

Positive health, prevention and dignity: Meeting the needs of young learners living with HIV

By Joanna Herat, Adam Garner, Dhianaraj Chetty and Fiona Samuels



Comprehensive sexuality education is critical for all young people, including those living with HIV. Individuals in this photo are not necessarily living with HIV. [Photo by UNAIDS/G.Pirozzi].

With improved access to care and treatment, young people living with HIV (YPLHIV), irrespective of their mode of infection, are living longer and healthier lives (Ferrand et al. 2009; UNICEF and WHO, 2010). However, as YPLHIV transition from adolescence to young adulthood, they often face a range of obstacles including treatment adherence, stigma and discrimination related to their positive status, and largely unmet sexual and reproductive health needs. While programmes and policies on younger children have proliferated in recent years, the needs of young people living with HIV have remained largely unmet.

Within the education sector, responses have largely focused on HIV prevention or awareness, with little attention paid to the existence, or needs and desires, of HIV-positive learners. Before treatment became

more widely available, the future of young people living with HIV was uncertain; this has now changed, meaning, responses and policies also need to change.

There are about 5.4 million YPLHIV worldwide (UNAIDS, 2010) with 45 per cent of new HIV infections occurring among 15-24-year-olds (WHO, 2009). It is very important to acknowledge that the term 'young people living with HIV' includes a large and diverse group of people who differ in terms of age, gender, maturity, development (physical, emotional and social); in the ways they contracted HIV and in their socio-economic status.

Young people living with HIV therefore face diverse and complex needs that will change as they move from childhood through adolescence to young adulthood.



Engaging young people in a meaningful way will enhance the quality and effectiveness of the education sector response. Individuals in this photo are not necessarily living with HIV. [Photo by UNAIDS/P. Viro].

Their experiences of life and of education are also diverse, differing according to a range of factors including cultural contexts, education systems and HIV prevalence. In some countries, the impact of HIV may be extensive and clearly visible; in other settings, it may be more concentrated among often already socially-marginalised populations (such as people who use drugs, men who have sex with men, transgender people and sex workers).

The education sector's role is intrinsic to the future of young people with HIV and schools have been identified as critical to influencing young people's health and well-being. HIV-positive young people may experience stigma and discrimination, forced disclosure, exclusion from school because of their status and other barriers to accessing, remaining and achieving in school.

To better articulate the responsibilities and opportunities of the educational sector in supporting these young people to realise their personal, social and academic potential, a partnership between United Nations Educational, Scientific and Cultural Organization (UNESCO) and the Global Network of People Living with HIV (GNP+) was created. The aim was to develop a better understanding of the challenges facing HIV-positive learners and to develop recommendations for education sector responses that will increase their access, retention and achievement in schools while also increasing its responsiveness to their needs and respecting human rights. The recommendations are centred on the GNP+

and UNAIDS Positive Health, Prevention and Dignity framework (GNP+ and UNAIDS, 2011) and also build on outputs from a number of recent regional and international consultations by GNP+, UNICEF and others. GNP+ and UNESCO conducted a literature review and, in December 2010, held a global consultation with representatives of YPLHIV,

ministries of education and health, NGOs, researchers and development partners. The findings of this work will be published in a forthcoming publication. This article outlines the issues identified by UNESCO and GNP+ and steps that can be taken by the education sector to support YPLHIV to complete their education and transition safely towards



productive, healthy adulthood.

The barriers YPLHIV face in schools are multiple but largely linked to the high levels of stigma and discrimination experienced from school staff and other students. Instances of forced disclosure or breaches of confidentiality are of major concern, and may result from 'procedures' during school admission, such as the need to disclose medical history, or by routine searches of personal belongings which may reveal the presence of ARVs. Disclosure may happen unintentionally (e.g. a learner misses school because of a medical appointment) or by intent either well-intentioned or malicious.

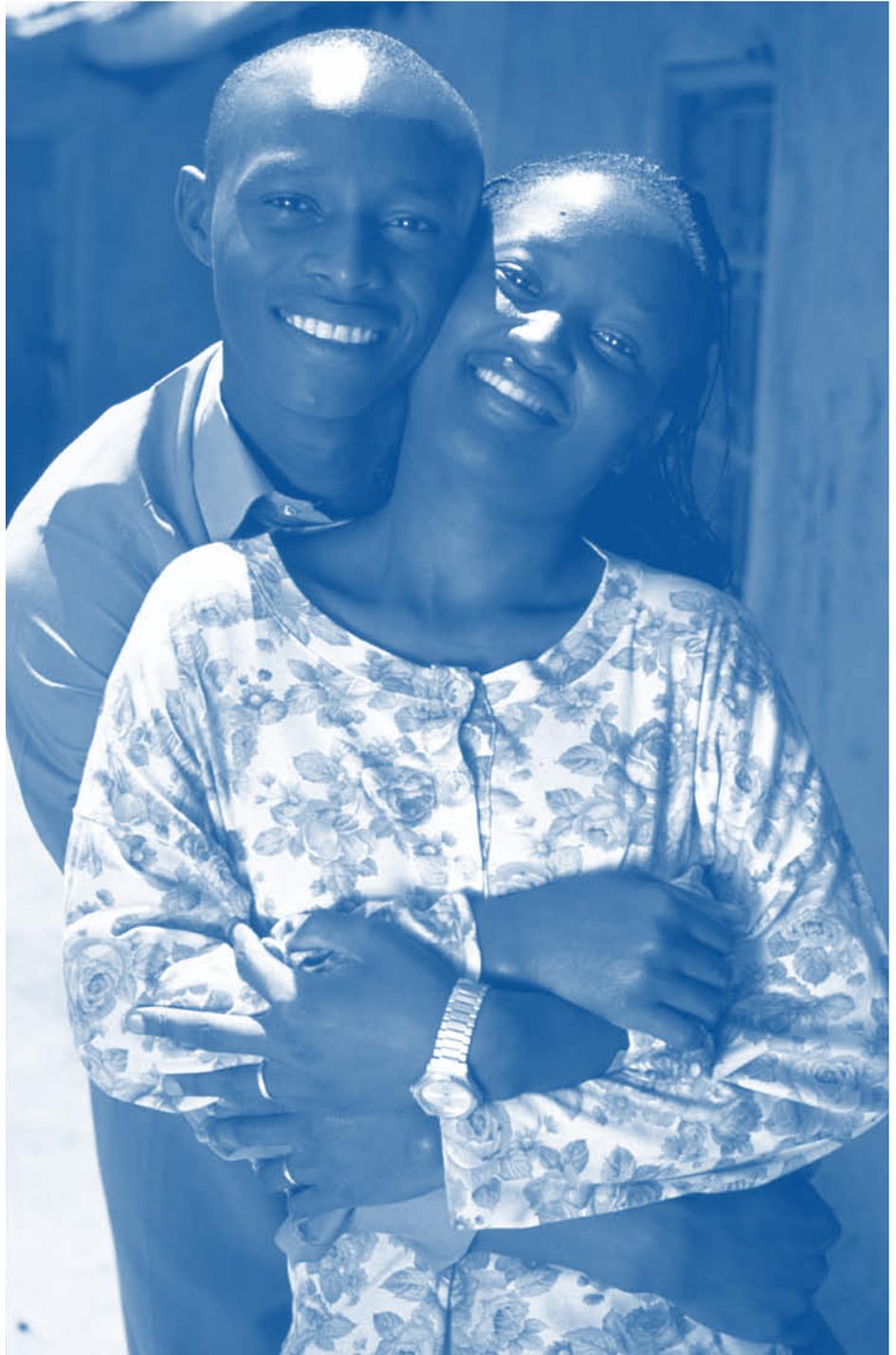
For many YPLHIV, balancing their treatment and other medical needs while in school is a challenge that can add a huge amount of stress to their lives as adolescents. This is often worsened by the learner's desire to maintain confidentiality about his or her HIV status while facing the pressure to disclose information related to their school absenteeism or performance. As a young adolescent living with HIV/AIDS put it, "Disclosure [in school] is a good thing and a bad thing. It's a good thing because I might be able to get support. But it's a bad thing because I have to know that I can really trust that teacher" (Female, Namibia, age 14).

As with all other adolescents, YPLHIV need accurate and non-stigmatising information about their sexual health; current HIV prevention efforts are not providing this information, and could actually add to stigma by using such phrases as 'anti-AIDS club'.

Recommendations

In order to make schools a safe learning environment for YPLHIV, UNESCO and GNP+ have developed the following recommendations through wide consultations:

1. The education sector, particularly at school level, must recognise the presence of HIV-positive learners and support actions that eliminate stigma and discrimination against them, and provide a safe and enabling environment for all learners;
2. The right to confidentiality is fundamental and must be protected if YPLHIV are to attain their education potential;
3. Disclosure is a personal choice and should be made in a supportive environment;
4. Efforts should be made to address stigma and discrimination against YPLHIV throughout the education sector; from the policy to the school level. Countries with low HIV-prevalence should not be neglected as school-based stigma and discrimination against YPLHIV could be just as serious and damaging;
5. The school community, including management, staff, learners and parents, needs to be 'HIV-literate' and sensitised on issues relating to prevention, care and treatment, and the rights of YPLHIV;
6. Many YPLHIV require support accessing and adhering to treatment; schools can be a key part of this support if flexible systems are adopted alongside linkages with health services;
7. Schools need to provide comprehensive, good quality and non-stigmatising sexuality education, to all young people – such education also has to address the needs of YPLHIV;
8. Care, support and protection measures must be tailored to the needs of adolescents – linkages between schools, health services and the community are critical;
9. The involvement of YPLHIV is critical and will ensure that the real issues facing HIV-positive learners can be understood and mitigated;
10. Education and health sectors need to collectively evaluate their responses to HIV and AIDS to better serve the needs of HIV-positive young people. They should strengthen their linkages at local levels.



Adolescence is a time of significant change which is made more complex for young people living with HIV. Individuals in this photo are not necessarily living with HIV.

[Photo by UNAIDS/G.Pirozzi]



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Some school-based programmes already exist to better address the needs of YPLHIV. For example, in southern Africa, HIV programmes such as the Botswana Baylor Clinic of Excellence, and Namibia-based Positive Vibes are working with teachers to raise understanding and provide training on stigma reduction. In Thailand, HIV prevention education in schools with younger learners has led to decreased stigma as learners understand more about modes of transmission and care for people living with HIV.

Transition from childhood to adulthood can be stressful for all young people with HIV-positive adolescents experiencing greater physical, psychological and social difficulties. The education sector can do a lot to mitigate this by ensuring that YPLHIV are able to access school and complete a full education. Education can create the conditions of understanding, respect and tolerance which contribute to reduced stigma and discrimination. These actions are critical to ensuring that every young person has equal access to a healthy and successful future. ■

Lessons learned

- Within the education sector, responses have largely focused on HIV prevention or awareness, with little attention paid to the existence, or needs and desires, of HIV-positive learners.
- The barriers YPLHIV face in schools are multiple but largely linked to the high levels of stigma and discrimination experienced from school staff and other students.
- For many YPLHIV, balancing their treatment and other medical needs while in school is a challenge that can add a huge amount of stress to their lives as adolescents.

References

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