suggest that only a small percentage of adolescents will become sexually active before 15 (roughly 11% for girls[6]), learning from programmes suggests that some children as young as five are exposed to sexual activities directly or indirectly. Child marriage is a key driver of early sexual debut, and in some settings up to 45% of adolescent girls reported that their first sexual experience was forced.[7] It is common for young people to become sexually active by late adolescence; UNICEF estimates that between 30-50% of girls will give birth to their first child before 19.[8] Reluctance to acknowledge children's and adolescents' early exposure to sex can lead to age restricted laws that govern access to SRHR counselling, HIV testing and treatment as well as health services that are unappealing or unfriendly to adolescents and young people. This results in unmet SRHR needs.

"There is this thing called, fitting in, doing things that other people of your age are doing."

Lehlohonolo Mohasoa, Lesotho, 26

Two key elements of the brain develop during adolescence. The limbic system develops first, and changes to the reward circuits of the brain mean that adolescents will seek out and derive pleasure from new and unfamiliar experiences.[9] They may begin to experiment with sex, alcohol, drugs, and relationships. As the pre-frontal cortex develops, capacity for decision-making, impulse control and planning for the future increases. Brain development will continue into the early 20s.[10]

Younger adolescents rely heavily on parents' and guardians' decision-making and often lack autonomy to choose to access services. At the same time, they may reject authoritative figures in favour of peer influence. The wider community, including faith leaders, will also influence behaviour. Capacity for autonomous decision-making evolves throughout adolescence, gradually becoming less mediated by parents or guardians. Decisions and values will also slowly become more influenced by peers. Young adults will have less support and guidance from family as they leave home and build independent lives.

The daily routine of many adolescents will involve school – although some, especially girls, may be forced to drop out early because of responsibilities within the household, including caring for family members or due to pregnancy. After education, young adults will face increasing economic responsibilities and challenges. Currently young people make up 40% of the world's unemployed.[11]

Around 70% of adolescents living with HIV have acquired HIV via vertical transmission and have been living with HIV since birth.[12] They will only be aware of their HIV status if their parents or guardians have chosen to tell them this. Telling children their HIV status, is delayed when parents are concerned about the emotional impact or their child's capacity to understand the implications of an HIV diagnosis. Guilt around the transmission of HIV, or fear of their own HIV status being disclosed by the child, can also delay disclosure. Disclosure comes with additional challenges if left until adolescence when young people are undergoing puberty and beginning to explore their sexuality and consider relationships.

"Most of the young people … are mandated by their parents and the parents and even the communities are not supportive. Some of the young people are having HIV but their parents have told them they are having malaria."

Mariam Nassaka, Uganda, 21

For young people living with HIV who have acquired HIV since infancy, the most common route of transmission will be sexual transmission followed by sharing unsafe injecting equipment.[13] Age-restricted laws will prevent adolescents from accessing HIV prevention and testing services in some settings.

What does this means for HIV programming?

1. Parents, guardians and caregivers

Given the low levels of autonomy afforded to younger adolescents, HIV programming will involve working closely with parents, guardians and caregivers. Parents will determine whether adolescents are allowed to attend activities,

CASE STUDY

Stepping Stones with Children

Salamander Trust has designed a programme *Stepping Stones with Children*, specifically for use with children aged 5-8, 9-14 and their caregivers. *Stepping Stones with Children* is a holistic interactive training process in gender, inter-generational issues, human rights, communication and relationship skills in the context of HIV. The programme comprises 29 sessions in total and uses positive language, mindsight, virtues, role play, games and drawing to build positive cross-gender and intergenerational communication skills and critical literacy.

The programme was designed with young people, to answer the question, 'How do we talk to our children?' and to break the life-cycles of violence which affect many families deeply as children grow up. The programme facilitates children living with or affected by HIV and their caregivers to establish and strengthen positive relationships and to dialogue effectively on sensitive issues. Participants first discuss issues in separate peer groups and then come together to share views and develop positive solutions together. Preliminary results from evaluations of *Stepping Stones with Children* have found that, after the workshops, relationships between caregivers and children became more open and loving, and that violence against children has reduced. In addition, preliminary data have suggested that children within the group are supporting one another with increased treatment adherence. Salamander Trust has also wholly revised and updated its programme *Stepping Stones* and *Stepping Stones Plus*, designed for use with adolescents aged 15 or so and upwards and adults.

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***Stepping Stones with Children* participants role play a family discussion about sending the daughter back to school.**

participate in programmes or access services, and so their buy-in is critical to reaching younger adolescents. Parents and caregivers are also an important source of information to their children, and programming should equip them with the information and tools to speak to their children about puberty, sex, HIV and relationships, including how to identify and avoid coercive or exploitative advances. Intergenerational communication has been demonstrated to improve HIV outcomes, both by delaying the age at which adolescents start having sex and increasing condom use when they start. Facilitating communication can also guide parents and guardians to feel more able to disclose HIV status to children living with or affected by HIV and improve levels of treatment adherence.

> "Some of the young people are lacking information concerning HIV. They don't know the importance of HIV testing. This is making them very vulnerable to HIV."
>
> *Mariam Nassaka, Uganda, 21*

2. Comprehensive sexuality education

Comprehensive sexuality education is an essential element of HIV programming for adolescents and young people and UNESCO has developed extensive guidelines on implementation (to be updated later in 2016).[14] Ensuring adolescents and young people have accurate and comprehensive information about HIV and SRHR is critical to HIV prevention and reducing stigma and other forms of violence. Information shared should reflect the reality of a young person's daily experiences and the challenges they face at that stage of life. It should also take account of what community members will see as acceptable information to share with young people, even if part of the project aim is to shift this. For younger adolescents, beginning the conversation with wider messages about puberty, health, rights and life skills builds the foundation to later introduce specific messages about HIV, sex and sexuality, gender-based violence and SRHR. As adolescents consider becoming sexually active, the principles and practices of healthy relationships should already be well established and further information about SRHR should be able to build on this as it is shared. Older adolescents and young adults will be able to more clearly articulate what they want from HIV and SRHR programming, including any gaps in their knowledge. As a result, programmes and the information shared within them can gradually become more focused and increasingly guided by young people's priorities.

Given that most adolescents will be in school, using schools as a channel to communicate messages around preventing HIV and living with HIV is key. Especially for adolescents who may not have a parent or caregiver able to share and discuss information around HIV, educators play a significant role in influencing adolescents' health behaviour. As young adults exit education, delivering HIV messaging through workplaces can also be an effective strategy. For programmes working through schools, a strategy should be developed for also reaching adolescents and young people not in school. For young women, who may be starting families, delivering HIV, SRHR and gender-based violence services through family planning and antenatal services can also be effective.

CASE STUDY

Students train in stigma reduction

STRIVE partner in India, the International Center for Research on Women, has piloted a promising approach to reducing stigma towards people living with HIV through training faculty members and young people at universities. Students took part in three days of workshops including sessions on stigma as a social construct and the causes and effects of stigma.

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Students were guided to reflect on their personal moral judgements and question their beliefs related to gender, sexuality and relationships. Students also visited community-based organisations working with people living with HIV and key populations including men who have sex with men. With support from college faculty, students were then able to conduct a campaign on stigma reduction with their wider peer groups. Post intervention surveys revealed important attitude changes; For example, blaming attitudes towards people living with HIV regarding 'wrong' or 'immoral' behaviour declined from 21% to 5% and the proportion of students who tested for HIV increased from 9% to 19%.[15]

CASE STUDY

Education on the football pitch

TackleAfrica trains football coaches across Africa to deliver interactive HIV and SRHR education to young players on the pitch. Tackle Africa's partner in Kenya, Moving The Goalposts (MTG), works primarily with young girls, 10–14 years old in a rural, low literacy setting. Most of the group are not reportedly sexually active. As players in this group find it difficult to handle criticism and need greater sensory input to concentrate, MTG sessions don't focus on tactics or results, but on movement and participation. Training manuals are in Swahili and are simplified and colourful. Sessions are full of praise and positive reinforcement, and scores are rarely kept. Health messaging is simple and depersonalised to avoid embarrassment. Each session focusses on one key piece of information to take away, for example 'getting tested is the only way to know your HIV status'.

With older players, sessions are more complex in terms of football and health messaging. Sessions are designed to start in-depth discussions, for example about why people don't test, and even about why the players themselves do or don't test. The informality of the football pitch allows young people to discuss intimate issues more freely, and the game itself means young people can play out the consequences of different decisions in an enjoyable and safe way.

TackleAfrica football training session.

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3. Activity-based learning

Activity-based learning works well with adolescents. Younger adolescents' shorter attention spans and reliance on concrete thinking means that using interactive music, dance, drama and sports will help to conceptualise HIV messages, and provide the sensory input needed to keep focus. Organising HIV and SRHR services around activities can also make parents feel more comfortable with their children participating in programming. Active learning models continue to be relevant when working with older adolescents, allowing the more sensitive and context specific messaging to be delivered in a relaxed setting that attracts and engages adolescents to participate.

4. Safeguarding

Safeguarding is an important element of working with adolescents under 18, enabling them to live free from harm, abuse and neglect. In the HIV context this can mean balancing protection of children with promoting the autonomy of young people to make decisions about their own lives. Given adolescents' evolving capacity to make rational and informed decisions, a key element of programming will be working with healthcare providers to enable them to assess adolescents' decision-making as it advances and work out the best approach to their care, based on the individual. Particularly, making the case to service providers that harm reduction approaches do not *encourage* behaviour that compromises their SRH will be important. Service providers working with adolescents living with HIV must recognise a paediatric patient's growth and the changing set of issues and concerns that may emerge as a young person becomes sexually active and experiments with drugs and/or alcohol.

> "The young people who are born with HIV get more responsibilities as they grow into adolescents, but the health workers in the clinics where they access treatment tend to not realise that they have really grown and still treat them like children which makes adherence and disclosure complicated."
>
> *Allen Kyendikuwa, Uganda, 25*

5. Programming led by young people

HIV programming for young people should be led by young people. Young people are tuned into the specific needs of their own peer group and will be best placed to design programmes that meet those needs and appeal to other young people. The level of responsibility young people take within a programme will evolve as they develop and build capacity. Younger adolescents might shape the format and content of sessions and lead elements of or all of implementation. They might take on responsibility for monitoring programme outcomes and contribute to reports. Older adolescents and young adults will need less support and can take responsibility for managing budgets, reporting and writing grant proposals. Often the most difficult element of youth-led programming can be partners

adapting to reduced oversight of a programme. Global policy partners on the Link Up project, ATHENA Network and the Global Youth Coalition on HIV and AIDS (GYCA), have developed a tool to guide and monitor the meaningful engagement of young people, *Aiming High*.[16]

> It is very important for young people to lead the response. These programmes are meant for them, so they should have ownership of the programme. There should be consultative meetings with them on programme design so they can have input on how the programme should be run. Imposing leads to programme failure."
>
> *Lehlohonolo Mohasoa, Lesotho, 26*

6. Peer support

With all age groups, peer support is well evidenced as an effective approach. During adolescence, when peers have a significant influence over behaviour, adolescents describe how hearing messages from those close to their own age helps to reframe messages from doctors or parents, in a more positive light. Young people also describe peer educators as easier to relate to and more influential. They are able to establish trust and higher levels of comfort, facilitating young people to talk about sensitive subjects and speak honestly about the challenges they are facing and what support they need. This is especially true for young people from hard to reach, hidden or marginalised populations who may particularly fear authority figures. Peer support can have a positive impact on the peer educator as well, building their confidence and encouraging them to continue living healthy lives.

> [Peer support] brings in that change of behaviour from a negative to a positive. If your doctor said to you, you need to take your medication; you're thinking that's just your doctor telling you that. But if it was someone that you are close to or you have a connection with, it makes it serious but it also changes your behaviour and how you see yourself progressing medically."
>
> *Becky Kroger, 21, UK*

CASE STUDY

Link Up consultations

The International HIV/AIDS Alliance led a consortium of global partners and country implementing community-based organisations to deliver the Link Up project, which aimed to improve the SRHR of young people (10-24) living with and most affected by HIV in Bangladesh, Burundi, Ethiopia, Myanmar and Uganda.

Consultations with the most vulnerable young people identified stigma and judgemental attitudes from service providers as one of the main barriers to accessing services. Further conversations with service providers revealed few had received any guidance on working with vulnerable young people and many lacked understanding about their particular sexual and reproductive health and rights needs.

> If you want to know what is happening with young people, you need to ask the young people."
>
> *Mariam Nassaka, Uganda, 21*

Service providers were also conflicted about the legal and ethical issues of providing services to those under 18 where there was an age restriction or requirement for consent from parents. In response, Link Up developed and implemented the five-day *Sexual and reproductive health and rights, and HIV 101 workshop guide* for service providers in each country, to sensitise them to the needs of young people who sell sex, young people living with HIV, young men who have sex with men and young transgender people. Members of young key population communities were involved at the country level to review the training material and deliver the training.

Service providers subsequently requested further capacity building on how to assess the ability of young people to make decisions around their own health. The guide *Safeguarding the rights of children and young people* was developed to address this need, and focuses on the duty of care of all service providers and their role in protecting the space for young people to be decision-makers in their own health.

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Young women perform a traditional dance at Uganda Development Link in Masooli, Uganda.

© Youth Stop AIDS

CASE STUDY

Youth Stop AIDS

Youth Stop AIDS is a youth-led movement campaigning for a world without AIDS, supported by STOPAIDS and Restless Development. With a network of youth activists across the UK, Youth Stop AIDS organises direct action (stunts, protests, demonstrations), lobbies decision-makers and raises public awareness around HIV and AIDS. As part of this, Youth Stop AIDS organises an annual Speaker Tour, where young people living with HIV from around the world tell their personal stories and inspire young people and decision-makers across the UK. In February 2016, three young speakers from Uganda, the UK and Ireland spoke at 22 events across the UK, reaching around 420,000 people directly and indirectly through the media. Young people also control the decision-making of Youth Stop AIDS, through a 12-person steering group made up of 18–30 year olds.

7. Transitions to adulthood

In early adulthood, programming should take into account that young adults will have less support from their families and communities as they transition to working and living independently. For young adults living with HIV, adherence can be challenging in this transition period as a young person learns to juggle responsibilities in the workplace with attending appointments and picking up and taking medication. Across adolescence and early adulthood, stigma and discrimination, fear of involuntary disclosure, quality of services and side effects are additional barriers to adherence.[17]

> "As we get older you have to factor in work life. You have to separately take time out to make that phone call to arrange that appointment and then to go ahead and get your medication. That ties into adherence. There are some times where people can't afford to take time off work."
>
> *Becky Kroger, UK, 21*

The correlation between economic empowerment and HIV vulnerability becomes important as a young person begins to be financially independent. Unemployment and economic vulnerability are important determinants of HIV vulnerability; for example unemployment and poverty can motivate young people to engage in selling sex.[18] Economic vulnerability may also prompt girls and young women to enter into relationships with older men who are economically able to provide for them or stay in violent relationships.[19] This increases their vulnerability to HIV as older men may have or have had multiple sexual partners already and age-related and gender-related power dynamics can make it extremely challenging for girls and young women to negotiate condom use with male partners.[20] Intimate partner violence has been shown to increase vulnerability to HIV by up to 50% in high prevalence settings.[21] Young adults living with HIV may face additional barriers related to health or stigma when joining the workforce. Creating pathways so that adolescents graduate from school with skills and experience to participate in the labour force can significantly affect HIV outcomes. A further adaptation of the *Stepping Stones* programme, *Stepping Stones Creating Futures*, seeks to encourage reflection and action among young people on their livelihoods through participatory activities, which aim to strengthen young people's livelihoods and economic power.[22]

> "Girls at university or colleges always want nice things and this tempts them to get older men who can afford such a lifestyle especially if their parents can not."
>
> *Allen Kyendikuwa, Uganda, 25*

CASE STUDY

Project REACH

One to One Children's Fund implements REACH (Re-engaging Adolescent and Child in HIV Treatment) across Cameroon, Democratic Republic of Congo, Ethiopia, Malawi and Uganda. The project engages young people (18–24) living with HIV as facility-based Peer Supporters to address a severe staff shortage in the HIV work force and promote the implementation of adolescent- and child-friendly services. The Peer Supporters receive training through a Community Health Worker Toolkit and ongoing guidance from their supervisor at the clinic. In 2016 the project was implemented in 18 clinics with three Peer Supporters in each.

The Peer Supporters have bridged a gap between adolescents and children living with HIV, healthcare workers and their local communities. Preliminary results demonstrate Peer Supporters are playing a critical role in expanding adolescent treatment access and addressing gaps in adolescent-friendly services.

The Peer Supporters have empowered young people to make active, informed choices that contribute to better life and health outcomes by relating to their fears and concerns, helping them navigate the healthcare system, motivating them to adhere to treatment and stay in care and serving as positive role models.

© One to One Children's Fund

Peer Supporter, Olive, provides adherence counselling.

CASE STUDY

Youth-friendly and rights-based services

AVERT has been in partnership with Phelisanang Bophelong (PB) since 2015, helping young people (aged 15-24 approximately) in Lesotho access youth-friendly HIV services and have open discussions with peers and parents about sexual health.

PB trains community-based volunteers to run youth groups linked to clinics, and runs a prison youth group and an LGBT group peer-led by an LGBT young person.

The focus of the LGBT group is to build knowledge of HIV, sexual health and human rights and provide a mutually supportive environment in a context where homosexuality is criminalised. The project focuses on creating an enabling environment by raising awareness of key stakeholders, such as government, police, and health workers, and by giving LGBT young people a voice to demand their rights and improve their experience at health services. The group uses WhatsApp to mobilise and support each other outside of youth group meetings, which has proved a useful way to share information safely and quickly.

Through sensitisation work with local stakeholders, including training on gender and sexual diversity, PB has enabled the LGBT group members to tell their stories and in just 15 months they are seeing a shift in the way they are being treated. Being part of the group has increased their confidence to demand their rights, access health services and built solidarity.

© Avert

Young people at 2016 Pride in Maseru, Lesotho

Conclusion

Adolescence and early adulthood is a formative period within a person's wider life. It is a period that needs to be treated distinctly because of the unique changes and challenges within it. What happens within childhood, adolescence and early adulthood impacts and sets the path for a person's entire adult life. The most effective strategies for working with adolescents and young people will evolve as a person grows up so programmes must be adaptive and driven by young people's experiences. Effective strategies for working with adolescents and young people will be grounded in listening to and responding to expressed needs, desires and ambitions.

KEY RESOURCES

- **Link Up Impact site**: www.aidsalliance.org/our-impact/link-up
- **Link Up Aiming High film**: www.youtube.com/watch?v=OpzIEeX-Hf0&feature=youtu.be
- **Avert summary page**: www.avert.org/professionals/hiv-social-issues/key-affected-populations/young-people#footnote13_7256a5q
- **Stepping Stones films**: https://vimeo.com/salamandertrust
- **Stepping Stones programmes**: www.steppingstonesefeedback.org
- **One to One Children's Fund, Project REACH**: www.onetoonechildrensfund.org/publications/reach-promising-practice
- **One to One Children's Fund, Toolkit for Community Health Workers**: www.onetoonechildrensfund.org/wp-content/uploads/2016/03/Community-Health-Worker-Toolkit-FINAL.pdf

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