



United Nations  
Educational, Scientific and  
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# Positive Learning: Meeting the needs of young people living with HIV (YPLHIV) in the education sector

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# Foreword

Ensuring the right of every child and young person to good quality education is at the heart of UNESCO's work. Ensuring the right of every person living with HIV to equitable access to health and social services and a life free from stigma and discrimination is equally at the heart of the work of the Global Network of People Living with HIV (GNP+). Today, young people with HIV around the world continue to be denied their right to good quality education because of fear, stigma, discrimination and a lack of understanding and support from schools and the community.

The shared commitments of UNESCO and GNP+ to human rights, and particularly the rights of young people, have been the driving force behind this collaboration and we are delighted to have brought our combined efforts to focus on the critical issue of young people living with HIV, and education. This publication is the first of its kind to analyse the educational experiences of young people living with HIV from a global perspective. It builds on work that both UNESCO and GNP+ have undertaken in recent years, and brings a new spirit of collaborative action and greater depth to ongoing efforts to support and meet the needs of positive young people. The recommendations are simple, practical and feasible, and are intended to give guidance to educators, policy- and decision-makers as well as activists and professionals working with young people.

Our common commitment is clear: HIV cannot be a barrier to learning. All young people, regardless of HIV status, must have access to quality education and an equal opportunity to realise their full potential. We all have a role to play in making this commitment a reality.

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# Acronyms

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ART</b>	Antiretroviral therapy
<b>ARV</b>	Antiretroviral
<b>CSE</b>	Comprehensive sexuality education
<b>CSO</b>	Civil society organisation
<b>EFA</b>	Education for All
<b>EMIS</b>	Education Management Information Systems
<b>GNP+</b>	Global Network of People Living with HIV
<b>HIV</b>	Human Immunodeficiency Virus
<b>IPPF</b>	International Planned Parenthood Federation
<b>MDG</b>	Millennium Development Goal
<b>MoE</b>	Ministry of Education
<b>MoH</b>	Ministry of Health
<b>MSM</b>	Men who have sex with men
<b>NFE</b>	Non-formal Education
<b>OVC</b>	Orphans and vulnerable children
<b>PHDP</b>	Positive Health, Dignity and Prevention
<b>PLHIV</b>	People living with HIV
<b>PMTCT</b>	Prevention of mother to child transmission
<b>PTA</b>	Parent Teacher Association
<b>SRHR</b>	Sexual and reproductive health and rights
<b>SRH</b>	Sexual and reproductive health
<b>STI</b>	Sexually Transmitted Infection
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNESCO</b>	United Nations Educational, Scientific and Cultural Organization
<b>UNICEF</b>	United Nations Children's Fund
<b>WHO</b>	World Health Organization
<b>YPLHIV</b>	Young people living with HIV

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# Executive Summary

There are an estimated 5.4 million young people living with HIV (YPLHIV) worldwide (UNAIDS, 2010) and 45% of new HIV infections occur among 15-24 year olds (WHO, 2009). While YPLHIV share certain needs in common with both younger children and older adults, conceptually and programmatically they represent a group whose needs are complex, shifting and, too often, unaddressed. It is also important to acknowledge that the term 'YPLHIV' includes a large and diverse group of people who differ in terms of age, gender, maturity, development (physical, emotional and social), ways of contracting HIV and socio-economic status<sup>1</sup>.

Thanks largely to improved access to ARV treatment and care, more children born with HIV are surviving, reaching adolescence and adulthood (Ferrand et al 2010). It is therefore necessary to broaden our understanding of the needs of young people living with HIV (YPLHIV) and go beyond the well-established focus upon infants, orphans and vulnerable children, to include a more sophisticated and nuanced response to the ways in which HIV affects a growing child and young person. As YPLHIV transition from childhood through adolescence to young adulthood, they face a range of needs, including treatment adherence, tackling stigma and discrimination, and sexual and reproductive health.

Meeting these needs requires a response that takes into account the evolving capacities of a young person, their changing health and education needs and the emerging responsibilities of adulthood. It also requires a response that is connected and

<sup>1</sup> In the context of this publication, *young people living with HIV* (YPLHIV) refers to a broad chronological age range (10-24), reflecting key conceptual and programmatic implications of the experience of children, adolescents and young people living with HIV.

coordinated across a range of services and institutions. This includes, but is not limited to, educational institutions, health services, child protection services, civil society and trade unions. In recent years, young people have been making increasing calls for greater attention to services that meet their needs, for greater protection and promotion of human rights (Mali Call to Action, 2011), and for better involvement of young people including those living with HIV, in the responses that affect them (GNP+, 2010).

The role of the education sector and the future of YPLHIV are intrinsically linked and schools have been identified as one key environment that impacts on young people's health and well-being. YPLHIV may experience stigma and discrimination, face forced disclosure, be excluded from school because of their status, and face other barriers to accessing, remaining and achieving in school.

The overall purpose of this publication - the result of a partnership between UNESCO and the Global Network of People Living with HIV (GNP+) - is to articulate the role and responsibilities of the education sector in supporting young people who are living with HIV to realise their personal, social and educational potential. The publication builds upon previous work including a literature review and consultations, the most recent of which was held in December 2010 in Paris including participants living with HIV from four continents. The contributions from the young people living with HIV in this consultation drew attention both to the diversity of needs and experiences that exist as well as the importance of creating spaces in which the voices of those most affected by HIV can be heard.

The barriers facing YPLHIV in their education are multiple but largely linked to the high levels of stigma and discrimination being experienced from school staff and other learners. Instances of forced disclosure or breaches of confidentiality are an issue of major concern and may be caused by standard procedures during school admissions, by accident (for example, a learner missing school because of a medical appointment) or by intent. For many YPLHIV, balancing their treatment and medical needs with their schooling needs is a challenge that can add considerable stress to the already-pressurised schooling and personal lives of an adolescent. This is often exacerbated by the learner's desire to maintain confidentiality about HIV status and the school's pressure to disclose information related to absenteeism or performance. As one young adolescent living with HIV 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."* As with all other adolescents, YPLHIV need readily available accurate and non-stigmatising information about their sexual and reproductive health; current HIV prevention efforts are not providing this, and may even add to stigma by phrases such as 'anti-AIDS club'.

In order to ensure that schools become supportive and conducive learning environments for YPLHIV, the following recommendations have been developed:

- The education sector must recognise the presence of HIV-positive learners and support actions that eliminate stigma and discrimination and provide a safe and enabling environment for all learners;



- The right to confidentiality is fundamental and must be protected if YPLHIV are to be able to reach their educational potential. Disclosure should be made a matter of personal choice, with a supportive environment for those wishing to disclose;
- Concerted and sustained efforts need to be made to tackle stigma and discrimination throughout the education sector from the policy level to the school. Countries with low and concentrated HIV-prevalence should not be neglected since the potential stigma and discrimination effects on YPLHIV in schools could be just as serious and damaging;
- The school community (including management, staff, learners and parents) needs to be 'HIV-literate' and sensitised to issues relating to prevention, care and treatment, as well as to the rights of YPLHIV;
- 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;
- Good quality, non-stigmatising, comprehensive sexuality education needs to be provided for all children and young people, including consideration of the particular needs of YPLHIV;
- Social protection measures must meet the needs of adolescents – linkages between schools, health services and the community are critical;
- The involvement of YPLHIV is critical and will ensure that the real issues facing HIV-positive learners can be understood and mitigated.

Some of these recommendations echo previous calls for improved services or reduced stigma, whilst others are new calls for an education-specific approach to the needs of young people living with HIV. Education and health sectors need to collectively evaluate their responses to HIV to better respond to the needs of YPLHIV, and to develop improved linkages between the sectors,

particularly at local level. Some programmes already exist to support schools (and the education sector more broadly) to improve their response to the HIV-positive learners in their care. For example, in southern Africa, some HIV programmes are working directly with teachers to raise understanding and provide training on stigma reduction. In Thailand, HIV prevention education in schools with younger learners is leading to lower levels of stigma as learners understand more about modes of transmission and care for people living with HIV.

The transition from childhood to adulthood can be a stressful period for all young people – adolescents living with HIV may experience greater physical, psychological and social difficulties during this period. There is much that the education sector can do 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 a critical part of ensuring that every young person has equal opportunity to enjoy a healthy and successful future.

There are an estimated 5.4 million young people living with HIV (YPLHIV) worldwide and 45% of new HIV infections occur among 15-24 year olds.

(UNAIDS, 2010; WHO, 2009)



# Introduction

Young people living with HIV have diverse, complex and changing needs.

There are an estimated 5.4 million YPLHIV worldwide (UNAIDS, 2010) and 45% of new HIV infections occur among 15-24 year olds (WHO, 2009). Young people living with HIV have diverse, complex and changing needs. While they may share certain needs in common with both younger children and older adults, there are specific issues that they face linked to their evolving capacity, their physical and emotional development and the transition from protected childhood into independent adulthood.

Young people living with HIV refers to a broad chronological age range from 10 to 24 years, reflecting key conceptual and programmatic implications of the experience of very young adolescents (10-14 years), older adolescents (14-18 years) and young adults (18-24 years) (UNICEF, 2011). Conceptually and programmatically, they represent a group whose needs are complex, shifting and, too often, unaddressed.

Meeting these needs requires a response that takes into account the evolving capacities of a young person, their changing health and education needs and the emerging responsibilities of adulthood. It also requires a response that is connected and coordinated across a range of services and institutions. This includes, but is not limited to, educational institutions, health services, child

protection services, civil society and trade unions. In recent years, young people have been making increasing calls for greater attention to services that meet their needs, for greater protection and promotion of human rights (Mali Call to Action, 2011), and for better involvement of young people, including those living with HIV, in the responses that affect them (GNP+, 2010a).

Given the importance and central role of education (both formal and non-formal) in the lives of children, adolescents and young people, the education sector represents a critical entry point for the mobilisation of such a response, and is therefore the primary intended audience for this publication.

In many countries, YPLHIV are less likely to be attending school than their peers (Beyeza-Kashesya, 2011). While educational institutions are clearly limited in what they can do to overcome structural barriers to access (such as poverty, household decisions about allocation of responsibilities, etc.), initiating effective action on stigma, discrimination, disclosure and support will certainly make them more accessible to YPLHIV and their families.

In recent years, young people have been making increasing calls for greater attention to services that meet their needs for greater protection and for promotion of human rights (Mali Call to Action,

2011 and UN Political Declaration on HIV/AIDS, 2011), and for better involvement of young people, including those living with HIV, in the responses that affect them (GNP+, 2010a). The importance of focusing on young people has been highlighted by programmatic guidance from UNAIDS in its Business Case on Young People (UNAIDS, 2010) and is now attaining greater global attention through advocacy at such events as the UN High Level Meeting on HIV held in New York in July 2011.

Throughout this publication, evidence, recommendations and best practice are highlighted for ministries of education, teacher training colleges, primary, secondary and tertiary institutions, vocational training and community schools. It is acknowledged that these represent only the formal institutions of the education sector, and for many young people, this does not reflect the educational realities in their lives. This publication does not seek to provide explicit recommendations and guidance for non-formal education programmes; however, it is expected that several of the cases of best practice can be applied and adapted to be relevant for other non-formal education programmes.

While it is important to recognise that the majority of YPLHIV globally are living in East and Southern Africa, there are thousands of young people outside of this region who are living with HIV and whose education may be equally adversely affected as those from the most highly affected regions. The evidence presented here, and the recommendations made are therefore global in scope. The publication attempts to address a range of epidemiological contexts and the role of education and partners

in those contexts. It also recognises the need for differentiated responses where the epidemic is concentrated amongst key populations.

Given the range of stakeholders required to be involved in an effective response, and the need for strong partnerships, this publication is intended for a wider audience that includes other key sectors (health and social welfare, in particular), stakeholders (such as civil society organisations, in particular networks of people living with HIV and young peoples' organisations) and, of course, donors and other development partners.

In order to address the gaps and challenges discussed in this publication, UNESCO and GNP+, based on consultation with stakeholders, have identified practical responses to be planned, implemented and scaled up by the education sector that:

- put young people living with HIV at the centre of the response;
- are relevant to differing epidemiological scenarios<sup>2</sup>;
- build upon and harmonise existing policy frameworks and principles (e.g., Education for All, Positive Health, Dignity and Prevention and previous work in this field);
- reflect good practice and are evidence-informed;
- are realistic and achievable;
- draw from the comparative strengths of other sectors.

2 i.e. Generalised, concentrated and low level HIV epidemics

## Education for All (EFA)

The Education for All movement was launched at the World Conference on Education for All in Jomtien in 1990. Since then, governments, non-governmental organizations, civil society, bilateral and multilateral donor agencies and the media have taken up the cause of providing basic education for all children, youth and adults. After the first decade of action, the first EFA assessment was conducted in 180 countries evaluating progress in basic education. The results showed increases in primary school enrolment, globally, but significant gaps in adult literacy. In April 2000 in Dakar, 164 governments together with partner institutions adopted a Framework for Action, "Education for All – Meeting our Collective Commitments" which focused on achieving six *Education for All* goals relating to:

- Expansion of early childhood care and education
- Achievement of universal primary education (UPE)
- Development of learning opportunities for youth and adults
- Spread of literacy
- Gender parity and gender equality in education
- Improvements in education quality

Education for All commits governments to achieving quality basic education for all by 2015. Future challenges for achieving EFA include reaching large numbers of children and young people affected by HIV and, among others, "how to help education overcome poverty and give millions of children a chance to realize their full potential".

Source: UNESCO. Retrieved 11 February 2011 from: [http://www.unesco.org/education/efa/ed\\_for\\_all/](http://www.unesco.org/education/efa/ed_for_all/)

## Positive Health, Dignity and Prevention

Positive Health, Dignity and Prevention is a new conceptual framework developed by the Global Network of People living with HIV (GNP+). Broader in scope than 'positive prevention', Positive Health, Dignity and Prevention offers a rights-based approach to supporting the health and wellbeing of people living with HIV. It states that the public health and human rights goal of preventing new HIV infections can only be achieved when the human, sexual, and reproductive rights of people living with HIV are protected and supported; when the broader health, dignity and security needs of people living with HIV are met; and when access to timely and uninterrupted treatment and care encourages greater uptake of voluntary counselling and testing.

Positive Health, Dignity and Prevention also emphasises that responsibility for HIV prevention should be shared, and that policies and programmes for people living with HIV should be designed and implemented with the meaningful involvement of people living with HIV. While the focus of much of the operational content is aimed at the health sector, Positive Health, Dignity and Prevention can

only be achieved with commitment from a range of actors.

The education sector has a clear responsibility to ensure that all young people have access to safe and conducive learning environments where they are able to maximize their educational potential. The purpose of education is to prepare young people to contribute actively and responsibly in society and to maximize their social and economic capital. This is no different for young people living with HIV. Moreover there are specific areas where learning environments can support young people living with HIV, not only through academic and social education, but also through treatment literacy, psychosocial support and promoting and protecting sexual and reproductive health rights. The opportunity for young people living with HIV to manage their own health and wellbeing depends upon equitable treatment and the ability to make and exercise informed decisions. The education sector has a considerable amount of influence over both of these aspects of young people's lives and must respond accordingly in their commitment to promote Positive Health, Dignity and Prevention.

(GNP+ and UNAIDS, 2011.)

## About this Publication

This publication is the result of a partnership between UNESCO and the Global Network of People Living with HIV (GNP+). It builds upon the respective work of these organisations in relation to supporting the ideals of Education for All and the role of the education sector in the global response to HIV (UNESCO)<sup>3</sup> and the Positive Health, Dignity and Prevention framework (GNP+).

The overall purpose is to better define the role and responsibilities of the education sector in supporting young people who are living with HIV (YPLHIV) to realise their personal, social and educational potential. UNESCO and GNP+ have looked at the issues from the perspective of the young person living with HIV, putting the individual and her/his needs at the centre of the debate. As such, this approach moves on from a more bio-medical or social protection approach found in much of the literature and work

focusing on orphans and vulnerable children, and young people, to date.

This publication will be of particular interest to policy-makers, planners and implementers in the fields of education, health and social protection in addition to teachers and others who work with young people. Young people living with HIV themselves can also use this publication to identify what they can expect from the education sector and provide support as appropriate. The evidence presented and the recommendations made are intended to provoke a shift in the way that the issues of young people living with HIV are perceived by the education sector, with a list of suggested actions that will reflect this new approach in practice.

On the basis of analysis of the available evidence concerning the needs of YPLHIV and the Education Sector response to date, including consultations with YPLHIV, a set of recommendations has been developed. These identify practical steps that will support YPLHIV to complete their education and transition safely towards productive, healthy adulthood.

3 Both in terms of UNESCO's own strategy on HIV, as well as its role as a cosponsor of UNAIDS (reflected in *UNAIDS Strategy 2011-15 Getting to Zero* and *We can empower young people to protect themselves from HIV. Joint Action for Results UNAIDS Outcome Framework: Business Case 2009-2011*)

The overall purpose is to better define the role and responsibilities of the education sector in supporting young people who are living with HIV (YPLHIV) to realise their personal, social and educational potential.



The publication also has an advocacy function in terms of summarising the available evidence base, highlighting key gaps and identifying specific measures to be promoted. Finally, the recommendations provide a measure against which progress can be assessed.

This publication is divided into two parts.

**Part 1** presents a summary of the available evidence concerning YPLHIV and education, building upon a number of relevant consultations, declarations and recommendations and from a UNESCO-commissioned desk review. It identifies and explores a number of key themes including: stigma and discrimination, disclosure, treatment and broader health concerns, psychosocial needs, educational support and sexual and reproductive health. In so doing, the publication highlights critical gaps and challenges for the education sector.

**Part 2** builds upon the outputs of this technical consultation and presents a set of **Recommendations**. These are practical actions, grounded in both existing policy frameworks and good practice that form the basis of effective responses to the needs and aspirations of YPLHIV. Certain key points for specific epidemiological settings are noted but all recommendations need to be adapted to take into account specific socio-economic and cultural characteristics. The respective and complementary roles of different sectors and partners are articulated.

As well as a set of general actions and cross-cutting issues, recommendations are presented thematically:

- Confidentiality and Disclosure
- Stigma and Discrimination
- Treatment and Care
- Sexual and Reproductive Health (SRH) and Rights
- Protection, Care and Support

Recommended resource materials and sources of support are also provided.

This publication is informed by the first-hand experience of YPLHIV and those working with them who participated in a UNESCO technical consultation meeting on the subject in Paris, 7-9 December 2010.

While the overall intention of this publication is to be practical, it has a potentially broad audience and is therefore not intended to be a 'how to' guide for managers or teachers. Such guidance may need to be developed in future together with resources for monitoring and evaluating progress in the education sector response to the needs of YPLHIV.

#### Understanding Human Rights in relation to HIV and AIDS

“The relationship between HIV and human rights is profound. Vulnerability to HIV infection and to its impact feeds on violations of human rights, including discrimination against women and violations which create and sustain poverty. In turn, HIV begets human rights violations, such as further discrimination, and violence. During the decade [to 2006], the role of human rights in responding to the epidemic and in dealing with its effects has become evermore clear. The international human rights system explicitly recognized HIV status as a prohibited ground of discrimination. At the same time, the impact of HIV highlighted the inequities and vulnerabilities leading to increased rates of infection among women, children, the poor and marginalized groups, and thereby contributed to a renewed focus on economic, social and cultural rights. In this regard, the content of the right to health has been increasingly defined and now explicitly includes the availability and accessibility of HIV prevention, treatment, care and support for children and adults. Either through legislation or litigation, many countries have recognized that their people have the right to HIV treatment as a part of their human rights, confirming that economic, social and cultural rights are justiciable.”

Excerpted from : UNAIDS and UNHCR. 2006

# Part 1: The Evidence Base

*“When I found out I was HIV positive I started taking ARVs. I wondered where I had got the virus from, as I am still young. I was then told that I was born with the virus. My mother and father died of it.”*

*“When I was born I was HIV positive. Now I’m on second line drugs. The challenges I face on drugs is that the drugs are big. I always take them because I care most about my health but I always feel pain here in my throat... The other challenges I face is when you are with friends. Most of the time I get to school before 6:30, because that’s the time I take my drugs. Most of the people here see me getting up at 6:30 and ask me why. My answer is that it’s none of their business.”*

It is too easy for governments and NGOs to respond to the needs of PLHIV – thinking that they are also addressing YPLHIV needs.

<http://www.voicesofyouth.org/en/sections/hiv-and-aids/posts/diversity-of-yplhiv-community>

# HIV, Education and Young People

## Young People Living with HIV: Who are we?

In the context of education and the HIV epidemic, young people tend to be discussed primarily in terms of education for HIV *prevention*. HIV prevention is undoubtedly important. However, there is a risk in adopting such a narrow focus: obscuring the fact that approximately 5 million young people (aged 15-24) around the world are living with HIV together with another 2.5 million children below the age of 15, 90% of whom live in sub-Saharan Africa (UNAIDS, 2010). According to WHO (2009), 45% of new HIV infections globally occur among 15-24 year olds. Of the 6000 new HIV infections that occurred daily during 2009, 1000 were among children aged below 15, and 2500 among those aged 15-24. In sub-Saharan Africa, young women are *eight* times more likely to be living with HIV than their male peers.

With earlier and more accurate diagnosis of HIV, together with increased availability and effectiveness of antiretroviral therapy (ART), 28% of eligible children are now accessing treatment (WHO, 2010) and the implications of this for attendance and achievement at school are becoming apparent. More children born with HIV are surviving, reaching adolescence and adulthood. It is therefore necessary to broaden conceptualisations of the needs of

YPLHIV. This should go beyond the established focus upon infants, orphans and vulnerable children, to include a more sophisticated and nuanced understanding of the ways in which HIV affects the growing child and young person. Consideration also needs to be given to the implications of this expanded conceptualisation in terms of 'joining up' the links between different age-related services in order to ensure continuity as individuals transition from one group (e.g. infants) to another (e.g. children).

In this publication, the term *young people living with HIV* refers to a specific age group, 10-24 years, which is sometimes broken down further into very young adolescents, older adolescents and young adults. The needs of younger children including those living with HIV have been extensively analysed in other literature and are not included here. The broad age-range identified reflects a conscious effort to highlight key conceptual and programmatic challenges involved in responding to the needs of older children, adolescents and young adults who are all living with HIV, making their way through the transitions that map the path towards adulthood. It also acknowledges the reality that in many regions of the world young people

are often attending secondary school well into their twenties, despite the legal age of majority, and the end of childhood, often being 18 years. While YPLHIV share certain needs in common with both younger children and older adults, conceptually and programmatically, essentially they represent a *new* group whose needs are complex, shifting, and, too often, unaddressed. It is important to acknowledge that the term 'YPLHIV' includes a large and diverse group of people who differ in terms of age, maturity and development (physical, emotional and social). Other critical distinctions among YPLHIV relate to gender, sexual diversity, socio-economic status and culture.

The transition from childhood to adulthood is a complex process of physical and emotional changes coupled with psychological and intellectual development. Young people are experiencing 'evolving capacities', which can be characterised as moving from a stage of dependence to independence, or from a phase of protection to one of autonomy. This can be seen in terms of familial support, financial capacity, personal and legal responsibility, the ability to have children, engage in long-term relationships or get married, and, finally, the expectations that

**FIGURE 1: Estimated number of young people aged 15–24 living with HIV, 2009**

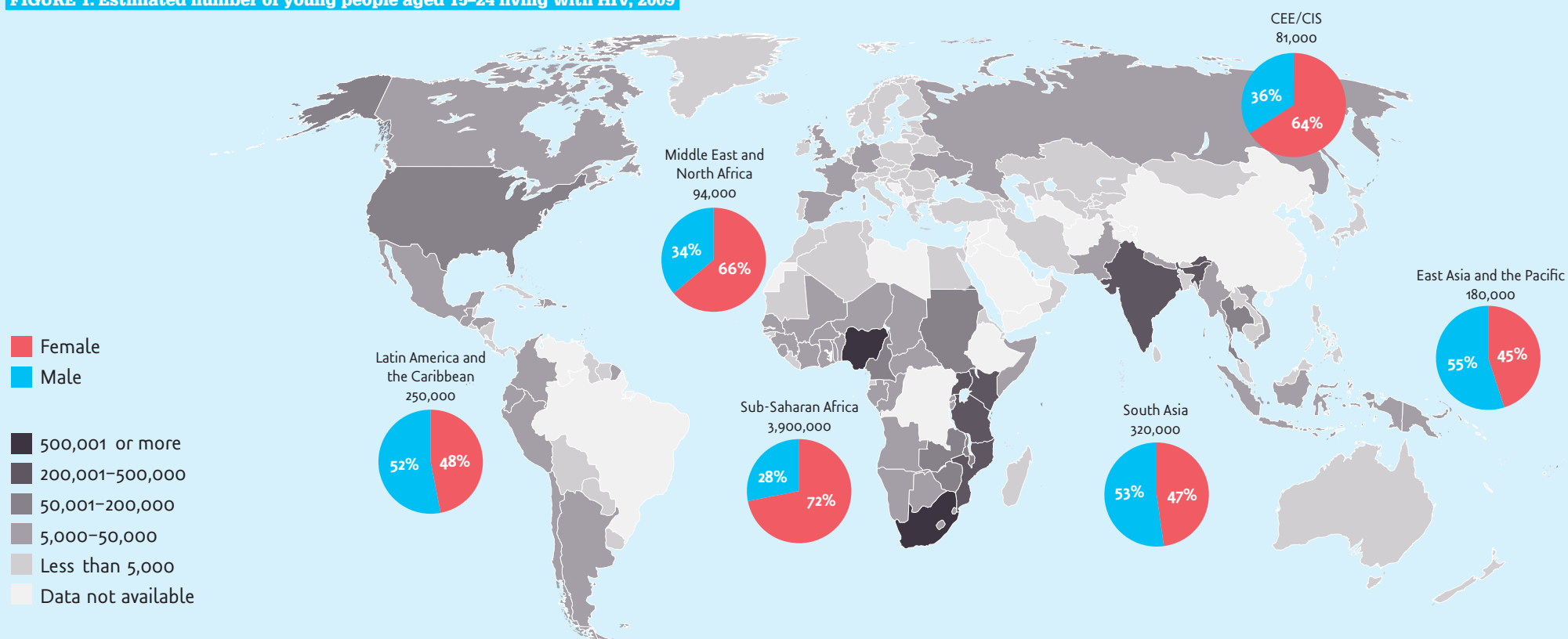


Figure taken from *Opportunity in Crisis: Preventing HIV from early adolescence to young adulthood* UNICEF, June 2011, with permission.  
Data Source: UNAIDS, unpublished estimates, 2010

Note: The map is stylized and not to scale. It does not reflect a position on the part of UNICEF on the legal status of any country or territory or the delimitation of any frontiers. The dotted line represents approximately the Line of Control in Jammu and Kashmir agreed upon by India and Pakistan. The final status of Jammu and Kashmir has not yet been agreed upon by the Parties.

the surrounding community have of an individual as an adult. For all young people, this period of evolution and change can be stressful, and also liberating. For young people living with HIV, these stresses and liberation come in addition to the medical and psycho-social challenges of managing a chronic health condition. The practical issues such as adhering to ARV

treatment or transitioning from paediatric to adult health care are felt in addition to the social challenges of engaging in romantic and sexual relationships and dealing with pervasive stigma and discrimination.

#### **Investing in the Future: the rationale for focusing on adolescents**

Adolescence – the second decade of life – is a period of great physical and psychological change. It also rings changes in social interactions and relationships. It is a time of opportunity, but also of risk. Adolescence is the window of opportunity to set the stage for a healthy and productive adulthood and to reduce the likelihood of health problems in the years to come. Yet it can entail risk, as a period when health problems that have serious immediate consequences can occur or when problem behaviours that have serious adverse effects on health in the future can be initiated. There are sound public health, economic and human rights reasons for investing in the health and development of adolescents.” Source: WHO (2010)



*Low HIV prevalence = low priority. If there is a very low HIV prevalence, HIV gets given very low priority. Young people living with HIV are almost invisible and our needs are given low priority*

#### **Diversity among YPLHIV**

Being a young person living with HIV does not mean that we necessarily share the same needs and desires as each other or our older counterparts. Beyond our age-specific diverse needs YPLHIV represent diversity in our sexuality, culture, religion, gender and age... We are not a homogenous group, nor can we be treated as one.

Source: GNP+, 2010

The scale and distribution of the epidemic will affect the experience of *living with HIV* for individuals in different settings. The difference in access to health services, poverty, community support and levels of stigma has been shown to vary greatly between urban and rural areas. Those in rural areas experience increased levels of hardship and difficulty, in particular with less access to ARV treatment, longer distances to travel for any health treatment and more limited

nutritional support programmes (UNESCO, 2008e).

Some YPLHIV live in communities and countries where the impact of the HIV epidemic is extensive and clearly visible, while others come from places where prevalence is generally low or else confined to particular (often already socially marginalised) affected populations (such as people who use drugs, men who have sex with men, transgender people and sex workers).

The HIV burden within any country may also vary greatly between the sexes. This is particularly true for the age group with which this report is concerned where there is an increasing feminisation of the epidemic in many regions. Young women aged 15 – 24 make up more than 60% of all young people living with HIV globally but this is driven by the huge disparity in sub-Saharan Africa where the figure is 72%.

The transition from child to adult is particularly perilous for young women. In terms of their sexual and reproductive health, globally, 11% of adolescent girls have had sex before age 15 (ranging from 8% in south Asia to 22% in Latin America) and between 1%-21% of women experience sexual abuse before age 15. The most common place where young women and girls experience sexual coercion and harassment is in school. The experiences of young women living with HIV may differ from their male counterparts as concerns about puberty, menstruation and their sexual and reproductive health become more urgent. In particular, many young women

living with HIV feel concern and confusion with regards to the possibility of getting pregnant and having healthy children. (UNICEF, 2011).

Irrespective of the prevalence in the country, all national governments have a responsibility to understand the dynamics of the epidemic in their own country. This may mean that within a generalised epidemic scenario, there are concentrations of higher prevalence among certain populations. In many cases, the young people from these key populations are disproportionately affected by HIV. Understanding the nuances and changes in the epidemiology within the country is a critical first step to knowing what kind of scenarios YPLHIV are living and how to provide adequate and appropriate support. This is true for the education sector as for the health sector and other sectors and services.

Some YPLHIV will have been living with HIV since birth or early infancy while others will have acquired HIV at a later stage in life, most commonly through unprotected sex (which may be consensual, or as a result of rape or child abuse), or in some settings, through injecting drug use. Many young people living with HIV are *unaware* of their status, either because they have not been tested, or else because families or carers have not yet disclosed to them. The reasons for non-disclosure are varied but include the desire to protect a child from stigma, to preserve a parent's dignity by avoiding talking to the child about a sexually transmitted infection

and in some cases to maintain a sense of innocent ignorance.

At the country level, low HIV prevalence may be interpreted as a sign that little needs to be done about HIV, or those people living with HIV. This is particularly true in countries where health education and social welfare services are well-established and functioning. However, there are nonetheless people living with HIV in that country, or area, who have specific needs. If the epidemic is concentrated among vulnerable populations, it is likely that the same factors that contribute to vulnerability to HIV in the first place will also make people reluctant to access services. For example, a young woman engaged in sex work may have experienced excessive stigma or be too poor to access health services. As a result, her needs may be invisible to service providers. Young people may find that they are invisible within an HIV response that primarily focusses on adults, and does not reach out to adolescents in an appropriate way. At the personal level, low prevalence can have profound impact in terms of isolation and the public (in) visibility of people living with HIV. When low prevalence is also reflected in low priority, by default, responsibility for raising the issue of HIV falls to those most affected (i.e. PLHIV).

# Education for All: Access, Retention and Achievement

## Understanding the right to education

Education is a basic human right for children and young people that provides knowledge and skills, increases life opportunities and supports social and psychological development (UNESCO, 2008a; UNESCO, 2008b; USAID & Catholic Relief Services, 2008.). The global commitment to ensuring that all children have access to complete, free and compulsory education by 2015 is reflected in both *Education for All* (EFA) and the *Millennium Development Goals* (MDGs). *Education for All* promotes the importance of quality basic education for children, young people and adults. It highlights the central role of education in enabling individuals, communities and nations to respond effectively to the challenges of the HIV epidemic. To meet the EFA goals, education has to be inclusive (UNESCO, 2010b) and a key pillar of inclusion is the Convention against Discrimination in Education adopted by UNESCO in 1960. The convention not only aims to eliminate discrimination in Education, but also promote the adoption of measures that promote equality of opportunity and treatment, ideals which are of particular relevance to YPLHIV.

Despite these commitments, more than 70 million eligible children are *not* enrolled in school and many of those who are enrolled do not attend on a regular basis, with only two out of every three children completing five years of education (UNESCO, 2008a). Almost

three-quarters (70%) of all children who are not enrolled in school live in Sub-Saharan Africa and South or West Asia (UNESCO, 2011). Access and retention are even lower at secondary and tertiary levels.

## HIV and Education: impact on access, retention and achievement

Education plays a pivotal role in the lives of all children and young people, the majority of whom spend a considerable amount of time in school and other educational settings. Educational institutions also have potentially important links to local communities and to key services and resources. Moreover, schools have important social functions in terms of promoting equality and inclusion. The education sector (including non-formal education for those not attending school) is therefore an important focal point for mobilising effective responses to the needs of YPLHIV and modelling appropriate attitudes towards learners within and beyond educational settings. Working to address the needs of HIV-positive learners is part and parcel of the programme of mainstreaming HIV into the education sector.

There are two potential ways in which HIV can impact upon the educational experience of young people living with HIV. The first, and relatively unexplored, concerns the effects of the virus (and the drugs used in its treatment) upon cognitive development and capacity. The second relates

to the broader physical, psychological and social effects of living with HIV and the range of needs that these create (e.g. in relation to treatment, disclosure, sexual relationships).

A challenge lies in responding to the specific needs of YPLHIV without drawing unwanted attention to individual members of the school community or creating or reinforcing inequalities with peers who may be only marginally better off (Mamdani et al, 2008; Olson, R. personal communication October 2010).

In sub-Saharan Africa, where entrenched poverty and the impact of the HIV epidemic

## Harnessing the value of education in the response to HIV and AIDS

Good quality education that focuses on empowerment within safe and protective environments and that creates a circle of support within the community can have a sustained impact on reducing vulnerability and behaviours that create, increase or perpetuate risk. It can do so by: providing information and skills and developing values that allow young people to make healthy decisions about their lives; increasing young people's connectedness and security; and giving them the possibility to make independent choices and to be economically productive.

Source: UNAIDS IATT, 2009.

## Eastern Europe Adult-focused interventions neglect the needs of YPLHIV

Many adolescents and young people in Eastern Europe and Central Asia experience overlapping risks and vulnerabilities in relation to HIV. For example, a 2008 survey of 300 young female sex workers in Romania found that 21% were under the age of 18, almost a quarter had never been enrolled in school, and a disproportionate number (27%) were from the Roma ethnic group. In Bucharest, 44% of surveyed sex workers reported injecting drug use. While younger respondents in the study (under 18) were less likely to be injecting drug users, they were also less likely to use condoms with commercial or casual partners, less likely to have been tested for HIV and less knowledgeable about HIV transmission. In Bosnia and Herzegovina, half of injecting drug users surveyed in Sarajevo reported having had sex for the first time before the age of 15. In 25 cities in Ukraine, 31 per cent of girls aged 15–19 selling sex reported starting to sell sex between the ages of 12 and 15 years. A study of 288 young Roma people in Montenegro indicated extremely low school enrolment rates, especially among girls: 44% of the young women compared to 22.3% of their male peers had *never* been to school. Half were married and 83.3% had been pregnant. Knowledge of HIV transmission was generally poor but males were significantly better informed than females.

Source: UNICEF, 2010a.



### Gender-related benefits of education for young women living with HIV

Girls and young women with post-primary education are five times more likely than their illiterate peers to be educated about HIV and AIDS. This is critical in terms of enabling young women living with HIV to understand their condition and treatment, as well as considering reproductive health options and choices, including PMTCT.

In Malawi, 27% of women with no education know that the risk of HIV transmission can be reduced if the mother takes treatment during pregnancy. For women with secondary education, this rises to 59%.

Nor are the benefits of education confined to HIV. Empowering girls and the young through education is a key factor in reducing risks to maternal health: those with higher levels of education are more likely to delay and space their pregnancies, and to seek health care and support.

Source: UNESCO, 2010a.

are most profound, education systems are already stretched in terms of their capacity to deliver basic services with inadequate human and material resources. The impact of the HIV epidemic exacerbates existing problems for schools in terms of access, retention and achievement. A strategic response has been mobilised at regional and sub-regional levels, for example, through initiatives such as *Schools as Centres of Care and Support (SCCS)* and *Circles of Support and Learning Plus* that support ministries of education and schools to address health and poverty-related barriers to teaching and learning.<sup>4</sup>

In heavily affected countries, HIV is diminishing the quality of education through absenteeism and loss of experienced staff, including teachers, managers and planners (Robson & Kanyata, 2007; UNESCO, 2008b; USAID & Catholic Relief Services, 2008; World Bank & UNICEF, 2004). For example, across sub-Saharan Africa, more than 260,000 teachers are believed to have died of HIV-related illnesses in the last decade (Mulkeen and Chen, 2008) and HIV is estimated to account for up to 77% of teacher absenteeism in high prevalence countries.

In several countries, significant numbers of teachers are living with HIV and carrying out their professional responsibilities while coping with concerns about their own employment, health and families. While such personal experience

<sup>4</sup> See for example the work of MIET: <http://www.miet.co.za/>

*could* make HIV-positive teachers valuable role-models and supporters for YPLHIV, breaches of confidentiality, stigma and discrimination within the workplace and in local communities, act as strong deterrents to disclosure for staff, as for learners. The toll of HIV upon teachers in highly-affected countries, in turn, affects learners' quality of education (Robson & Kanyata, 2007) through increasingly larger class sizes, led by teachers who are often younger, inadequately trained, with little supervised teaching experience (Mugimu and Nabadda, 2010).

The HIV epidemic constrains educational access, retention and achievement and compounds pre-existing gender inequalities: YPLHIV are less likely than their peers to be enrolled in school or to attend regularly, and are more likely to perform poorly or to drop out (Buzducea et al, 2010; WHO, 2009; Robson & Kanyata, 2007; UNESCO, 2008a). In Kenya, for example, it is estimated that almost 60% of YPLHIV are not attending school (H. Birungi personal communication, November 2010), while a study in Romania (Buzducea et al, 2010) concludes that 40% of YPLHIV are not in school, compared to the national average of 25%.

Policy-makers, programmers and planners are urged to '*know your epidemic*' in order to plan appropriate, relevant responses. Lack of robust, HIV-related data collection and analysis at both school and ministry level, masks the extent of the impact of the epidemic upon the sector, implicitly perpetuating the assumption that learners are HIV negative, and hindering

the development of appropriate responses. In addition to age and sex disaggregated epidemiological data, it is important to gather HIV-sensitive data concerning enrolment, retention, and performance in order to assist in the identification of children and young people in particular need of support (Bialobrzeska et al, 2009; UNESCO 2008e).

In some countries, while there may be no major barrier to educational access on the basis on HIV status, poverty does constitute a significant barrier and its effects are amplified for HIV-affected households. Moreover, HIV impacts both directly and indirectly upon retention and achievement at school. Illness and medical treatment, as well as HIV-related changes in living arrangements, may require regular absence from school that cumulatively reduces academic performance, especially in the absence of provision to make up for missed education. In Zimbabwe, YPLHIV who have returned to schooling after a significant absence for ill health find themselves having missed several semesters from the curriculum and unable to achieve the same exam results as their peers (Judith Sherman, UNICEF. Personal communication, December 2010). The challenges for both learners and educators in this scenario are multi-fold and impact on motivation as well as academic achievement. Reluctance to disclose HIV status because of actual or perceived stigma may lead to HIV-specific learning needs being overlooked and individual potential unfulfilled.

HIV is also deepening existing gender inequalities in educational access. Young women who are living with HIV face even greater barriers than their peers in accessing education (UNICEF 2004; Commission on HIV/AIDS and Governance in Africa, 2004). Girls comprise 57% of those not enrolled in schools (UNESCO, 2007; UNESCO, 2008a) and are less likely than their male peers to attend secondary or tertiary education. Girls'

access to education is constrained by factors such as low value accorded to female education, domestic responsibilities, lack of funds, unsafe learning environments, and early marriage and or pregnancy. For girls living with HIV these factors can be exacerbated by their sero-status, especially for those whose household is affected by HIV and where financial insecurity or the burden of care falls disproportionately on them.

The following sections explore some of the particular challenges faced in educational settings by young people who are living with HIV. Many of these are persistent problems over many years which now take on new dimensions for young people as they transition from adolescence to adulthood.

## Increasing our Understanding: Recent Research and Consultations on Young People Living with HIV, their Health and Education

Responding to the needs of children affected by AIDS has been an established priority in the global HIV response over the past 15 years. Programmes have largely focused on prevention of mother to child transmission (PMTCT), paediatric treatment and care, social protection and community support for orphans or vulnerable children (OVC) (UNICEF 2010b). Many programmes have focussed specifically on infants and younger children, particularly before increases in access to ARV treatment. Whilst the term OVC includes those up to 18 years of age, the specific needs of older children and those transitioning into adulthood have not been analysed to the same extent.

As a result of this gap, a number of national, regional and international meetings and consultations on children and YPLHIV have taken

place over in recent years. Two consultations have been held on *Service Provision for Adolescents Living with HIV* (Malawi 2006 and Uganda 2010), both having a major focus on health needs in East and Southern Africa. During these consultations it was noted that:

High levels of stigma and discrimination in health facilities, communities, schools and families have left millions of adolescents and their families and partners without essential treatment, care, support and prevention leading to high levels of unnecessary morbidity and mortality. (UNICEF, 2010c)

A set of recommended actions have come from both consultations. These highlight the need for services delivered across different sectors (e.g. health, education and social), better understanding and protocols around disclosure

and a reduction in all forms of stigma and discrimination. Education was noted as a key player in supporting YPLHIV and in facilitating access to care and services.

In 2007, UNESCO convened a technical consultation in Botswana on *School-centred HIV and AIDS care and support in Southern Africa*. Participants identified five broad and interrelated actions, as relevant now as they were in 2007, that should be in place in order to provide a comprehensive response to HIV:

- Develop a caring school environment;
- Develop schools as centres for integrated service delivery;
- Create programmes that are child-centred;
- Build on existing services;
- Involve communities.

...All schools should create a supportive environment that puts the interests of the child first, treats all children equally and promotes inclusion, including of HIV-infected and affected children.

(UNESCO 2008a)



This consultation was followed up by research into the experiences and needs of HIV-positive learners in Tanzania and Namibia. The findings show that HIV-positive children have special needs and that “as a consequence of the infection they are more likely than other children to be orphaned, malnourished and deprived of an education.” (UNESCO, 2008e). The research highlights the following major challenges: Poverty, Urban/Rural divide, Stigma and Discrimination, Home Environment, Orphans and Vulnerable Children. Recommendations for action by the education sector focus on:

- Improved implementation and monitoring of policy, regulatory frameworks and guidelines;
- Strengthening the role of HIV and AIDS Management Units at MoE level;
- Reduction of stigma and discrimination
- Strengthening school staff capacity in counselling, and improving linkages with HIV testing and treatment;
- Improved curriculum content and information on HIV and sexual and reproductive health;
- Improved nutrition;
- Maximising multisectoral partnerships;
- Mitigating the effects of poverty.

GNP+, in partnership with the World AIDS Campaign, facilitated a global consultation by and for young people living with HIV in Amsterdam, June 2010. Participants identified key actions that need to be implemented in order

to make schools supportive, conducive learning environments for young people living with HIV (GNP+, 2010c):

- The right to confidentiality must be respected and disclosure made a matter of personal choice;
- The school community (including management, staff, learners and parents) needs to be ‘HIV-literate’ and sensitised to issues relating to prevention, care and treatment, as well as to the rights of PLHIV;
- Concerted and sustained efforts need to be made to tackle stigma and discrimination in school settings;
- Good quality, non-stigmatising, comprehensive sexuality education needs to be provided for all children and young people and this should include consideration of the particular needs and experiences of YPLHIV;
- Schools have a critical role to play in terms of promoting inclusion and equality, for example in relation to gender and sexual diversity.

In December 2010, building on the outputs of these previous consultations, UNESCO convened a Technical Consultation, in partnership with GNP+ and IPPF, on the education sector’s Response to the Needs of YPLHIV. The meeting brought together representatives of YPLHIV, ministries of health and education, NGOs and

researchers. The consultation had a global focus and included contributions from Asia, Latin America, Europe (Eastern and Western), Central Asia and Africa. The need for this consultation was informed by evidence from previous UNESCO research and reports (UNESCO 2008c and 2008e) that highlight ongoing failures in attempts to address the needs of YPLHIV, even where policies exist. The 2010 consultation used this evidence, which comes from east and southern Africa, to stimulate debate on the evolving needs of young people, and to hear for the first time the issues facing young people in the education sector outside of sub-Saharan Africa.

The consultation process drew upon the personal and programmatic experience of participants, through presentations, structured discussions in small groups and plenary sessions. The focus throughout was upon the identification of the key actions that need to be taken for young people living with HIV to be able realise their educational potential.

Three key thematic areas formed the basis of the first part of the consultation. These addressed:

- Individual needs of YPLHIV: personal, health and educational;
- Creating a conducive learning environment for YPLHIV: the role of teachers, schools and other learners;
- Schools within a broader setting: how does the wider community respond?

During the consultation, the education sector generally, and schools in particular, were identified as key environments that impact up on young people’s health and well-being. The critical connection between education and other sectors and spheres (such as health, social support, community and family) was regularly highlighted, and potential areas for collaboration identified. The contributions and recommendations articulated by participants at this meeting, together with a review of the available evidence, inform this publication and form the basis of Part 2.

The evidence from research, programmes, advocacy and consultation leads GNP+ and UNESCO to conclude that there is a need for a fresh look at the way in which YPLHIV are treated and their needs understood with in the education sector, starting with the questions: What can we do better? What is not working? What can be done to create a dynamic response that reflects the new realities and needs?

# Young & Living with HIV: Key Issues and Challenges

Rooted within the broad frameworks of *Education for All* and *Positive Health, Prevention and Dignity*, this section identifies key issues and challenges faced by YPLHIV in realising their educational, social and personal potential<sup>5</sup>. It goes on to explore how the education sector can best respond to the educational needs and overall aspirations of YPLHIV. In so doing, it provides the rationale for the second part of the publication, which sets out specific, concrete actions that can be undertaken by the education sector, working collaboratively with other sectors and civil society in helping YPLHIV to achieve their aspirations.

Many of the issues visited here have been explored before, yet the problems persist in the education sector. It is clear that a new approach and stronger action are required; it is necessary to pause to reflect on what should be done, and how to move the response forward in a way that puts the needs of YPLHIV at its heart. In addition, some new issues are emerging, such as long-term HIV treatment support and sexual and reproductive health needs, and this publication is intended to alert policy-makers and practitioners in education of these changes and engage the sector to make schools accessible and supportive places for YPLHIV to achieve their potential.

The following pages present the major issues as perceived by YPLHIV and those working in education, health and social care to support them. These issues are: stigma and discrimination; disclosure; health needs including ARV treatment; psycho-social needs; education needs; and sexual and reproductive health.

<sup>5</sup> This section is informed by a review of recent literature and consultation with YPLHIV themselves, together with representatives of the education and health sectors and civil society.

## **'I want to be heard': Putting young people at the centre of the response**

The 2010 Paris technical consultation included participants with a range of expertise, including young men and women living with HIV from four different continents. Their contributions drew attention to the diversity of needs and experiences among positive learners as well as to the value of their involvement in responding to these needs. YPLHIV have a critical role to play at all levels of the education sector's response to supporting positive learners.

*Ignorance is such that if I come to a school and say 'hello I'm HIV positive' – everyone will run out.*

*I think we, the YPLHIV, should give our ideas on what we feel needs to be done, then take it to the ministry of education and ministry of health ... because it involves us as people living with HIV.*

## HIV-related Stigma and Discrimination

These quotes, from participants at the 2010 Paris Consultation, articulate critical dimensions of HIV-related stigma and discrimination as faced by YPLHIV. Pervasive and inextricable linking of HIV and blame, which means that, in addition to the physical burden of infection, individuals have to carry the burden of self-stigma. In a study in Namibia and Tanzania (UNESCO, 2008e), every HIV-positive learner interviewed cited personal and continuing experience of stigma, and emphasised greater safety in silence about their status.

The reality of stigma and discrimination needs to be acknowledged and addressed accordingly.

It is unacceptable to place responsibility for challenging prejudice and championing rights upon individual YPLHIV. Education institutions and their managers have responsibility for ensuring that school environments are supportive and protective of privacy and dignity for *all* young people, including those who are living with HIV.

Third, as indicated above, lower HIV prevalence can actually mean *more* stigma and discrimination. Therefore, small numbers should not be mistaken for an insignificant problem or permission to do nothing.

### Namibia

#### **Positive Vibes: Children should be seen and heard**

Positive Vibes' *Children's Voices* programme in Namibia promotes the voices of vulnerable children, including those affected by HIV, creating an environment in which children's perspectives and participation are respected.

Child-centred, participatory communication techniques and media are used in a structured process with children (while a parallel process is undertaken with relevant adults, including parents, carers and teachers to help them be more responsive) in order to equip them with the confidence and skills to make themselves heard. Three key approaches are involved:

**Disclosure** – to assist parents to break the silence surrounding their own and their child's status

**Foundation** – to help children explore their lives in relation to HIV and to identify and express their related concerns

**Children's participatory media** – to help children to use creative media to share their stories and concerns with wider audiences.

The programme is conducted in conjunction with organisations working in the field of children's rights, with a view to enabling children to participate more meaningfully in the promotion of a child rights agenda.

Source: [http://www.positivevibes.org/01\\_Children's%20Voices\\_In%20detail.pdf](http://www.positivevibes.org/01_Children's%20Voices_In%20detail.pdf)

*Their ignorance is killing me because HIV is not and was never a reality to them.*

*As well as the biological transmission of HIV there is also the social transmission of HIV stigma.*

*We are few YPLHIV in my country... but we have to deal with just as much stigma because people think it isn't a problem.*



Stigma and discrimination fundamentally undermine the educational aspirations of YPLHIV. Actual and anticipated HIV-related stigma and discrimination (including self-stigmatisation) are reflected in teasing, bullying (including physical violence), isolation and rejection of YPLHIV by school management, staff, peers and parents, and make schools fundamentally unsafe and unsupportive places for YPLHIV (H. Birungi, personal communication, November 2010; Conway, 2005; Obare et al., 2009.).

HIV-related stigma is also likely to be internalized, with the result that YPLHIV come to share the negative perceptions of others. For example, research in India by the International HIV/AIDS Alliance in India (2010) reported that the majority of boys living with HIV described being abused and teased by peers because of their stunted growth, delayed development and sexual inactivity. They told researchers that they did not want to engage in relationships for fear of 'spoiling other people's lives with HIV'. Some younger boys believed that even masturbation was unavailable to them because it would lead to divine retribution. Girls shared concerns about physical development and sexual desire, as well as wondering if they would be able to marry and have children. A 15 year old girl in Zambia concluded that, "*I won't get married when I grow up since I drink medicine i.e. (I'm HIV-positive). I would rather be a nun.*"

Stigma and discrimination thrive on ignorance; however, all too often, HIV-related programmes are limited in scope and reach too few learners to have a lasting impact on knowledge and attitudes.

In many communities, schools have an important function in terms of establishing and demonstrating social norms. The standards they establish, for example in relation to stigma and tolerance, can set the tone for the wider community in which learners live.

Three key issues emerged in a study of HIV-related vulnerabilities in the education sector in Eastern Europe: i) mandatory disclosure of HIV status; ii) negative responses from peers to learners living with HIV; and iii) separation and segregation of children living with HIV. In Romania, for example, 15.5% of YPLHIV out of school have been denied access to school following disclosure of their HIV status (Buzducea et al, 2010) while in Vietnam, parental opposition is identified as the primary reason why schools exclude HIV-positive children (Mydans, 2009).

Stigma and discrimination can also occur by default, for example, through the application of ill-considered or poorly planned policies on health and safety, or school-based testing or treatment that breach confidentiality or require disclosure. For example, an HIV prevention

#### **Jamaica** **Involving YPLHIV in changing community perceptions**

Jamaica has come a long way in terms of increasing family support for YPLHIV. To date, the National HIV/STI Programme has used the faces of four, local, young people and adults in its campaign to challenge stigma. The young people share stories of their experiences of living with HIV with the communities where we work has brought home to community members the reality of the epidemic and increased their ability to empathise and accept PLHIV.

While progress has been made, ignorance and misinformation persist in many places where people believe HIV is contagious, or else the concern only of gay men or sex workers, and that marriage provides

protection from HIV. Encouraging changes in sexual behaviour is particularly challenging in the current socio-economic climate and in the context of Jamaica's complex sexual culture.

Seeing their peers come forward and speak out about their experiences of living with HIV is encouraging for YPLHIV. Nonetheless, considerable barriers remain in terms of making disclosure to friends, families and communities a safe and realistic option. Minors have difficulty accessing HIV testing services, and obtaining and negotiating the use of condoms present considerable challenges for YPLHIV.

Source: Kerril N. McKay, personal email communication, February 2010.

#### **Mexico** **Jóvenes Positivo: using new technology to address discrimination**

*Jóvenes Positivo* is the name of the Latin American network of YPLHIV. Through a website, the network offers social network services for YPLHIV to express themselves, share and make positive friends. A blog facility offers a space for discussing and sharing ideas and thoughts about relevant topics.

One of the main services of the website is the *Ushuahidi* which provides a platform for mapping situations of discrimination

at schools, clinics, or any other public or private space. Through this mechanism, the network can collect statistics on violations of the rights of YPLHIV rights and identify those places and service that do not respect human rights. On the basis of this evidence, recommendations will be made to the Ministry of Education, health sector, NGOs and human rights commissions. The website was launched in early 2011 and is advertised in clinics, school and public spaces.

Source: Pablo T Aguilera, personal communication, February 2011.

campaign to make a school an 'HIV-Free Zone', or establishing an 'Anti-AIDS club' can actually increase HIV-related stigma and discrimination and exclude YPLHIV. As one young person pointed out, "I am living with HIV. Does this mean that I am also excluded from school?"

Stigma and discrimination can be further compounded for YPLHIV who (or whose family members) belong to marginalised or already stigmatised groups. Assumptions may be made about the behaviour or sexuality of young people living with HIV, especially in countries with concentrated epidemics that disproportionately affect sex workers, drug users and men who have sex with men. YPLHIV (and young women in particular) who have acquired infection through sexual activity (or injecting drug use) may also face particular judgement and blame (WHO, 2006a). For young men who have sex with men, homophobic stigma, discrimination or bullying may lead to further isolation – schools can have a critical role to play in addressing homophobia, given the appropriate legislation. The law, as it relates to HIV transmission and disclosure of HIV status, is often confusing and potentially threatening to those whose HIV status may be indicative of illegal practice (e.g. injection drug use or sex between men).

In concentrated epidemics, in order to avoid stigma and discrimination, it may be preferable to address HIV within the context of other medical conditions. For example, in the UK, HIV is considered a disability, allowing for integration into existing policies and approaches (including

sexuality and relationships education) that support inclusion and tackle discrimination (Conway, 2005). Consideration should also be given to addressing HIV-related stigma and discrimination within the context of other forms of prejudice (e.g. bullying, homophobia, racism).

*They would gossip about me and I always felt like an outcast. But my worst experience was when I heard that a girl I knew at school told most of the learners about my HIV status and they made a joke of me, teasing and laughing at me. That hurt me a lot.*

#### **Russian Federation** **Increasing access to school by YPLHIV**

In the Russian Federation, access to kindergartens and schools for HIV-positive children is limited by pervasive stigma. To help these children benefit from early childhood development opportunities and allow them to study in a non-discriminatory environment, UNICEF cooperated with the National Ministry of Education and Science and regional education departments in seven of the most heavily affected regions of the country. The aim of the programme was to raise educators' awareness of HIV and of Russian laws that prohibit discrimination against people living with HIV. A special

#### **Latin America** **Homophobia fuels HIV epidemic**

Some countries in Latin America have introduced socially progressive legislation on sexual freedom and orientation. In 2008, Brazil's President Lula inaugurated the *First National Conference of Gays, Lesbians, Bisexuals Transvestites and Transsexuals*. Brazil also created the *Brazil without Homophobia* programme, a government-led initiative to promote homosexual "citizenship" and eliminate discrimination against the GLBT community, which led to the introduction of Human Rights Reference Centers designed to prevent and tackle homophobia.

Nonetheless, despite this progress at policy level, in some countries in the region, homophobic prejudice and discrimination are reflected in very high levels of violence, including murder. For example, in Brazil, between two and three people are killed each week because of their sexuality. Mexico comes a close second with nearly two such killings on average per week. Most victims are men who have sex with men (MSM) or transgendered people. What makes Brazil and Mexico unusual in the region is that this particular kind of violence is monitored.

Homophobia not only affects the physical and mental health of those directly victimised. In a region where sex between men is the leading mode of HIV transmission (for example, in Brazil MSM are 11 times more likely to be HIV positive than the population as a whole), homophobia fuels the epidemic, isolating individuals and making them less likely to seek help and support.

Sources: UNAIDS, 2009; Immigration on Refugee Board of Canada, 2008.

advocacy, communication and capacity-building programme was developed for use with administrators in the education sector, parents, teachers and caregivers.

Some 2,050 schools, kindergartens and residential institutions, with over 400,000 students aged 3–18 years, were reached. A total of 8,380 educators received HIV education and tips on how to support HIV-positive learners in the classroom. After the training, more than 90 per cent of teachers and caregivers (compared to 45 per cent before) reported that they would not object to having an HIV-positive child in the classroom, and would support and protect them against discrimination. Such

attitude changes are an initial step in the long process of reversing widespread social prejudice and improving the lives of HIV-positive children.

Two training kits were designed for schools and preschools and for residential institutions that care for children born to, or abandoned by, HIV-positive parents. The kits include a Trainer's Guide, a set of slides, a documentary, an Information Booklet for Educators and Caregivers, and a set of tips for school/residential institution management and teachers/caregivers. These are available at [www.unicef.ru](http://www.unicef.ru).

Source: UNICEF, 2010a.

## The Dilemma of Disclosure

Disclosure cannot be undone: once shared, information is beyond the individual's control. YPLHIV have to consider this every time they decide to disclose their HIV status. The dilemma of disclosure recurs throughout life, in response to new and changing situations and relationships. Responsibility for deciding to disclose rests with the individual concerned (with appropriate support as necessary) based upon consideration of the respective advantages and disadvantages. However, depending upon the circumstances and age of a child, decisions about HIV-related disclosure may need to be taken by parents or carers, at least until such time as the individual is sufficiently mature to appreciate the implications of disclosure. While the Convention on the Rights of the Child acknowledges the right of children below the age of 18 to information about their own health, in practice, parental consent may be required by law or custom.

YPLHIV have the right to decide whether or not to disclose their HIV status to others, including within the context of educational institutions. There is *no* justification whatsoever for making access to or retention in education conditional upon disclosure of HIV status as this may limit a learner's right to education. The basic human right to education is further supported by conventions such as the Convention against Discrimination in Education which specifically promote equality and non-discrimination and are the cornerstone of achieving EFA. In many, but not all, countries policies already exist

prohibiting discrimination on the basis of HIV status. In some circumstances, particularly for boarding schools, rules may require that learners disclose medical conditions or medication in order to support or manage any health problems. Clear protocols around disclosure and confidentiality may not be present, meaning that a learner's status could be disclosed either to any member of staff, and even other learners.

Pervasive stigma and discrimination are effective deterrents to disclosure by YPLHIV. In order for schools to respond appropriately to the needs and aspirations of YPLHIV, they need both to

**Disclosure:** the issue of **if, when, how and to whom** to disclose our HIV status is a personal decision that must be respected. We must have all the elements necessary to create a safe and conducive environment for these rights to be realised and all the support we need to build our own skills and manage our own disclosure strategies.

Source: GNP+ 2010c

*Disclosure 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.*

### Uganda

#### Young peoples' experiences of HIV-related disclosure

A study in Uganda explored disclosure practices and concerns among 20 young women and men living with HIV, the majority of whom live in challenging economic and social circumstances.

Respondents were aware of HIV-related stigma within their communities and were afraid of rejection, abandonment, abuse, and ostracism. Most respondents considered their HIV status and treatment to be private matters, but many felt that disclosure to family members was unavoidable. All described how beneficial disclosure had been in terms of the support received from caretakers and other family members (including love, money for transport to the clinic and reminders to take their medication).

The young people described disclosure as a skill, one that they refine in response to new situations. Some 'joked' with friends to 'test the waters', before disclosing. *Implicit disclosure* was another strategy, demonstrated, for example, in taking HIV medications publicly rather than in secret or displaying ART literature.

All the young women and men wanted to be in full control of decisions about disclosure and felt this was their personal responsibility. However, almost all reported that they knew or suspected that a third party had disclosed their status to others. Some respondents also revealed that while they had wanted to disclose they were prevented from doing so by caretakers.

Several agreed that disclosure to partners, with the associated fear or rejection or loss of respect, was especially challenging. Several talked about not wanting to subject their loved ones to 'psychological torture' and viewed non-disclosure as a mechanism to protect loved ones. In particular, disclosing to a parent was very painful.

Source: Bakeera-Kitaka, et al. 2010

acknowledge the possible presence of YPLHIV within their communities and tackle stigma and discrimination accordingly.

Increasingly, especially in higher prevalence settings, schools are now looking to establish ways of offering HIV testing and counselling, either in-school or through referral or partnerships with local health facilities. This presents opportunities for increasing the numbers of those who know their status and can subsequently access care and support. However, this also raises complex issues relating to:

- Legal age of consent (to test and initiate treatment);
- Confidentiality;
- Provision and quality control of care and support;
- Location and visibility of testing facilities.

Disclosure is a challenging area for any sector to manage but advances have been made, particularly within the health sector, to develop protocols and engender daily good practice around confidentiality. The education sector does not have the same foundations in patient confidentiality as the health sector, but nonetheless can use data management systems and coherent approaches to confidentiality that can respond to the pervasive issue of disclosure for HIV-positive learners in educational settings.

Whilst increasing the numbers of young people who know their status is a well-grounded strategy, the current challenges lie in meeting

the needs of those learners in school now, who may or may not know their status. School staff and learners alike need to acknowledge the possible co-existence, within the same school, of several distinct groups of YPLHIV:

- Those who do not yet know their status;
- Those who know their HIV status and have made limited disclosure;
- Those who know their HIV status and have made general disclosure;
- Those who know their status but have not disclosed to anyone, either within the school setting or elsewhere;
- Those whose status may be known by a parent / guardian but not by the young person themselves.

By developing a standard approach with regard to confidentiality for all learners, schools and the education sector could take a critical first step towards protecting the rights of young people, whatever their disclosure decision, and supporting them with HIV-related needs. The key approach is to create a safe environment in which YPLHIV are free to choose whether or not to disclose their status, and if so, to whom.

While disclosure may enable individuals to access support and services (where these are available), it also carries a risk of stigma and discrimination. This dilemma is reflected in findings from UNESCO's research in Namibia and Tanzania where researchers report that YPLHIV are sometimes discouraged from disclosing by school staff in order to avoid potential stigma

from other staff and learners<sup>6</sup>. However, secrecy and the stress involved in concealing one's status (especially selectively) can also create considerable emotional burdens for young learners. As one young person living with HIV described it:

*This places a heavy burden upon the young person: to assess whether or not a particular adult is trustworthy and to live with consequences if the judgement turns out to have been misplaced.*

Evidence from Kenya (Human Rights Watch, 2010) highlights the importance of supporting parents and carers<sup>7</sup> to provide age-appropriate disclosure of their HIV status to infected children in order to prevent problems associated with delayed disclosure. These can include poor adherence to treatment, anxiety and feelings of betrayal. Furthermore, young people who are embarking on romantic and sexual relationships will need significant levels of support in making decisions about disclosure, decisions which in some cases are mediated by the law which may have strong penalties for those who do not disclose their HIV status to a sexual partner. Managing disclosure within the family, among friends, within relationships, and with other adults, community members, educators and medical staff is therefore a

multi-layered issue that requires individualised and context-specific support.

The health sector takes a very different approach to the issue of client confidentiality. A critical aspect of the duty of care that the health sector has for a patient or client is the confidentiality of medical, clinical and personal information (including HIV status). This confidentiality is crucial in building trust and respect between client and service provider and also in creating a conducive environment for future care. Service users have come to expect this level of professional care and attention to confidentiality to such an extent that breaches of this confidentiality have in many cases led to legal proceedings.

Young people attending school should be able to receive this same level of respect for their personal information from the education sector. Issues related to HIV status and disclosure are just as sensitive inside the school setting as they are in a clinical setting and as such the education sector has a responsibility to the same sense of security that is felt by service users the world over.

UNAIDS *Guidelines on protecting the confidentiality and security of HIV information* stipulate clear protocols around the protection and security of personal information as it relates to HIV (UNAIDS 2007). While these guidelines are aimed at strengthening patient management systems they can provide excellent guidance to the education sector on the level of attention that is required to ensure the confidentiality and privacy of young people living with HIV is respected.

<sup>6</sup> Others, for example in Uganda, found they received better treatment upon disclosure (UNESCO 2008e)

<sup>7</sup> The Kenya National AIDS/STD Control Programme (NASCO) has developed training materials on child disclosure.



## Health Needs of YPLHIV in the School Setting

With increasing access to effective treatment, HIV is becoming a manageable condition. However, in the school setting, treatment, care and support are often unavailable to YPLHIV. Indeed, many schools lack sick bays or nurses, and staff are often equipped to provide only the most basic first aid. With a sufficient understanding of what HIV treatment involves, its side effects, the adherence requirements and the nutritional needs of a young person who is taking treatment, school staff such as nurses could be an invaluable link in the overall health support that a young person receives.

### India Children and HIV testing

Research in India concluded that the challenges relating to HIV testing of children and subsequent disclosure issues vary with particular age groups. For example, the main challenge identified in testing for 0-6 year olds is one of availability of suitable technology, compounded by insensitivity to children's needs within Integrated Counselling and Testing Centres (ICTC) and parental concerns about confidentiality.

For those aged 7-14, insensitivity of ICTC staff and lack of confidentiality pose significant challenges together with issues relating to disclosure, psychosocial problems and the capacity of children to cope. Among adolescents (defined in the study as 15-18 years) key concerns related to the lack of access to testing centres together with age-appropriate information that deals with the need for testing, disclosure, nutrition and treatment. For this group, these concerns are further compounded by the more mundane pressures faced by adolescents everywhere.

The study highlighted several factors that prevented parents from taking children for testing. Most important among these

was stigma and discrimination, closely followed by financial constraints in relation to time and travel costs. Fear of local disclosure was also an important concern which sometimes led parents to visit services in other districts. Some parents were simply unaware of HIV and when children of these parents were found to be positive, the parents experience difficulties in explaining the information and its implication to their children. Another important factor concerned negative attitudes on the part of service providers. Parents still in shock over their own diagnosis found it difficult to accept the idea of potentially exposing their children to the same traumatic news.

Parents and service providers were most likely to disclose to children aged 7-14, and doctors tended to be responsible for disclosing to adolescents. While disclosure by parents was preferred, NGO staff who had good rapport with the local community were also trusted sources of informing children about their diagnosis, and exposure to NGOs appeared to increase the likelihood of parents disclosing to children. While expectations of ICTC staff were high, services were not always experienced as approachable or affordable.

Source: Adapted from India HIV/AIDS Alliance, 2009.

*I really wish that the education sector and the health sector would come together as one and just do something about the needs of YPLHIV, such as lack of healthy food.*

*We, young people living with HIV, are getting tired of the lack of essential medicines that determine whether we live or die. It is our right to have the highest attainable standard of health and in the case of PLHIV this means ART. It's our future and also the future of our countries! Without the necessary drugs we will die. Around the world positive youth face interruptions of essential antiretroviral therapy every day. Those interruptions have irreversible consequences to our health and threaten our lives. We need people to understand it and try their best to change this situation!*

### What is Treatment Education?

Treatment education is a critical part of efforts to prepare people for treatment and to engage communities and individuals to learn about antiretroviral therapy so they understand the full range of issues involved with treatment.

Treatment education informs and engages individuals and communities about ART, including how the drugs must be taken and adhered to, treatment benefits and side effects, criteria for enrolment into ART programmes, and issues relating to equity of access. Without effective treatment education including treatment preparedness, the full potential of ART is not likely to be realised.

Treatment education provides an opportunity for community members,

educators, health workers and others to become active partners in addressing HIV prevention, care and treatment needs, it strives to ensure that people on treatment are at the forefront of such efforts.

To recognise the full potential of treatment education, the education sector must be fully engaged in treatment education efforts. Treatment education should be addressed in all modalities of education – formal, non-formal, and informal, at all levels from early childhood through to higher and adult education, and in all aspects of the sector such as policy and legislation as well as curriculum and materials. The development of policy and practice will be greatly strengthened through the involvement of people with HIV, including those on treatment.

Adapted from: IATT on Education 2006,

### Children's Treatment Literacy Toolkit

A package of materials developed by SafAIDS - Kids ART Education Series (KAES) - provides information and a series of creative, child-centred activities that explore the issues raised for children and their carers in relation to antiretroviral therapy. The materials are intended for use primarily with children aged 6-12, but can be adapted for older children and young people.

The package is comprised of:

- Eight booklets:
  - Introduction to Children's ART Literacy Series*
  - HIV & AIDS and My Treatment*
  - My Family and My Treatment*
  - My Body and My Treatment*
  - People who Support me with My Treatment*
  - My Daily Life and My Treatment*
  - My Future and My Treatment*
  - Learning About My Treatment can be Fun*
- A training of trainers (ToT) handbook: Supporting Parents and Caregivers of Children LWHIV
  - ART Knowledge Board Game
  - ART Quiz cards
  - Interactive Poster
  - Advocacy Stickers
  - Kids ART Adherence Calendar
  - A Watch to help with adherence
  - TB, HIV and Children Brochure

Source: <http://www.saf aids.net/?q=node/520>

Research from Uganda concludes that care and support provided to YPLHIV are often crisis-driven and dependent on the goodwill of individual members of the school staff (Obare et al, 2009). None of the schools in the study were found to have organised programmes or health services through which the needs of YPLHIV could be addressed. However, individual staff members do make personal, informal attempts to respond to these needs with the limited resources available. However, asymptomatic YPLHIV were assumed to have no special needs.

This makes it all the more important that strong partnerships exist between sectors, including health service providers and networks of PLHIV. Treatment literacy is essential for YPLHIV and important too for peers and staff alike (Lightfoot et al., 2007). Resources on HIV treatment literacy are available to education institutions and, in addition, schools should disseminate information on locally available HIV testing and treatment services, including any on-site arrangements for counselling and testing. More effective collaboration between schools and health services, for example by providing on-site services, could help YPLHIV manage the competing priorities of health and educational needs and relieve them of the burden of having to decide between attending medical appointments or maintaining academic performance.

When HIV goes unidentified or untreated, the health of individuals is at risk, particularly so for those infected since birth who may become symptomatic during childhood or adolescence (Buzducea et al, 2010; Obare et al, 2009; WHO,

2009). Children born with HIV also face increased risk of neuropsychological damage, including developmental delays and learning problems, language difficulties and cognitive anomalies (Armstrong et al., in WHO, 2006b), all of which may adversely affect school attendance and performance.

YPLHIV have to deal with the physical consequences of living with HIV and the effects of HIV-related treatment. Side-effects of HIV-related treatment, as well as affecting attendance and performance, can also impact negatively upon body image and self-esteem.

YPLHIV may need assistance in managing their treatment in the school setting or when away from home, for example, on school trips or at boarding school (Conway, 2010). In at least one adolescent HIV treatment programme (Uganda), YPLHIV are actively discouraged from attending boarding school for this reason. Positive learners also experience challenges in adhering consistently to treatment (WHO, 2009), with some avoiding taking medication at school for fear of exposure and the desire to 'fit in' with their peers.

Older adolescents living with HIV are reaching the time when they will transition from paediatric to adult health services. This shift is significant especially for those who have been familiar with one medical practice since birth. Among other changes, adult services require greater personal responsibility; young people will benefit from a consistently supportive home and educational environment to cope with this change.

# Psychosocial Needs of YPLHIV in the School Setting

There is a real need for specific **psychosocial support** for our emotional, mental and sexual and reproductive health needs as they change through different stages of our young lives through to adulthood. With the support of many partners we can make sure that this is a reality for all YPLHIV. (GNP+ 2010c)

YPLHIV have particular psychosocial needs over and above the 'ordinary' developmental and maturational challenges faced by all children (Bialobrzaska et al., 2009; Obare et al, 2009; Robson & Kanyata, 2007). For example, positive learners also have to cope with particular stresses

relating to their own health status (as well as concern for the HIV-related crises of loved ones) which can manifest themselves in depression, anxiety, low self-esteem, withdrawal and behavioural problems (Ellis, 2010). When infection occurs or is discovered during adolescence, this can significantly compound an already difficult stage of life and may lead to social withdrawal and isolation (Obare et al, 2009).

Many YPLHIV have already lost one or both parents to HIV and experience considerable stigma as a result. Grief can be compounded by loss of family support as well as legal and financial security. Precarious socio-economic circumstances may necessitate relocation to unfamiliar households

and communities so that YPLHIV can be cared for by extended family members, who are often considerably older and may not be well-acquainted with the child. The physical, psychological and financial capacity of such households may be already stretched and the young person may face separation from siblings, friends and familiar surroundings, including school. A range of psychosocial support interventions have been developed by community groups, civil society organisations and networks which aim to respond to the range of needs experienced by YPLHIV in a holistic way. The example from Zimbabwe (box below) demonstrates how skills-development and financial security are increasingly important to young people and the ways that programmes can respond to these needs.

*I am a good performer [academically] but HIV caused my self-esteem to drop and caused me to lose trust in my teachers.*

*I do not feel free to share my fears and pain with my peers because of the remarks they usually utter about people living with HIV.*

*I really, really wish that our ministry can build up more support groups because there's a number of people who live with HIV and find it very hard to disclose our feelings to anyone close by.*

## Zimbabwe

### Community responses for young adults living with HIV

In 2004, a support group was initiated by Africaid for 20 orphans and vulnerable children (OVC) living with HIV in Zimbabwe, with the goal of creating a community of accepting friends, empowering children and young people to take control of their own health. The support group for children and young people aged 7+ was based on the idea that, from the outset, children would play a strong role in the leadership of the organisation. Since it began, *Zvandiri* activities have expanded to include community support groups and outreach, life skills training, youth groups and vocational training, individual counselling and educational materials development. When participants in the *Zvandiri* programme turn 18, they move on to the youth group. Members of this group face significant challenges in terms of earning a living. *Zvandiri* finds opportunities for members to gain experience and training that will benefit them in their search for jobs. So far, young people have been supported to train as hairdressers, nurse aides and first aiders. Some YPLHIV go back to school to make up for educational time lost to ill-health but find reintegration challenging when they realise that their academic peers are considerably younger while their age peers are more academically advanced.

With a retention rate of about 85% (some members have died), *Zvandiri's* success is attributed to a number of factors, including:

- Significant and meaningful participation by children in decision-making (for example, members decided that only children living with HIV could join);
- Strict adherence to confidentiality;
- Parental involvement in the organisation and in communications with children;
- Assessment, training and monitoring of professionally trained group leaders;
- Transparency and communication;
- Consultative policy development to ensure consistent messages;
- Willingness to seek external expert advice on non-core issues e.g. child abuse;
- Commitment to equality;
- Cost-effectiveness;
- Relevance, replicability, innovation and sustainability.

Source: SafAIDS, 2010.



## Responding to the Educational Needs of YPLHIV

Providing universal education is a highly effective way to support children affected by HIV. Facilitating access to education, for example through birth registration, provision of financial support, materials or school feeding (of particular importance to YPLHIV receiving treatment), not only benefits YPLHIV but potentially all vulnerable young people.

In some countries, and this may be especially relevant to low prevalence settings, increasing access to education can be promoted through policies and laws that protect the rights of people with disabilities, including HIV (Conway, 2005). For example, in the UK HIV is classified as a disability thus ensuring that people living with HIV are protected from discrimination and have access to support services as required<sup>8</sup>.

Teachers and other school staff play important roles in the lives of young people. They interact daily with large numbers of learners, often spending more hours per day with them than their parents or carers, especially in boarding school settings (UNAIDS IATT, 2008; Mugimu & Nabadda, 2010). The high regard and social status accorded teachers in many countries, combined with their leadership roles and skills, make teachers potentially well-placed to create a supportive environment for HIV-positive learners. Young people, including those living

with HIV, may look to their teachers for guidance and support and many teachers do the best they can with the resources and information available. However, without appropriate training, teachers may lack the necessary skills, knowledge and confidence to provide support (Mugimu & Nabadda, 2010). Where they exist, school-based counselling services represent a potentially valuable resource for supporting YPLHIV. Even where no formal service exists, in many schools, there are individual teachers who have pastoral responsibilities.

Flexible approaches to schooling can support YPLHIV. These include adjusting the curriculum to ensure it is relevant to the daily lives and long-term employment needs of learners, providing catch-up and remedial classes, adjusting school schedules to accommodate other responsibilities, and the use of community schools (Robson & Kanyata, 2007). Community schools can promote access to education for learners living in areas not covered by the formal education system. Community schools are usually initiated by community members, CBOs or faith-based organisations. They rely upon volunteer teachers who, while often untrained and dependent upon the community for their income, are flexible in terms of adjusting schedules to accommodate local needs. Curricula may be modified in order to meet the specific needs of learners and the wider community. There are no fees and uniforms are typically not required.

It is important to acknowledge that many young people, including YPLHIV, will already have left school for a variety of reasons (including poverty and illness) and both formal and non-formal education institutions can play a critical role in responding to their educational and employment-related needs and aspirations. For example, in Zimbabwe, UNICEF is supporting the concept of 'second chance' education through distance learning and study groups, focusing on

core competencies such as literacy, numeracy and vocational training (J. Sherman, UNICEF, personal communication, December 2010). A clear advantage of 'second chance' education lies in its inclusive approach which attempts to reach anyone, including YPLHIV, in need of a basic, flexible education.

### Kenya Positive action for HIV in schools in Kenya

A recent study by APHIA II Operations Research Project in Kenya found that only 42% of HIV-positive adolescents in Kenya are actually *in* school. The large proportion of those out of school indicates the potential vulnerability of this group of young people.

In response, APHIA II OR Project and the Kenyan Ministry of Education have launched a project in eight pilot schools to inspire change in the way school communities confront HIV so that more children and young people are informed about HIV and the benefits of early diagnosis and testing. Interactive communication will be used to sensitise the school community to the need to know one's HIV status through testing, and to reduce stigma and discrimination towards those living with HIV. Research will be conducted to assess students' willingness to accept HIV counselling and testing services and how they would like these to be delivered. If the results are positive,

arrangements will be made through the National AIDS and STD Control Programme (NAS COP) to provide services. School matrons and nurses will be given training by NAS COP in the care and support for HIV+ students.

The project has been designed after extensive consultation and following formative research with teachers, parents/guardians, and students. The findings confirm the extent to which HIV-related stigma is an issue within schools and provide some indication of the difficulties likely to be faced by YPLHIV in the school setting. Teachers were found to have empathetic attitudes towards young people living with HIV and to welcome supportive activities, while parents are receptive to making HIV counselling and testing services available to the school community.

Source: APHIA II Operations Research Project in Kenya Newsletter, December 2010.

<sup>8</sup> For a more global overview of issues relating to HIV and disability see: [http://www.who.int/disabilities/jc1632\\_policy\\_brief\\_disability\\_en.pdf](http://www.who.int/disabilities/jc1632_policy_brief_disability_en.pdf)

## Sexual and Reproductive Health Needs and Rights of YPLHIV

Like all young people, YPLHIV have sexual and reproductive rights, needs and aspirations. More often than not, these are overlooked or denied. YPLHIV have the same emotional and sexual needs and desires as their peers, but face specific challenges because of HIV. The nature of the challenges will be affected by gender, age, socio-economic status, sexuality, culture, relationship status (e.g. married, coupled, concordant, and discordant) and reproductive aspirations. Comprehensive sexuality education is therefore critical for *all* young people in order for them to acquire the understanding and skills necessary to develop and sustain emotionally and sexually satisfying healthy and fulfilling relationships.

Young women living with HIV are disproportionately affected when compared to young men in the same age-group. Globally, young women represent 64% of all YPLHIV 15-24 year olds living with HIV (UNICEF, 2011). For these girls and young women, sexual and reproductive health and rights are often not recognised or given priority. Existing patterns of gender inequality and socio-cultural practices can restrict a young woman's ability to control choices regarding her own sexual and reproductive health. In addition, stigma, discrimination and poverty may have a more profound effect on women and girls attempting to access information and services, which can

lead to dire consequences. Gender-based violence reduces a woman's ability to control decisions about her sexual health and increases the vulnerability of women and girls to HIV transmission (EngenderHealth and ICW, 2006).

A recent study of perinatally infected young people in Uganda (Birungi et al., 2008) found that 52% were currently in a relationship and that 33% were sexually active. Forty-four per cent of those who were not sexually active reported the *desire* to have sex. Among the sexually active group, 37% had used a method to prevent infection or re-infection at first sex. Just under one-third of those who reported *current* condom use did so explicitly

We should not have to disclose to get what is our right: relevant sexuality education.

"Sexuality is about a lot more than having sex. It is about the social rules, economic structures, political battles and religious ideologies that surround physical expressions of intimacy and the relationships within which such intimacy takes place."

Source: IPPF  
<http://www.ippf.org/en/What-we-do/Adolescents/FAQs+on+young+people+their+sexuality+and+their+rights.htm>

### **Namibia** **Positive Vibes: Helping teachers and learners 'inside-out'**

Positive Vibes training and facilitation methodologies empower people living with HIV to understand, process and re-frame their personal challenges in dealing with HIV. They assist individuals (regardless of HIV status) to personalise HIV issues, assess risks and responsibilities in order to break through fear and denial, to promote personal action. This process is called the "Inside-Out" approach and is designed specifically to:

- Regain self-esteem and adopt healthier attitudes and behaviour that reduce the risk of further HIV-transmission;

- Challenge stigma and discrimination that hampers the effectiveness of HIV services and policies;
- Advocate for better access to and delivery of services and support.

Training is provided for teachers to assist them to consider HIV-related issues within the contexts of their personal and professional lives: the assumption being that if teachers are competent to deal with HIV issues in their own lives, they will be able to address these within their work and social environments. Ideally, interventions targeting teachers (adults) and young people (learners) occur simultaneously in order to promote informed dialogue. Thus, teachers are resourced to address HIV through dialogue, support and empathy,

while YPLHIV find the confidence they need to be able to live with HIV and rise to the challenges they face in the school environment.

The methodologies (inspired by Paolo Freire's *conscientisation*) focus upon dialogue and the shared experience of the group, rather than traditional one-way flow of information from facilitator (teacher) to participant (learner). In so doing, the process assists participants to improve their self-image and enhance their capacity to act. The process is led by facilitators, affiliated to Positive Vibes Trust, who are openly living with HIV. This, in itself, helps to challenge stigma and encourage dialogue.

Source: Ingrid Louis, personal communication, January 2011

in order to prevent infection but were inconsistent in their condom use. Just over one-third (38%) disclosed their health status to their sexual partner, and disclosure emerged as a significant fear for many YPLHIV. Forty-one per cent of the sexually active young women had been pregnant, with three-quarters taking their pregnancy to term. More than two-thirds (69%) of those with children expressed the intention to have more in future, while 86% of those who did not have children intended to do so eventually. Sexuality was rarely discussed by parents and carers.

The recommendations arising from this study are relevant to many settings (Birungi H, et al. 2008):

- Strengthen preventive services for sexually active YPLHIV and include consideration of disclosure, dual protection, and consistent condom use;
- Make pregnancy safer for young women living with HIV, including provision of PMTCT and safe delivery services;
- Encourage more open communication about sexuality between parents and children, between teachers and learners, and among learners;
- Re-orient service providers and counsellors to provide more balanced support;
- Establish age-appropriate services;
- Strengthen support groups;
- Improve life skills and sexuality education.

## Sexuality Education

Comprehensive sexuality education is important for all young people (UNESCO, 2009) and particularly so for those living with HIV who face specific challenges in relation to sexual and reproductive life and romantic or intimate relationships. However, the particular needs of YPLHIV with regard to sexuality education are largely unmet (Bakeera-Kitaka, et. al, 2008; Birungi et. al., 2008; Fransen-dos Santos, 2009; GPN+ et. al., 2009; Gruskin et al., 2007). In part, this is a reflection of a general lack of good quality sexuality education. Not only does sexuality education tend to overlook the needs of YPLHIV, it can actually perpetuate HIV-related stigma and discrimination, for example by focusing exclusively upon HIV prevention instead of including consideration of the sexual choices of YPLHIV. Equally, the likelihood of any young person receiving school-based education on sexuality is very varied. While some countries (UNAIDS, 2010) report 100% coverage of Life Skills Based HIV education (e.g. Antigua, Botswana, Japan and Papua New Guinea), others show significantly less progress: Bangladesh (0%), Togo (0%), Ukraine (59%) and Vietnam (34%).

Sexuality education curricula should be rights-based and focus on the positive elements of sexuality, as well as associated risks (IPPF, 2010; UNESCO, 2009). Curricula should include consideration of feelings, values and attitudes, and should assist learners in developing skills in decision-making and communication, including negotiation (e.g. in relation to condom use) and

**Mexico**  
**Outcomes from the LAC Ministerial Declaration**

The *Mexico City Ministerial Declaration Educating to Prevent* supports HIV prevention efforts in Latin America and the Caribbean (LAC) by ensuring access to quality, comprehensive sexuality education and sexual and reproductive health services. The Declaration seeks to foster equity among all people and to combat discrimination, including that based on an individual's HIV status, sexual orientation, or gender identity. The needs of most-at-risk individuals are not forgotten and figure prominently in the goals of the Declaration.

In Mexico, the National Aids Program (CENSIDA) leads the implementation of the Declaration at country level. In collaboration with other Health Ministry focus areas - the National Programme on Health of Adolescents and Childhood, the National Programme on Gender, Sexual and Reproductive Health, and Health Promotion, a working group was created in order to support inclusion of the commitments of the ministerial Declaration.

National weeks for vaccination and Teenagers' Health now include information on sexual health, reproductive issues, emphasizing HIV prevention and the promotion of prevention products. At local level, activities include full participation of the States AIDS Programmes that contribute information, personnel and prevention experiences to ensure that families and adolescents receive basic information on HIV prevention.

To accomplish the goals of Ministerial Declaration goals, government clinics that provide sexual and reproductive health services, were reviewed and where necessary improved to ensure that youth-friendly services are provided.

A national meeting of key personnel from both education and health sectors is planned, under the leadership of the Minister of Health, to ensure that the goals of the Declaration are accomplished by 2015.

Source: Carlos Garcia de Leon (personal communication)

assertiveness. Values of mutual respect and responsibility should be promoted and attention paid to issues of consent, power, coercion, violence and abuse (UNESCO, 2008b; Lightfoot et al., 2007).

For sexuality education to be relevant to YPLHIV, it needs to acknowledge the rights and diversity of needs among all learners, including YPLHIV, across different ages, developmental processes and life stages. It needs to be inclusive as well

as sensitive to gender and sexual diversity. Specifically in relation to HIV, consideration should be given to sero-discordant relationships and emphasis placed on shared responsibility for prevention of HIV transmission.

Sexuality education presents an ideal opportunity to challenge gender stereotypes and to promote greater gender (and sexual) equality<sup>9</sup>. Appropriate

<sup>9</sup> "It's All One Curriculum" produced by Population Council takes a gender-transformative approach to sexuality education (see Useful Resources section).

selection, training and support for teachers are critical as the role of sexuality educator is not necessarily one in which all teachers are comfortable or suitable. Wherever possible, YPLHIV should be involved in the development of the curriculum.

While teachers are the logical providers of the educational component of sexuality education provision, a critical role also exists for the health sector in terms of the availability of youth-friendly, gender-sensitive services, such as pregnancy testing, contraception, condom provision, STI testing and management and HIV testing and treatment. Links between schools and health services providers are critical to ensure that consistent messages are being delivered together with continuity of care for young people living with HIV.

## Policies, Plans and Action

The education sector has a critical role to play in the response to HIV. Ministries of education should be represented and actively involved in national and local HIV policy development, for example, through representation on National AIDS Councils or Country Coordinating Mechanisms.

Policies are essential in setting out the context, principles and frameworks for effective responses to HIV. However, they need to be accompanied by relevant, practical action in the school setting undertaken by governing bodies, teaching staff and the broader school community.

To date, policies on HIV developed by the education sector have focused upon consideration of rights and responsibilities, together with overall management of the HIV response. However,

policies are often inadequately *implemented* at school level. This may be a consequence of perceived or actual lack of political will, insufficient capacity, resources or mechanisms for implementation, compounded by the challenges of juggling competing, pressing priorities (Bialobrzaska et al., 2009; Hartell & Maile, 2004; Obare et al, 2009; UNESCO, 2008b, 2008e).

In countries where policies do already exist<sup>10</sup>, what is often required is that these are updated, implemented and monitored. For countries that have yet to develop policies, the examples (footnoted below) provide useful templates.

The emphasis of the response at school level has focused primarily upon curriculum-based prevention (e.g. life skills and family life education etc.), often including particularly narrow interpretations of prevention options (such as 'ABC'), rather than implementing a 'whole-school' systemic and strategic approach to HIV (Robson & Kanyata, 2007).

Education has formed an important element of many HIV programmes designed to respond to the needs of orphans and vulnerable children. However, it is only relatively recently that systematic consideration has been given to the education-related needs of adolescents and other young people living with HIV and to engaging with them as partners in addressing these.

As demonstrated in the example left, partnership across different sectors is a critical part of many existing programmes working with young people living with HIV. Partnership between the education sector and other sectors, notably with civil society and health care providers, can be particularly beneficial where these partners can complement the expertise of the education sector with other key skills. Lessons from the health sector HIV response have shown that civil society can provide valuable support to state-led health services and ensure that health services are oriented towards the needs of their users. This concept of health system strengthening (IAS, 2010) can be applied to other sectors. In education, civil society can engage with schools and other education institutions (e.g. vocational training colleges, community schools) to provide training, regular support and referrals between community and the institution.

### Botswana Inter-disciplinary collaboration - Training teachers to support HIV-positive learners

The Botswana-Baylor Children's Clinical Centre of Excellence (BBCCCOE) launched its school staff training project in 2006. The project is designed to equip teachers and non-teaching staff with the knowledge, skills and attitudes to support HIV-infected children in schools.

The project is based on the realization that care for HIV-infected children could be maximized if the major elements in a child's life (family, school, community and health care) are responsive to their needs.

The workshops, given in Setswana, span two afternoons, with four hours each day devoted to lectures and question-and-answer sessions. Topics include the spectrum of pediatric HIV; treatment and medications; infection control; nutritional care; rights/ethics/legal issues; psychosocial needs of HIV infected and affected children; HIV prevention messages for pupils, students and school staff; and teaching strategies for all content.

BBCCCOE staff also helps schools tailor the course for their students and Parent Teachers Associations (PTA) or to integrate

paediatric HIV education into other school health activities.

School staff training is a collaborative project between BBCCCOE and the Botswana Ministry of Education and Skills Development (MOESD). BBCCCOE is currently working with the Department of Teacher Training and Development at MOESD to bring this course to students in Colleges of Education as part of pre-service HIV/AIDS training. The project is funded by I-CATCH and the MOESD.

Source: Personal Communication, Botswana-Baylor Clinic, September 2011

<sup>10</sup> For examples of sectoral and sub-sectoral policies, see the HIV and AIDS Education Clearinghouse: <http://hivaidsclearinghouse.unesco.org/>. Some country examples include: *Government of South Africa's national policy on HIV/AIDS for learners and educators in public schools and students and educators in further education and training institutions* (1999); *Kenya Teachers Services Commission sub-sector policy on HIV and AIDS* (undated); *Namibian national policy on HIV/AIDS for the education sector* (2003).



# Gaps in the Evidence Base on the Education-related Needs and Aspirations of YPLHIV

A recent literature review has highlighted a number of important gaps that need to be addressed in future.

## Lack of information on YPLHIV in secondary and tertiary education

The majority of the available literature focuses on *younger* children living with HIV and therefore on *primary*, rather than secondary or tertiary, education.

## Non-formal education

More evidence is needed to demonstrate the role that *non-formal education* (NFE) can play in helping young people return to education. For many YPLHIV, mainstream programmes of reintegration (e.g. provision of financial support, mobile or community schooling) will be of benefit without being HIV-specific. There is also a need to consider the value of vocational training opportunities (in accordance with community norms and market-driven employment options) for children who are above the legal age of employment.

## Limited information on the realities and experiences of YPLHIV beyond sub-Saharan Africa

The majority of the available literature relates, understandably, to the realities and experiences of the most heavily affected countries in sub-Saharan Africa. However, the relevance of this material to other regional and epidemiological settings is not always clear.

## Similarities and differences in the lives of YPLHIV

Relatively little information is available in relation to the similarities and differences among YPLHIV in relation to their socio-economic and cultural characteristics, educational experiences, health status, and gender and sexual identities. In particular, evidence is needed concerning the particular needs of YPLHIV from already stigmatised or marginalised communities.

## Understanding how HIV affects young peoples' physical, emotional and social development

More evidence is needed to increase understanding of the ways in which HIV and its long-term treatment may affect the physical, emotional and social development of young people together with strategies for addressing this.

## Implementing education sector policies on HIV

While HIV-related education sector policies and plans exist in many countries, too few are regularly reviewed, updated, appropriately resourced or fully implemented. Information is therefore needed in order to understand why some policies and plans succeed while others fail and in order to identify the essential characteristics of successful implementation.

## Learning from experience of other chronic conditions

As HIV gradually becomes a chronic, manageable condition, it is important to identify and learn from experience in the education sector of responding to other chronic conditions.

## Need for more evidence of successful cross-sectoral collaborations

Given the importance of effective partnerships across key sectors – e.g. education, health, social welfare, employment, youth, gender – in responding to the needs of YPLHIV, examples of effective cross-sectoral collaboration need to be documented and disseminated.

# Part 2: Recommendations

## From Evidence to Action

*The purpose of Section 1 of the publication has been to identify key issues and challenges that face the education sector and partners in responding to the needs and aspirations of YPLHIV. These issues and challenges are numerous and complex and will continue to have an impact on the goals of EFA and the rights of young people living with HIV unless serious attention is given and appropriate responses are put in place. Whilst there is a considerable way to go before YPLHIV can say that they have equal access to schooling, that they are treated without discrimination and that their health status has no impact on their education, the examples included have demonstrated what can be and is being done, even in the most resource-constrained HIV-affected settings.*

*Part 2 of the publication builds upon this by presenting concrete actions that can be undertaken across particular thematic areas, and cross-cutting issues that need to be considered. The recommendations are grouped around six thematic areas.*

*Annex 1 provides examples of some resources that may be useful in implementing these actions.*





# 1. General Recommendations

**1. Know your epidemic:** HIV-related action undertaken by the education sector must be responsive to the local and national reality of the HIV epidemic. For this reason, policy-makers and planners are urged to *know your epidemic* in order to recognise trends and appreciate the nature and implications of its impact on the education system and upon learners in relation to access, retention and achievement.

- **Identify what proportion** of young people in the education system is affected by HIV.
- **Map any differences** by gender, age group and regional variations.
- **Plan ahead** to be prepared for children living with HIV transitioning into adolescence, and their changing needs.

**2. Recognise the presence of people, including learners, living with HIV.** At the school level, it should not be assumed that all learners are HIV-negative. Some learners may know their status while others may not. Some will want to disclose and others will not. YPLHIV have both the same general needs as other learners, as well as particular needs that are HIV-specific.

**3. Establish and reinforce links with other sectors.** An effective HIV response requires collaborative partnerships between ministries relating to education, health, social affairs and gender. This will help ensure education sector participation in HIV response planning and resource allocation, as well as highlighting the added value of education sector engagement in the national response.

- **Identify which other sectors or organizations** are currently meeting the needs of young people vulnerable to HIV or living with HIV and develop appropriate partnerships.

**4. Review, adapt and reinvigorate existing policies and practices.** Numerous policies and guidance exist in most settings – revising these is more efficient and likely to be more successful than developing new policies.

- **Review existing approaches for education access, reintegration and retention** to ensure that they meet the needs of YPLHIV.
- **Review school health and well-being programmes**, such as FRESH, and policies on bullying or sexual abuse.

**5. Develop/implement monitoring and evaluation systems** that ensure the evolving needs of YPLHIV are being met. HIV-sensitive indicators can be integrated into existing Education Management Information Systems.

**6. Continue to improve knowledge levels on HIV** among all teaching, management and administration staff and include education on living with HIV. This will reduce stigma and increase understanding of the needs of YPLHIV. Take advantage of opportunities presented by pre- and in-service training.

**7. Encourage and support the provision of non-formal education** programmes that are relevant to young people living with HIV not in school. Improve communication and partnerships between formal and non-formal sectors to ensure that good practices are shared.

**8. Recognise the value of teachers, staff, parents and community members living with HIV** as part of the response and liaise with their trade unions, support groups and PLHIV networks.

## 2. Confidentiality and Disclosure

### Guiding Principle

Every person has the right to privacy and confidentiality and to choose if, how and when to disclose their HIV status. Together with health and local community partners, the education sector has a responsibility to acknowledge and respect the sensitive nature of the disclosure process and to support the decisions YPLHIV make concerning their status. The right to confidentiality and privacy is fundamental and must be protected if YPLHIV are to be able to reach their full educational potential.

### Summary of Issues

Disclosure of a person's HIV status requires careful consideration of a complex set of risks and benefits. Risks include rejection, stigma and discrimination (from peers or staff at school as well as in the wider community), whilst benefits can include increased access to essential support and services. Managing the issue of disclosure – within the family, community and at school – can be extremely stressful. Schools, particularly teachers and other adults, can be important supportive partners in the complex disclosure process.

### Actions

1. Ensure that no policy or practice requires disclosure of HIV status for access to education.
2. Protect young people's right to privacy, dignity and safe disclosure through:
  - Developing and implementing a robust confidentiality policy;
  - Increasing knowledge among all education personnel on the importance of confidentiality and how to protect it;
  - Increasing learner awareness of their rights and responsibility for confidentiality.

N.B. In high prevalence settings this should be an HIV-specific policy
3. Establish clear protocols and practical guidelines on disclosure in order to avoid forced, intentional or accidental disclosure.
  - Protocols should cover the school environment and the school's responsibilities within the community, including with parents and healthcare providers.
4. Pro-actively engage with health service providers, parents, etc., who are also involved in supporting, protecting and managing disclosure.

# What should you do?

## Education Sector

Since many young people will either not know or choose not to disclose their status for a variety of reasons, schools and other educational institutions have a responsibility to create a positive, conducive environment for all learners, *irrespective of HIV status* and to ensure that the confidentiality of all students, including YPLHIV, is respected and maintained. This should be reflected in a commitment to inclusive, non-judgmental language and terminology. There is no justification for restricting access to learning institutions on the grounds of HIV status.

Clear policies and protocols must be provided to guide teachers and other personnel on how to handle issues of confidentiality and disclosure. Students and staff must understand both the benefits and potential consequences of disclosure (together with any legal implications; for example, relating to criminalisation of transmission), as well as how to assist learners in accessing available support during the disclosure process.

Repeat disclosure can be extremely challenging to some young people living with HIV. Supportive adults must understand these challenges and be equipped to help a young person through them. School personnel should also be prepared to support parents or caregivers of YPLHIV who wish to disclose to their children.

## Health Sector

The health sector can support the education sector by ensuring that all schools and learning establishments have links and referral access to support services at local health care facilities. Health staff can also support school personnel in helping manage the disclosure process and providing advice on maintaining student confidentiality.

Problems can arise when agencies work to different confidentiality policies. This should be addressed at the outset of any working collaboration and a clear agreement made.

Given the increasing opportunities in some countries for young people to access VCT, including through school-based programmes, it is important that personnel in both education and health settings understand the implications for young people when accessing VCT. These implications include: independent or parental consent for testing and treatment, the legal aspects of disclosure and confidentiality, and the need for good quality counselling pre- and post-test for all people being tested .

## Civil Society and Networks of People living with HIV

Networks of people living with HIV and other community-based organisations that provide care and support services to PLHIV play a crucial role in the local response to the epidemic. Support groups and buddy systems coordinated through local NGOs provide an excellent alternative outlet (beyond the formal health care setting) for young people living with HIV. Learning institutions must be aware of and develop partnerships with such groups for appropriate referral. Local organisations and networks can be valuable sources of assistance, for example in the design and delivery of training and development of policies (e.g. on confidentiality and disclosure). In high prevalence settings, it may also be appropriate to liaise with other sources of support, such as legal services.



### 3. Stigma and Discrimination

#### Guiding Principle

Every person has the right to live free from stigma and discrimination. The education sector has a responsibility to provide a conducive and safe learning environment for all people, irrespective of their age, gender, sexual identity, religion, ethnicity or health status. The freedom of YPLHIV to participate in learning without fear of stigma, judgement or discrimination, is essential for their chances of attending, remaining and succeeding in school.

#### Summary of Issues

In many countries, including both those that are most and least affected, HIV-related stigma and discrimination are pervasive, with considerable impact at both personal and community levels. Stigma and discrimination undermine young people's right to education by making schools unsupportive and potentially unsafe places for PLHIV, and are thus inconsistent with the EFA goals of access, retention and achievement. School-based HIV-related stigma and discrimination can originate at the individual level (by learners, staff, parents or community members) or as a consequence of institutional policy or practice, such as decisions to identify, segregate or refuse entry to YPLHIV. In some cases, stigmatisation or discrimination are unintentional, such as HIV-prevention messages that promote 'HIV-free schools' based on the assumption that the school population is HIV-negative, a concept which risks further alienating young people already living with HIV.

#### Actions

1. Develop and enforce a sector-wide zero tolerance policy on HIV-related stigma and discrimination.  
  
NB. In low prevalence settings, integrating HIV into a general non-discrimination policy may be more appropriate.
2. Head-teachers and staff have a responsibility to promote a culture of tolerance, openness and non-discrimination.
3. Schools and young people should establish mechanisms for reporting and acting on incidents related to stigma.  
  
NB. Pay particular attention to other types of stigma and discrimination that YPLHIV may face, such as: gender, homophobia, poverty and disability.
4. Deliver good quality, comprehensive HIV and sexuality education to increase knowledge and understanding of prevention and care, eliminate misconceptions and therefore reduce stigma.
5. Engage parents and community members in stigma reduction and promoting a culture of tolerance.

# What should you do?

## Education Sector

The education sector needs to acknowledge and anticipate the reality of stigma and discrimination and take prompt and effective action. HIV-related policy and practices should be reviewed to ensure that they neither exacerbate nor reinforce stigma and discrimination against learners or staff. Appropriate training and education should be provided for the entire school community and commitments made and enforced in relation to zero-tolerance of stigma and discrimination. It is also important to initiate mechanisms for monitoring progress.

## Health Sector

The health sector can support the education sector (and *vice versa*) by ensuring that service providers do not perpetuate stigma and discrimination and are providing non-judgemental, psycho-social support services (or appropriate referral) for those experiencing stigma and discrimination. The health sector should also be pro-active in disseminating accurate information within local communities that acknowledges and challenges common misunderstandings and prejudices about HIV and related issues, including sexuality.

## Civil Society and Networks of People living with HIV

Networks of people living with HIV and other community-based organisations, in particular those led by young people, have a critical role to play in supporting those affected by stigma and discrimination. Moreover, they have an advocacy function in terms of monitoring and reporting stigma and discrimination and bringing these to the attention of appropriate parties (school-level, national, etc). Local and national media can also have a significant impact in promoting a stigma-free environment.





## 4. Treatment and Care

### Guiding Principle

Every person has the right to the highest attainable standard of health; good health is a critical enabling factor for educational achievement. Young people must be able to access treatment, including ART, as necessary, together with appropriate support for treatment adherence and management of side-effects. Access to school should not have a negative impact on HIV treatment, and HIV treatment should not have a negative impact on access to school. The education sector needs to promote understanding among learners and staff alike of the basic principles of HIV treatment and the implications of these for young learners who are living with HIV. The accessibility of relevant treatment, care and support options is critical to facilitating YPLHIV in realizing their educational aspirations. Transforming this principle into practice will require strong collaboration across education, health and social welfare sectors.

### Summary of Issues

For YPLHIV, health treatment options and milestones can involve complex issues and decisions that can affect personal well-being, school attendance and performance. These include: initiating and stabilising ARV treatment, adhering to treatment regimens, dealing with side-effects, managing opportunistic or co-infections (e.g. TB or Hepatitis C), visiting health facilities for follow-up and monitoring, and transitioning from paediatric to adult care.

With increasing numbers of YPLHIV (and teachers) accessing treatment, the education sector needs to engage with health care providers and ensure that the school environment is sufficiently flexible to meet the needs of YPLHIV on treatment, without the need for disclosure.

### Actions

1. Provide treatment literacy education for all staff and learners through HIV & sexuality education or other means.
2. Identify one focal point per school who can provide HIV-specific support, including adherence support.
3. Ensure that all teachers are aware and supportive of the health and medical needs of YPLHIV, including those on treatment.
4. Facilitate access to treatment and care services.
  - In high prevalence settings, schools should develop formal linkages with local service providers.
5. Put in place a system that allows learners to attend medical care without having to disclose, and which supports the catch-up needs of learners who have missed classes.
6. YPLHIV on treatment often need access to a healthy diet. All schools should accommodate YPLHIV nutritional needs and, where possible, provide healthy food.

# What should you do?

## Education Sector

The education sector can support YPLHIV on treatment by ensuring that all school authorities have a basic level of treatment literacy, that treatment-related absences from school (and any consequent need for catch-up) can be accommodated without the need for disclosure, and by making available health-promoting resources, such as appropriately trained school nurses, suitable nutrition, and provision of facilities for clean water and sanitation. Getting the best from the learners in your school means keeping them healthy, and this will involve providing adherence support to those YPLHIV accessing treatment.

## Health Sector

The health sector can support the education sector by providing basic orientation on treatment literacy to school staff and management and through student-friendly and flexible clinic opening times during term time that minimise the need for missing school.

## Civil Society and Networks of People living with HIV

Local organisations, in particular networks of PLHIV, can provide crucial support, for example in treatment literacy, to YPLHIV considering or receiving treatment. They can do this through the provision of peer support to address the practical, emotional and social implications of treatment. These organisations also have important roles in relation to community education (including schools) and advocacy to increase access to treatment by those who need it.

# 5. Sexual and Reproductive Health (SRH) and Rights

## Guiding Principle

Every young person, including those living with HIV, has the right to make their own sexual and reproductive choices, including choices about relationships, whether to have sex and when, marriage and family. The education sector must ensure that this right is respected and supported within education settings, among staff and students alike. YPLHIV must have access to accurate, up-to-date and evidence-based information and skills-building that supports them to make informed decisions about their sexual and reproductive health.

## Summary of Issues

Schools have a critical role to play in promoting the sexual and reproductive health of young people. This includes, but is not limited to, the provision of comprehensive sexuality education and appropriate links to local services. Schools can also promote sexual health through the implementation of policies and facilities that promote gender equality and that challenge all forms of discrimination. Sexual and reproductive health education curricula too often focus exclusively on prevention at the expense of the specific sexual and reproductive health needs of young men and women living with HIV. Young women living with HIV have specific SRH needs that can be addressed through schools.

All young people need education to prepare them for adult relationships, responsibilities and sexual life. To be effective and useful, this needs to respond to their particular needs as shaped by life experience, gender, age, sexual orientation, and HIV status, etc., which affect how young people feel about themselves, their bodies and their sexuality.

## Actions

1. Deliver good quality, non-stigmatising, comprehensive sexuality education to all learners, from an appropriate age (before sexual debut). This education must address the following specific issues:
  - YPLHIV have the same rights to fulfilling romantic relationships and sexual lives as any other young person.
  - Young women living with HIV have specific SRH-related needs, rights and aspirations particularly in relation to puberty, reproductive choices and gender identity.
  - Young people who are most at risk (men who have sex with men, those involved in sex work, people who use drugs) have specific SRH needs that should be highlighted.
2. Work with local communities and leaders to build support for sexuality education and sensitise parents on the importance of parent-child communication on SRH.
3. Strengthen links to young people-friendly SRH services.

N.B. Comprehensive sexuality education must address the range of SRH issues relevant to young men and women (including safe sex, pregnancy, STIs, HIV, and abuse and coercion) and present these within a framework of gender equality and shared responsibility for sexual and reproductive health.

## What should you do?

### Education Sector

The education sector needs to focus on three key areas: i) provision of non-stigmatising comprehensive sexuality education that takes into consideration the existence and needs of YPLHIV; ii) ensuring that the school environment itself is conducive to sexual health (e.g. tackling sexual and gender-based bullying, promoting gender equality, providing sanitation facilities); and iii) referral to sexual and reproductive services.

### Health Sector

The health sector has a critical role to play in the provision of non-judgemental, user-friendly services, including condom provision and PMTCT, that respond to the right to sexual and reproductive health for young men and women living with HIV, and the particular challenges they may face in realising these rights.

### Civil Society and Networks of People Living with HIV

Depending upon the context, civil society organisations may provide direct sexual health services, particularly to vulnerable groups, such as sex workers or men who have sex with men. They may act as points of referral to - and quality control of - local sexual and reproductive health facilities. They have an important role to play in sensitising service providers to the sexual and reproductive health needs of particular groups, such as YPLHIV, and in helping to reach those who may not be attending school. They also have an important advocacy role within local communities in sensitising members to the importance of and need for providing comprehensive sexuality education in school, together with suitable services.

## 6. Protection, Care and Support

### Guiding Principle

Every young person has the right to enjoy access to educational opportunities irrespective of their economic or health status. The education sector must support young people who are living with HIV by removing any HIV-related barriers that impede their rights to attend and potential to achieve in school. YPLHIV often experience increased psycho-social problems (e.g. anxiety, depression), which impact their attendance and achievement in school. Schools are a potential source of support and a key location for identifying young people who have specific care or protection needs.

### Summary of Issues

Social protection plays a critical role in helping people overcome the structural inequalities (e.g. poverty, lack of shelter, family status, gender inequality, stigma and discrimination) that drive the HIV epidemic and impede access to treatment, testing, schooling and other essential services.

Care, support and protection programmes have played an essential role in supporting orphans and vulnerable children, including child-headed households. However, care, protection and support measures that focus only on HIV ('HIV-exclusive') can actually be both stigmatising and inequitable. It is therefore important that general measures that support consistent school attendance and fulfillment of academic potential (such as bursaries, nutritional support, housing, income generating activities, etc.) address the particular needs of YPLHIV as well as others who are particularly vulnerable, without singling them out.

### Actions

1. Promote and protect the rights of the child and human rights, and recognise that these are also the rights of YPLHIV. Establish and implement a comprehensive child protection policy.
2. Play an active role as part of the local 'social safety net' identifying and supporting learners with specific needs.
  - Recognise and act on child protection issues, issues of absenteeism or poor performance and work with families and social services to understand and mitigate the causes and impact.
  - Provide appropriate school nutrition and feeding programmes wherever possible.
  - Alleviate the financial burden of education for YPLHIV through links to existing social protection schemes and school-specific initiatives, such as waiving school-fees.
3. Engage fully in the education sector's duty of care for its learners, recognising that these are different for young women and young men:
  - Recognise and respond to the psychosocial difficulties experienced by YPLHIV, including depression and anxiety.
  - Recognise the additional stress for learners coming from households affected by HIV, including burden of care, transition between different households, financial insecurity and grief.
  - Differentiate the specific needs and experiences of girls and young women, as compared with young men.



## What should you do?

### Education Sector

Schools must commit to creating safe, inclusive and egalitarian learning environments for all students and staff. In many places, a considerable number of social protection policies, projects and measures already exist. It is important to identify these, assess them for their relevance to YPLHIV and, if necessary, adapt them before scaling up. Actions at the policy level - such as enforcing anti-discrimination - can help schools prevent drop-out by YPLHIV and thereby increase retention. Social transfers (such as cash or food vouchers) can increase access to schooling by YPLHIV and others deemed vulnerable. It is important to take into consideration the extent to which specific measures could benefit those who either do not know or have not disclosed their HIV status.

### Health and Social Sectors

Health and social welfare agencies can sensitise schools to the availability of existing social protection measures, such as early childhood development for vulnerable children, health insurance schemes, exempting YPLHIV from service-user fees, or provision of other financial assistance. Health care providers are well-positioned to advocate for and on behalf of YPLHIV and liaise with adults in other sectors to ensure their needs are being met in a fair, just, and supportive manner (e.g. to have conversations about accommodating school

attendance). They can also work with the education sector to strengthen school and community-based feeding programmes to better meet the needs of YPLHIV.

### Civil Society and Networks of People living with HIV

Civil society and PLHIV networks need to familiarise themselves with available social protection needs and entitlements, promote these - for example, through better understand of available legal and social protection service - and assist the most vulnerable community members in accessing them. These groups can also draw attention to the importance of enacting child protection measures and work to identify ways in which current policy and legislation contribute to, or increase, HIV-related vulnerability, and advocate for appropriate changes.



# Cross-Cutting Issues

Before implementing any of the above actions, it is important to consider the following issues and related questions.

## Meaningful Involvement of YPLHIV

- Does the work respond to specific, expressed needs of YPLHIV? If so, to which need(s) and how have these needs been expressed?
- What coordination or collaboration has been done with PLHIV networks or organisations?
- What *specific contributions* will YPLHIV make to the implementation of this action?
- How does the work demonstrate respect for YPLHIV?
- Has the possibility of unintended *negative consequences* for YPLHIV (e.g. risk of exposure, increased stigma and discrimination) been considered and mitigated.

## Gender

- What are the key *gender dimensions* that need to be addressed regarding:
  - Access, retention and achievement
  - Stigma and discrimination
  - Disclosure
  - Sexual and reproductive health education and services
  - Sexual abuse and gender bullying and violence
  - Sexuality
  - HIV treatment
  - Social protection
- To what extent does each proposed action reflect careful consideration of the different needs of girls and boys, young men and women?
- How will each action increase gender equality?
- Are there any ways in which it might reinforce gender inequality?

## Diversity of young people living with HIV

- Does this action take into consideration important differences in age and maturity, sexuality, cultural background, socio-economic circumstances and health status?
- Does it address the needs of key populations of YPLHIV: people who use drugs, sex workers, men who have sex with men and transgender individuals?
- Does the action take into consideration the evolving capacities of YPLHIV?

## School & Community

- What mechanisms already exist:
  - For consultation and partnership with parents and the local community?
  - As entry points for referrals and/or linkages with other health and social welfare services?
- How will this action strengthen the ties between schools and their local communities?
- Does this action make the best use of available community resources (people, materials, etc.)?
- How might you avoid over-burdening local community resources?

# Conclusion: Moving Forward

In collaboration with young people living with HIV, UNESCO and GNP+ have identified and presented here the major issues facing young people living with HIV in many different areas of the world.

The most important task now is to identify next steps to address these issues.

It will be useful to take stock of your current situation. You can do this, for example, by working your way through the general and thematic recommended actions and indicating:

1. Which of these actions are **relevant** to your situation?
2. Which actions have **already been implemented** - and with what success?
3. Which actions should be **prioritised**, respectively, for the immediate, medium and longer term?
4. **Who needs to be involved** to make these actions happen?
5. Which should be the **most urgent** priority actions?

It is important to recognise that a considerable amount of experience already exists in relation to addressing these issues, particularly in countries which have been most heavily affected by the epidemic.

While it is essential that the actions and solutions you identify are locally relevant, appropriate and sustainable, take time to explore the large amount of material and resources from throughout the global response that are already available. Some examples can be found in Annex 1.

In the past year, young people have come together to make clear their needs in terms of educational support, health care and the realisation of their rights. Whilst the increasing attention being paid to the specific needs of young people living with HIV is positive, the prevailing levels of stigma and discrimination coupled with ongoing health and psycho-social concerns creates an unsafe, unsupportive and challenging environment for every young person who lives with HIV. Those young people in education have the opportunity to benefit from simple, yet transformative actions that can enable them to balance the competing goals of maintaining good health and achieving well in school. It is the responsibility of the education sector to engage with these needs, and to work in partnership with the health and social sectors, with civil society and, most critically, with people living with HIV, to ensure that the goal of offering quality education to every young person, regardless of their personal and health circumstances, can be met.

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# Annex 1: Relevant Resources

## Relating to Young people living with HIV

### YPLHIV Consultation Statement and Recommendations (2010).

A statement from Young People Living with HIV on their needs and recommendations for an improved HIV response.

Download: [http://www.gnpplus.net/images/stories/Empowerment/youth/Statement\\_Eng.pdf](http://www.gnpplus.net/images/stories/Empowerment/youth/Statement_Eng.pdf)

**Healthy, Happy and Hot (IPPF 2010)** is a guide for young people who are living with HIV to help them understand their rights, and live healthy, happy and sexually fulfilling lives. Young people living with HIV may feel that sex is just not an option, but this need not be the case. This guide is designed to support young people living with HIV to increase sexual pleasure, improve health, and develop strong intimate relationships. It explores how human rights and sexual well-being are related and suggests strategies to help them make decisions about dating, relationships, sex and parenthood.

Download: <http://www.ippf.org/NR/rdonlyres/B4462DDE-487D-4194-BoEo-193A04095819/o/HappyHealthyHot.pdf>

### What do I do if I'm living with HIV and... (IPPF 2010)

– a leaflet providing ideas for young women who are living with HIV.

Download: <http://www.ippf.org/en/Resources/Guides-toolkits/What+do+I+do+if+I+am+living+with+HIV+and.htm>

## Relating to Sexuality Education

### UNESCO International Technical Guidance on Sexuality Education Vols 1&2 (2009)

- An evidence-informed approach for schools, teachers and health educators. Available in hard copy, CD-Rom and online, this Guidance provides an evidence-based rationale for sexuality education, outlines the key characteristics of effective sexuality education programmes and gives a framework of recommended topics and learning objectives for a comprehensive sexuality education programme.

Download: [www.unesco.org/aids](http://www.unesco.org/aids)

### Best practices on life skills-based HIV and AIDS education

- The International Bureau of Education has produced an interactive CD ROM that contains life skills-based education activities, identified as best practices and relevant to both formal and non-formal contexts. The material has been gathered from all over the world and evaluated using criteria developed by the IBE. The resource provides practical activities to help teachers, teacher trainers and educators to prepare lessons.

Copies are available from: [ibeaid@unesco.org](mailto:ibeaid@unesco.org)

**It's All One (Population Council)** – a two-book curriculum support kit (also available as a CD-Rom) providing the essential elements for developing a rights-based, gender-sensitive, and participatory curriculum for sexuality and HIV education. The

first book provides an introduction that includes an evidence-based policy argument, recommended content (including learning objectives) and fact sheets. The second book contains effective teaching methods, sample activities and additional resources.

Download: [http://www.popcouncil.org/publications/books/2010\\_ItsAllOne.asp](http://www.popcouncil.org/publications/books/2010_ItsAllOne.asp)

## Relating to HIV and Education

**The UNESCO HIV/AIDS Clearinghouse** is a web-based library of documents pertaining to HIV and education from all regions of the world. Research articles, education sector policies, news items and other relevant information are collected in one place for ease of use. <http://hivaidsclearinghouse.unesco.org/>

**Opportunity in Crisis, UNICEF (2011)** – recent global data on the HIV epidemic and how it is affecting young people aged between 10 and 24 years of age. The report groups together recommended actions and numerous key data from all countries to inform programmes.

Download: [http://www.unicef.org/media/files/Opportunity\\_in\\_Crisis\\_LoRes\\_EN\\_05182011.pdf](http://www.unicef.org/media/files/Opportunity_in_Crisis_LoRes_EN_05182011.pdf)

**Treatment Education: Technical Consultation Report (UNESCO 2005)** is a publication aimed at education sector professionals seeking to learn more about HIV treatment. Lessons, recommendations and frameworks for action are presented.

Download: <http://unesdoc.unesco.org/images/0014/001461/146120e.pdf>

### Exploring your Right to Health: Teaching and Learning Activities (WHO 2011).

This booklet, due for publication at the end of 2011, gives practical examples of activities that educators can follow with learners to improve young people's understanding of their right to health, and how to achieve this.

Download: [www.who.int](http://www.who.int)

### Implementing the Right to Education: A compendium of practical examples.

(UNESCO 2010). This booklet gives practical examples of how different aspects of the right to education has been implemented in a range of countries around the world.

Download: <http://unesdoc.unesco.org/images/0019/001908/190897e.pdf>

## List of relevant websites:

**UNESCO** : [www.unesco.org/aids](http://www.unesco.org/aids)

**GNP+**: <http://www.gnpplus.net/>

**IPPF**: [www.ippf.org](http://www.ippf.org)

**IBE**: <http://www.ibe.unesco.org/fr.html>

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“Young people around the world with HIV continue to be denied their right to good quality education because of fear, stigma, discrimination and a lack of understanding and support from schools and the community.”

More children born with HIV are surviving, reaching adolescence and adulthood. Young people are also becoming newly infected with HIV in all regions of the world. However the needs of adolescents and young people living with HIV (YPLHIV) are largely not understood or met – this is equally true in the education sector. Young people living with HIV are experiencing stigma, discrimination and challenges in balancing their health and treatment needs with their education attendance.

In 2011, GNP+ and UNESCO collaborated to identify and document the needs of learners living with HIV and develop a set of recommendations for action. The results of this collaboration are presented in this current volume, *Positive Learning: Meeting the needs of young people living with HIV (PLHIV) in the education sector*. The recommendations are simple, practical and feasible, and are intended to give guidance to educators, policy- and decision- makers as well as activists and professionals working with young people to enable YPLHIV to realise their personal, social and educational potential.

For more information on UNESCO's work on HIV and AIDS visit: [www.unesco.org/aids](http://www.unesco.org/aids)  
For more information on GNP+ visit: [www.gnpplus.net](http://www.gnpplus.net)

